When Empathy Is Not Enough: Assessing the Experiences of Autistic Children with Technologies

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ABSTRACT
Capturing and describing the multi-faceted experiences autistic children have with technologies provides a unique research challenge. Approaches based on pragmatist notions of experience, which mostly rely on empathy, are particularly limited if used alone. To address this we have developed an approach that combines Actor-Network Theory and Critical Discourse Analysis. Drawing on this approach, we discuss the experiences autistic children had with technologies resulting from the collaborative design process in the OutsideTheBox project. We construct a holistic picture of the experience by drawing on diverse data sources ranging from interviews to log-data, and most importantly, the first-hand perspective of autistic children. In four case studies, we demonstrate how this approach allowed us to develop unique individual and structural insights into the experiences of autistic children with technology.

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H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

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Experience; Co-Design Evaluation; Autism; Children

INTRODUCTION
When evaluating technologies for autistic children[1] researchers rarely take their experiences into account. The design and evaluation of such technologies typically focuses on the perceived deficits of individuals diagnosed with autism. Examples include diagnostic tools (e.g., [38]), or assistive technologies in the everyday life (e.g., a communication aid [35] or a visual schedule [18]). Others target specific intervention goals (e.g., [3] following SCERTS[2]), or investigate the potential therapeutic effects of playful technology (e.g., [12, 37] on Topobos and Reactable respectively). It is uncommon that technologies are designed for experiences that are meaningful for autistic children or that aim at fun and enjoyment (notable exceptions include [27] or [33]).

Often, these are then evaluated along extrinsically defined measures. For example, technologies for diagnostic procedures are assessed based on whether they correctly identify autism [38]. Those aimied at everyday life are assessed based on whether they provide the intended support and whether the children like it – as reported by parents, teachers and formal carers [35, 18]. Others, involved with intervention or therapy evaluations, ask whether a child can do a given task better than before [12, 37]. Such evaluations use extrinsic benchmarks of success of a technology, but ignore the multi-faceted experience of autistic children and most importantly the child's own perspective.

Within OutsideTheBox we take a different approach that is focused on positive experiences of autistic children. The technologies we develop are aimed to make sense in an autistic child's life without reducing them to psychosocial limitations. The only two pre-defined requirements are that the technology enables children to make positive experiences through them and that they scaffold the children in sharing those experiences with others. While we have reported on the participatory design process elsewhere [15], this paper reports on the evaluation of the resulting artifacts. When preparing the evaluation of these technologies, we faced the challenge of needing to assess or qualify the experience autistic children have with technologies. To address this, we use a novel approach, based on Actor-Network-Theory (ANT) and Critical Discourse Analysis (CDA), to understand and capture the experience of autistic children with technology [32]. The main contribution of this paper is to show how that approach to experience evaluation can be applied across a range of case studies and what insights can be yielded from this.

[1]While the discussion about advantages and disadvantages of person-first language is still ongoing, we opt for label-first in order to respect the predominant self-chosen form (cf., [20]).

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[2]SC - Social Communication, ER - Emotional Regulation, TS - Transactional Support, see http://www.scerts.com

Figure 1. All Technologies developed during the first year of OutsideTheBox – from left to right: ProDraw, ThinkM, Adaja and DSmart

We start by providing background in autism before continuing with experience is currently used in Human-Computer Interaction (HCI). We then highlight the challenges in eliciting feedback from autistic children, which, we speculate, is one of the reasons that their perspective often remains excluded. We present four case-studies from OutsideTheBox, drawing out individual as well as structural insights and showing how we combined diverse data sources to paint a holistic and multi-faceted picture of the children's experience with the technology. We end by reflecting on the implications of our results on experience-centred design with autistic children.

BACKGROUND

To describe our research context better, we present related work in the areas of autism and sense making and discuss strategies to elicit first-hand perspectives from autistic children. We then review a prominent HCI experience concept and show the structural frame in which we embed our empathic research acknowledging, the unique situatedness of autistic children and including their direct opinions.

Autism & Sense Making

Current research suggests that autism is caused by a combination of environmental and genetic factors [11]. While symptoms differ greatly for each individual, differences of reciprocal socio-communicative interaction along with repetitive interests and behaviours are almost always present. It is estimated that about 1 in 68 children are autistic [29].

Ultimately, the symptoms are suspected to be rooted in an underlying perceptual difference. Through experiencing the world differently and, hence, making sense of it differently as well [5], communication between autistic and allistic[3] people can be difficult. Consequently, allistic researchers may have difficulties when trying to make sense of the reactions of autistic users appropriately. this is further complicated with non-verbal autistic children. Given this challenge, we deem it necessary to try and gather first-hand perspectives from autistic children via several elicitation strategies.

Eliciting Feedback from Autistic Children

Common strategies to gather data explaining the interaction between autistic children and technology are indirect measures such as observations or interaction logging. Since researchers can find it difficult to directly communicate with autistic children, qualitative feedback is often gathered from proxies such as parents or carers (see e.g., [27] or [1]). Doing so, however, partly ignores the limits of an outside perspective on felt experience. Egilson et al. showed recently, for example, that parents tend to report a lower quality of life for their autistic children than those children report for themselves [10]. Even though it might be challenging to consider direct input from autistic children [34], Kirby et al. provide an illustrative example of what a first-person perspective on the experiences of autistic children might offer [21]. In their research, children used normalising, storytelling and the description of responses as conversational strategies.

Little previous work is available that directly includes the perspective of autistic or non-verbal children in qualitative research. Dockett et al. successfully used video, photography and drawings to elicit feedback from very young allistic children who were non-verbal [7]. Other potential avenues to enable input from autistic children can be found in participatory design approaches. Qualitative interviews with autistic children with verbal skills, for example, should rely on contextual, closed questions [14]. Annotated screen-shots [2] or smileys [28] have also been used successfully.

Experience in HCI

Traditionally in HCI, quantitative methods such as questionnaires have often been used to evaluate user experiences (e.g., for games [19]). However, these often just address issues such as usefulness, usability, engagement etc. and are unable to access or capture the nuances or emergent aspects of many uniquely situated experiences. Exploring another perspective on experience, McCarthy and Wright conceptualised a pragmatist understanding of experience in HCI [25]. This established a notion of *felt* experience and aesthetic pleasure that puts the person in the centre .

McCarthy and Wright's concept relies heavily on the notion of researchers' empathy with users [39]. While they focus on the dialectical kind of empathy more than on the affective kind of 'being in another person's shoes', being empathic helps to inform design and evaluation with neurotypical users as long as they can draw from a similar set of lived experiences. It is limited, however, when daily life and experiences differ greatly between designers and the people they are designing with/for – as is the case with autistic children. There has been recent work into how potential tensions arising by the limits of empathy between researchers and autistic children can be addressed [17]. However, we deem the gap between the life worlds of allistic researchers and autistic children so

[3]Meaning non-autistic, as coined by [22]

fundamental, that we require an approach that does not solely rely on researchers' empathy, even though we are acutely aware of how necessary empathy is in our research context. By itself, it just is not enough.

Assessing Experience Beyond Empathy

In assessing the experiences autistic children have when interacting with technology we were driven by an understanding of disability that acknowledges the uniquely situated interplay between medically determined aspects and socially constructed conceptions that disabled people encounter (cf. [31, 13]). To meet this unique situatedness appropriately for every individual case, we require an approach that considers *multiple viewpoints*, is *flexible* in terms of data acquisition and *open* for contradicting statements, allows for constant *critical* reflection and, most importantly, goes beyond empathy.

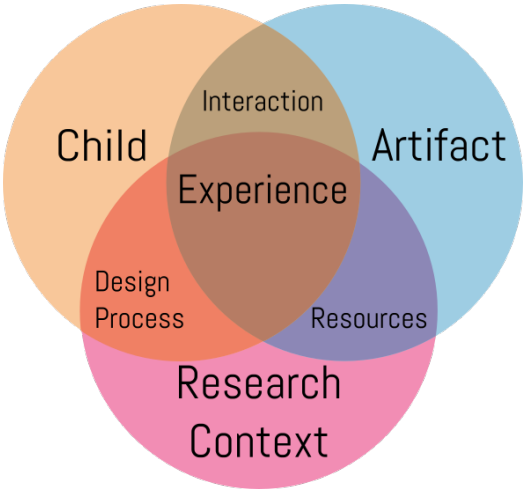

Figure 2. Core Actors Establishing the Experience an Autistic Child has with Technologies

Spiel et al. [32] offer such an approach using Actor-Network Theory and Critical Discourse analysis. ANT allows for the identification of human and non-human actors as well as the importance of actants, and then combined with CDA, the relationship between actors and actants can be critically qualified. The child is very prominent in our concept and their first-hand perspective is essential. Understanding the child as uniquely situated within their social context makes it important to directly elicit the first-hand perspectives of autistic children, while not solely relying on them because the perspectives of others are also included.

We identified three core actors contributing to the experiences an autistic child has with a technology in a research project: The child, the technology and the research context in which the experience is assessed. Further conceptual actors include the interaction between artifact and child, the researchers' resources, as well as the co-design process between researchers and children. Those address the mutual effects core actors have on each other (see also the nucleus of actors Figure 2).

Through an iteratively applied process, the structured approach allows for insights into the experiences autistic children have with technologies. The five steps of the process are

1. Define Context and Discourse
2. Gather Data
3. Analyse Data and Identify Statements
4. Contextualise Statements
5. Repeat previous steps until no new insights occur

These steps complement our empathic research in a flexible structure that can be adapted to unique research contexts as we show in our four case studies below.

CASE STUDIES

The goal of the OutsideTheBox is to develop individual smart objects with autistic children. We do this through a series of co-design sessions over the span of a school year, where we meet regularly with the children for several design sessions every other week. Table 1 shows the individual children of the first year who will be the basis of the case studies we present[4]. With each child we go through four phases:

- Contextual Explorations – to get to know each other
- Ideation and Conceptualisation – to find an idea of what we build
- Design and Prototyping – to establish how we are going to build the object
- Testing and Evaluation – to assess whether the object fulfils jointly defined research goals

The project consists of three core researchers, two of whom directly work with the children as either Play Partner or Active Observer. The Play Partner engages directly with the child, supports them and assists in solving tasks that the Active Observer poses. The Active Observer is gives out the tasks to the child and the Play Partner and structure the sessions as a whole. Both of the researchers played a consistent role during all of the collaborations with one child, but experienced both roles across children.

All four parts of the process with the first year co-operations presented here have been completed. We handed the final prototypes to the individual children, if wanted, and conducted a series of evaluation sessions with each of them. The finished objects are shown in Figure 1. We have described the design processes [15] as well as the final prototypes in more detail elsewhere [33], as well as the theoretical and conceptual foundation of our experience approach using ANT and CDA [32]. Here, we report on the final phase – testing and evaluation to illustrate how ANT and CDA were applied and what they can offer for design.

For each case study we performed the steps mentioned in the description of our methodological approach. Our data sources

[4] All of the children we worked with during the first year were male and will be identified with male pronouns. However, we recognise that autistic experiences differ for female individuals and that part of that experience is framed by the invisibility of the condition in women [4].

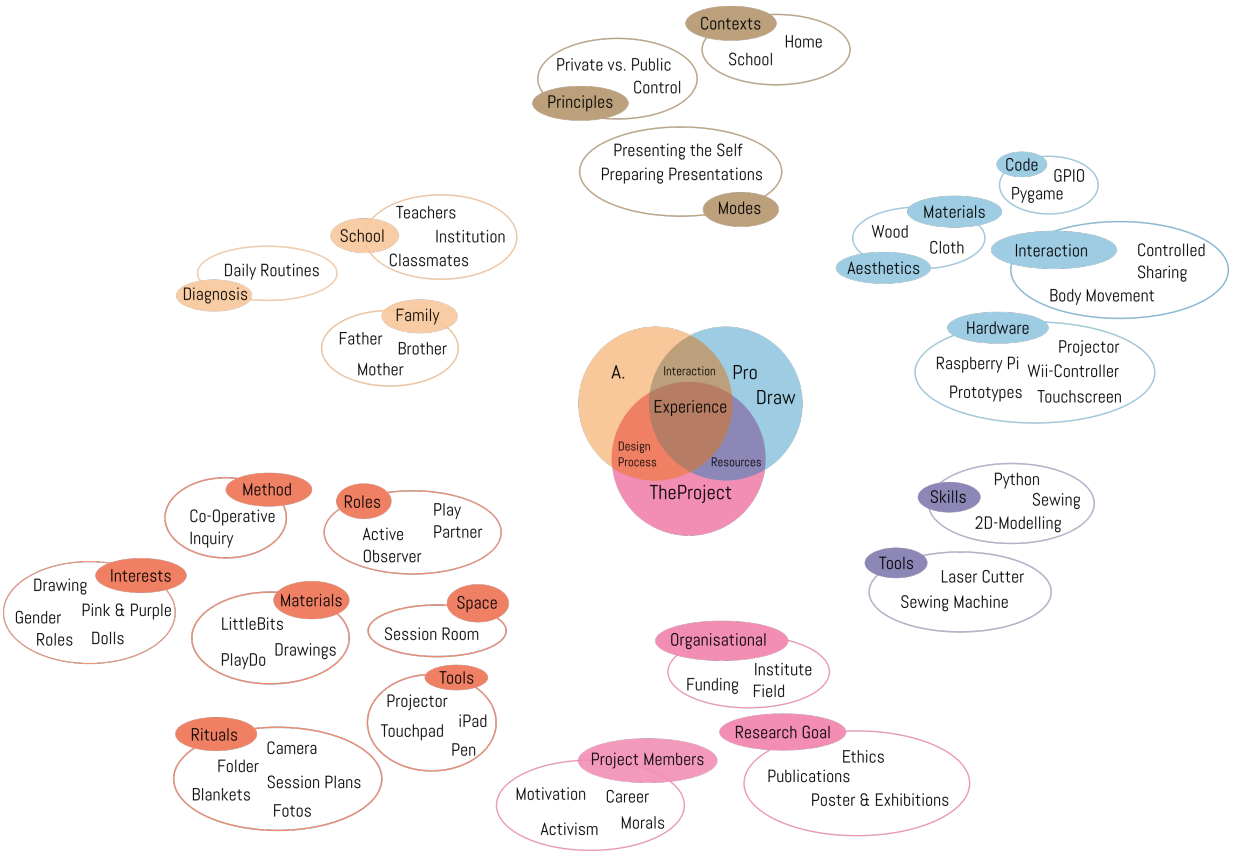

Figure 3. Evaluation Actor-Network for Andy

Name (Age)	Diagnosis	Method	Object name	#
Andy (8)	PDD-NOS	CI	ProDraw	10
Blaine (6)	HFA	CI	ThinkM	14
Claude (6)	HFA	FW	Adaja	13
Dean (8)	Autism	FW	DSmart	14

Table 1. Research Partners in the first year of OutsideTheBox together with age, diagnosis, design method used, name of the finished object and number of meetings; FW: Future Workshops, CI: Co-Operative Inquiry; HFA: High Functioning Autism, PDD-NOS: Pervasive Developmental Disorder - Not Otherwise Specified;

included contextual interviews with parents and teachers, research diaries from the researchers, protocols of meetings within OutsideTheBox, session plans, evaluation questionnaires , logs, protocols of team meetings, reflection on the prototypes, sketches, workshop materials, audio recordings of evaluation meetings within the university as well as video recordings and photos of the design and evaluation sessions.

Since neither the research institution nor the funding body requires a formal ethics procedure, we developed our own ethical framework inspired by the ethics procedures of the Economic and Social Research Council in the UK and an applied in-action reflective approach [16] – including a review board consisting of members of the same institution who were not part of the project.

In order to provide the necessary depth and breadth, we show only selected steps of the process for each case study. Andy's case illustrates the construction of actor-networks, Blaine's case shows how log data can be converted in statements, Claude's actor-network is presented in contrast to Andy's to extract more general knowledge and with Dean's case we emphasise the importance of diverse data gathering methods. To identify which of the concept step we performed, we use the icons assigned to each step above. Repetitions of steps are not explicitly detailed, but rather, all results identified in one step are discussed together. Each case study first describes the design context before the evaluation steps are presented. Furthermore, every case includes a paragraph about direct elicitation of first-hand perspectives of the autistic children and closes on a description of their experiences with their technologies. We argue that our systematic approach uncovered a richer and more detailed picture about these experiences than an evaluation solely relying on designers' empathetic assessment.

Andy and ProDraw

We always met Andy[5] in the same room directly next to his classroom. He used the German language on a very basic level and refused to speak in the language his family was mainly communicating in. However, he loved drawing and was quite good at it. He communicated his thoughts and

[5] All names have been changed to protect the children's identities.

ideas with sketches, which he was eager to share. Using Cooperative Inquiry [9] we explored several materials during the initial session. It soon became clear, that Andy's preferred pastime as well as mode of communication were expressed using pen and paper. As a result of the co-design process, Andy's final object, called ProDraw, facilitates the sharing of these drawings by allowing Andy to project them on a wall and animate them through body movements. Our main interest in the evaluation was whether Andy used ProDraw as an enjoyable communicative device.

Define Context and Discourse

Figure 3 shows the actor network as established by the final iteration of our methodological approach. Of Andy's social network, we have mostly interacted with his teacher who also joined us for the first session and was available in the adjacent room if needed for later ones. Andy's classmates played a role by continuously showing appreciation for what he did together with us. At early prototype stages they were impressed by what Andy might be building. When they investigated the final prototype, they expressed jealousy and admiration. As per feedback of the teacher, this was rarely the case before.

The interaction paradigm for ProDraw was based on both Andy's desire for drawing and controlling the process in sharing it with others, as well as the parents' and teachers' remarks that it was difficult to get Andy to exercise. So, for example, since Andy enthusiastically jumped up and down to animate the drawings, this aspect was implemented in the final object.

Resources available to the research team determine the material properties of any finalised object. We reflect on this by showing how access to certain tools and certain skills of the team members shaped ProDraw aesthetically and determined which hard- and software components were used.

All of the project members come with individual motivations and are at different stages of their career. Their morals influence their actions and decisions not only within OutsideTheBox, but also in their own everyday lives. We also identify as activists for disability rights to different degrees.

Each session was filled with little rituals between Andy and the research team. For example, Andy started out refusing to work with the research team every single time. He sat in a corner and tried to hide. One time, a researcher grabbed a nearby blanket and encouraged a hide and seek game. Andy took it and used it as a security blanket that encouraged him to interact with us. Without this ritual our cooperation could not have happened. It is crucial for the existence of ProDraw.

Gather Data

We gathered first-hand impressions of Andy on his experiences with ProDraw in several ways. In an evaluation session we asked him to freely draw on ProDraw and then draw the interaction scenario and how he felt about it on a piece of paper. We also recorded his interactions with ProDraw on video so that we could analyse utterances and behaviours during that interaction.

Analyse Data and Identify Statements

Table 2 shows selected statements for actors contributing to Andy's experience, together with the data sources they were extracted from. It shows that an actor can have multiple statements assigned to them to express different aspects. A statement can be a salient quote from the data (as might be the case with human actors) or a paraphrased sentences (as is the case for non-human actors). More details about this process can be found in Blaine's case study. For quite a while, we did not know anything about Andy's preferred placing for ProDraw or how the family integrated the object into their daily life. The process of identifying statements helped us uncover these missing perspectives and fill this gap in our knowledge.

Contextualise Statements

The actor-network, together with the statements, let us determine individual insights for Andy's experience with ProDraw. The object enabled Andy to express control and execute it (compare the first statement attributed to him in Table 2; this insight is established by *content* analysis of statements). Andy was proud about building the object together with us, especially because envy and admiration was expressed by classmates, teachers and his parent (this insight is established by a *contextual* analysis of statements). However, Andy did not want to use and share the object in the home environment – probably also because there was a bug that made it crash upon certain actions (this insight is established by *contextual* and *power* analysis). Hence, Andy wanted ProDraw to be placed within the school environment, where it could facilitate positive experiences.

Andy's experiences with ProDraw were deeply entangled with different use contexts and how other people reacted to him using it. To Andy it was a sharing device that could be used to communicate with all the positive and negative feedback that comes with communicating with others. While Andy's classmates and teachers gave positive and encouraging feedback, Andy's brother teased and made fun of the drawings. ProDraw, hence, mediated communicative experiences for Andy. It was only enjoyable as much as the communication was enjoyable.

Blaine and ThinkM

Blaine's interest in science and technology inspired us to follow a very technical approach with him. Using Future Workshops [36] to conceptually rid ourselves from current technological limitations, we developed ThinkM together. He expressed pride in what he co-created by presenting and explaining ThinkM happily to others, but refrained from using it much. During the last evaluation session he enquired about potential fixes we implemented, but was especially enthusiastic when allowed to use prototyping tools he knew already from the main design phase. We were interested in evaluating the effect ThinkM had on Blaine and whether it supported reflection on situations, actions and reactions.

Gather Data

With Blaine's case study we demonstrate how log data can be converted into a statement. ThinkM consists of two parts: a headband recording pictures and pulse data and a base station which allows for ret-

Actor	Statements	Source
Classmates	Wow, Andy, you've made this? I want to have what Andy has.	video recordings researchers' diaries
Parent	Andy preferred playing outside during summer. Andy did not interact with us through ProDraw.	interviews
Andy	Look, what I do. Don't look now! I don't want to take ProDraw home. It's ok, if ProDraw stays in school. Let me show you, what I've seen on TV.	session recordings researchers' diaries drawings
ProDraw	I couldn't function properly due to a bug.	logs
OutsideTheBox	ProDraw enables embodied sharing.	protocols of team discussions
Blankets	I provided Andy with security.	video recordings

Table 2. Selection of Statements Identified in Andy's Actor-Network

rospective analysis of those pictures together with the pulse data. The base station deletes pictures over time to emulate forgetfulness and counteract privacy concerns. ThinkM records pulse data alongside the pictures taken with the headband. The timestamps of the recordings give implicit information about when the headband was used and for how long. Additionally the base station recorded whenever it was switched on or off, when it acquired new pictures from the headband and whenever it would delete pictures. During evaluation, the pictures were only moved and not actually deleted to be available for later analysis.

While Blaine had high verbal skills, he preferred talking about concrete things that were to his core interest and remained largely silent when prompted about abstract qualifying judgements. We gathered first-hand data by asking closed contextual questions and observing situations in which Blaine explained ThinkM to other children during an exhibition.

Analyse Data and Identify Statements

The pulse data shows us that the headband was used two times during the time ThinkM was with Blaine for evaluation purposes. Since on both those occasions, the data was split into separate files (the headband had been put on and off again), we can see that the initial pulse was higher when the headband was put on the first time (mean: 108 and 99) compared to the second time (mean: 78 and 75). Two statements can be attributed to ThinkM from this data: "I'm barely used." and "It's exciting to use me, but the excitement doesn't seem to last long."

According to parents, the first set of pictures shows the inside of the home environment, when Blaine initially presented ThinkM to family members. The second set consists of only one picture in which Blaine's grandparent can be seen. This event was also tied to demonstrating the functionality of the object. The statement attributed to ThinkM from the picture data (contextually analysed) can then be: "If I'm used it's to explain to others how I work."

The base station repeats the pattern, but was used for a total of seven times during the evaluation phase. Pictures had been transferred at the beginning of two of those, which coincides with the data of the headband. The base station confirms the statement given by the headband: "I'm barely used."

Contextualise Statements

Both parts of ThinkM combined provided us with three statements. Critically analysing how they were constructed, though, we have to reject the statement "It's exciting to use me, but the excitement doesn't seem to last long.", because we did not have enough data to confirm this. The statement coming from the pictures relied heavily on the interpretation of the parents, which means, the statement should be attributed to them instead of the pictures. This leaves us with one statement for ThinkM: "I'm barely used." This does not describe all aspects of the experience, but the main perspective of the object on it.

Combining more statements and putting them in context to each other, we have several insights. During evaluation sessions and in the final phases of design, Blaine expressed a close connection to ThinkM and the way it was designed and built. Despite these findings, the object was barely used outside in the home environment. This might indicate, that Blaine considered ThinkM more as a tangible token of our cooperation than an object that can be used.

Hence, ThinkM facilitates an 'in-memento' experience for Blaine. Using the object evokes the experiences of the design process anew instead of creating newly situated ones. Blaine shares this experience with others, which could be interpreted as following the design brief of OutsideTheBox, even if in unexpected ways. While this does not answer the question we were initially set out to answer, the methodology allowed us to learn more about the failure of the device as intended next to the positive effects of the process of designing it.

Claude and Adaja

In Claude's school we were first located in a nurse's room that was equipped with only a table and three chairs. Our collaboration drew on Co-Operative Inquiry as design method. After a couple of sessions we met in a brighter and more engaging therapy room. Claude was verbal, but sometimes switched to his mother tongue, which was not spoken by any of the researchers. Claude's interests constantly changed, which made it hard for the researchers to extract a core interest. More consistently, though, Claude was fascinated by visual patterns that he could manipulate. Still, his smart object, Adaja, only temporarily caught Claude's attention. The evaluation was driven by the question of how and what Claude investigated.

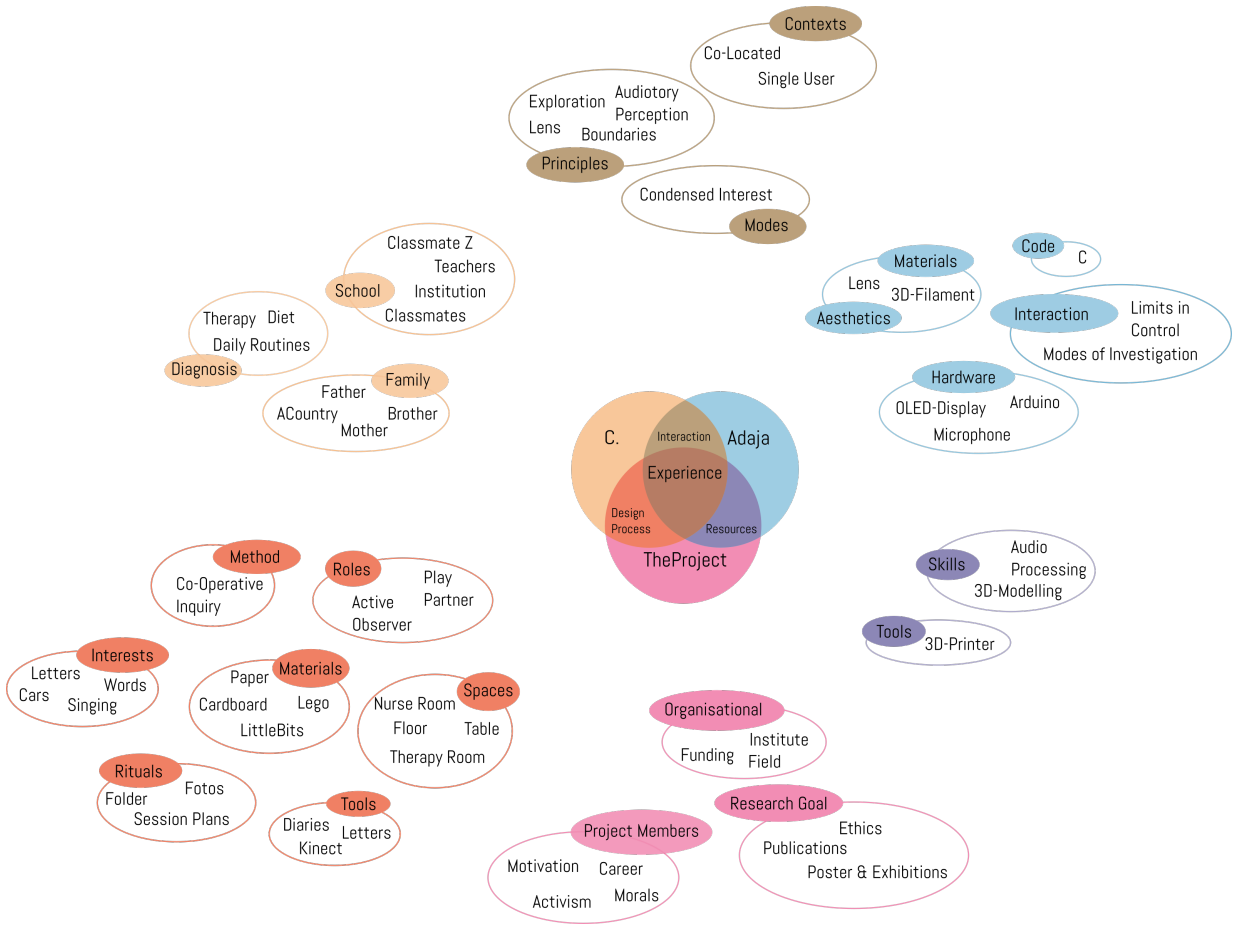

Figure 4. Evaluation Actor-Network for Claude

Define Context and Discourse

Figure 4 shows Claude's actor network, which we analyse in contrast to Andy's actor network (see Figure 3). Regarding his immediate environment, Claude had a close friend in class. Additionally, Claude's life was more impacted by the diagnosis. There were therapy sessions and dietary rules to consider. While both children's families came from foreign countries, for Claude this was much more part of his identity, which was expressed e.g., by singing in his mother tongue.

There was no overlap in interests between Andy and Claude that we could identify. Consequently, their objects follow different interaction paradigms, aesthetics and even hardware, which also required different resources from the researchers. Adaja has the form of a lens and displays the intensity of noise around it. If there is too much noise, it has a regulatory function in that it displays the words 'too loud'. Claude constructed the name Adaja through a play with letters and words which reflected interests in that area.

While OutsideTheBox and its sub-actors remained stable, the interaction in the design process was volatile, even though method and roles stayed the same. We used different materials and rituals played a less important role. Different tools addressed the different interests and needs of Claude. We can explore which actors remain stable and which are flexible by comparing two or more actor networks directly.

Gather Data

To account for Claude's perspective on the interaction, we developed a small game inspired by Theater Workshop methods [30]. Three large pieces of paper signified answers of 'yes', 'no' and 'don't know' at different spots on the floor in the room. One facilitator asked closed contextual questions while the other together with Claude each answered the question by moving to their answer spot in the room. He quickly picked up on the rules of the game and moved around consistently. We tested the validity of answers given with a couple of test questions about things we knew Claude liked or disliked. When directly interacting with the object, he referred to how it had been created together, but did not engage with it in a self-driven manner. He seemed to enjoy playing with Adaja during the evaluation sessions, but handed it back afterwards and was not interested in keeping it.

Contextualise Statements

As insights for Claude we determined that the experience with Adaja was tied to the design process. While he liked meeting and spending time with us, he had limited interest in taking the object with him

or using it outside of dedicated meetings. The researchers expressed frustration and a feeling of Adaja not being made from a co-design procedure as much as made for Claude out of time pressure and the need to create an object. However, the researchers gathered valuable insights about the design process, which helped them restructure future design co-operations. For Claude, the object in its actualisation was less important than the experiences made while designing it.

Dean and DSmart

Dean's main interest lies in movies and stories. Our sessions took place at a room in school as well as at his home as per request of his parents. Through Future Workshops in combination with Fictional Inquiry [6], we developed DSmart, a tool to support storytelling and show trailers of upcoming movies. When encouraged, he liked using it (according to the parents), but did not suggest doing so on his own. Dean also expressed a strong preference for the trailer function. The focus of our evaluation was on the feelings Dean had when interacting with DSmart.

Gather Data

At the time we conducted evaluations, Dean was quite friendly with the researchers. Even though he was shy about expressing his own opinion unfiltered. Because of that, we conducted a dedicated evaluation session with them that was based on a mix of Fictional Inquiry and Theater Methods. In a social outing Dean and one of the facilitators watched the movie *Inside Out* [8] in a cinema. Inspired by the five emotions in the movie (Joy, Sadness, Anger, Fear, Disgust) , we supplied five chairs with five coloured cloths as props. We also provided three different scenarios that were familiar to Dean. He could pick any emotion for each scenario and show us how he would interact with DSmart in that context. Through that we could identify core emotions affecting the experiences Dean had with DSmart.

Analyse Data and Identify Statements

In Table 3 we show selected statements for actors in Dean's actor network and the data sources we analysed to extract these statements. It shows how the silver carpet, a piece of cloth that spatially marked the area of future in form of 'the Year 3000', was relevant to the experience of designing DSmart, but not any more for the final physical realisation. Dean expressed a lot of frustration in cases where DSmart did not function properly or as quickly as expected. This explained why the buttons had been damaged.

Contextualise Statements

More generally: Dean had to be encouraged to make direct experiences with DSmart, but did express preferences in how to use it then. Positive experiences were also provided by the acknowledgement of what he achieved through our design work together in that others wanted to engage with him through it. While the storytelling function was tied to an audience, to Dean it was also related to the task of telling a story. The experience of watching trailers of upcoming movies together and deeply engaging with others in their topic of interest was more important to Dean. The feelings they had when interacting with the prototype were determined by the robustness with which it worked. While this overshadows the experiences they had with DSmart, it gave us the valuable insight on how important it is to create more robust research products [26] instead of research prototypes when designing for the lived experiences of autistic children.

DISCUSSION

Through the application of our approach on evaluating the experiences of autistic children with technology [32] on a range of case studies, we were able to gain methodological insights, especially into potential research settings in which the approach could be used. Additionally, we could extract implications for experience-centred design with autistic children. We did so by combining the children's first-hand perspective on their experience with the perspective of other important actors such as the technology, the social environment or the research team. Andy's case showed how an experience can be mediated by a technology, whereas Blaine re-appropriated the object into a memento of a school project. Claude refused to make experiences with Adaja and Dean created specific use cases for the interaction with DSmart.

Methodological Insights

Several insights help us understand the methodological approach better. We present these here, again tied graphically to the step within the process, if a clear one can be attributed.

Define Context and Discourse

We found a set of stable actors that played a role for all of the case studies (see Figure 5) within OutsideTheBox. This does not mean that they are the only actors or actor groups that are relevant to a single case study, but that they, in principle, span over all of ours. As can be seen by the comparative analysis of Andy's and Claude's actor networks, each child brings their own unique contexts. Due to the nature of research projects, the actors tied to the project are comparatively stable. The sub-actors for the nucleus are partly stable (such as family, diagnosis and school as sub-actors to the child) and the sub-sub-actors are even more volatile. The further an actor is away from their core actor, the more flexible it is. For future case studies, we can draw on this to set up initial actor networks faster.

The actor networks show us what kinds of information we can get from the child's environment and teach us about the involvement of the child. By adapting, for example, materials, methods and tools, we can see that our process addresses the skills and abilities for every single child and, hence, fulfils the part of the research goal where we desire to conduct research in which the child can express their own agency.

Contextualise Statements

Across all case studies, we could see that acceptance in the home setting was lacking. Parents reported in three of the four cases that their children rarely tell them anything about school. For Blaine, this was especially pronounced. All of our design sessions, however, were done within the school building of each child, although our goal was to design holistically for their lives. With a strict separation of these contexts, we worked in a limited space. Hence, for future case studies we will attempt to carefully

Actor	Statements	Source
Teacher	I'm very impressed by what Dean achieved with you.	interviews
Parent	Dean never uses DSmart on his own. Dean only uses DSmart with me. Dean is in an ABA therapy programme.	interviews
Dean	Let's look at trailers! I am frustrated by DSmart not working properly.	session recordings researchers' diaries
DSmart	My buttons have been pressed a lot and hard; some of them are damaged.	object appearance
OutsideTheBox	Within DSmart reactive embodiment emerges.	protocols of team discussions
Silver Carpet	With me, Dean travels into the year 3000.	video recordings

Table 3. Selection of Statements Identified in Dean's Actor-Network

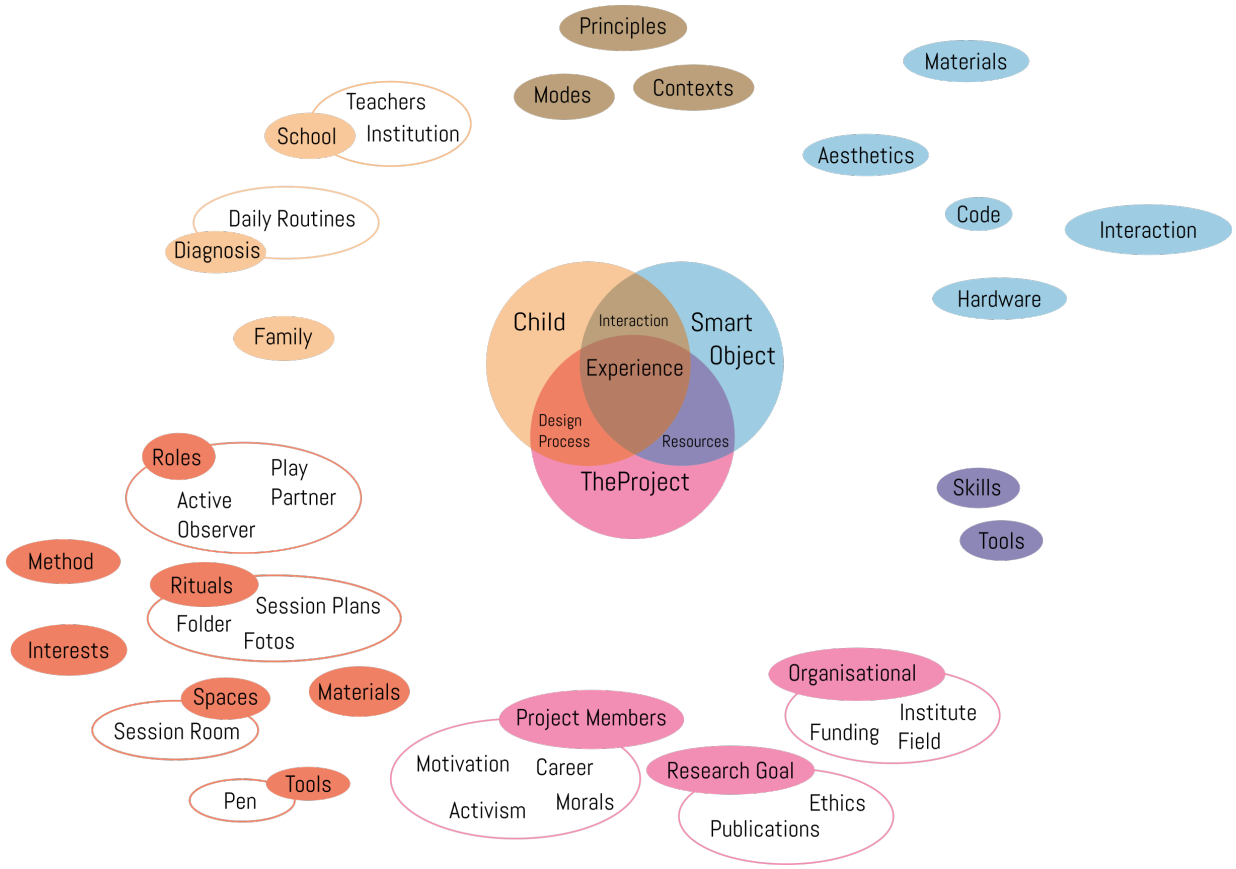

Figure 5. Stable Actors in an Actor Networks within the Context of OutsideTheBox

bridge into the everyday lives of the children by conducting dedicated sessions at other places such as the university and occasionally also visiting the home or meeting the parents together with their children. This way, the design activities might be associated less with the school environment.

Gather Data

In terms of data acquisition we found that dedicated evaluation meetings with parents and children yielded more than continuous little tasks. None of the children or parents filled in their evaluation diaries although the intervals were designed so that they required comparatively little time investment (about 10 min/week) – regardless of how involved the parents were within the project. It could be that keeping track of regularly answering diary questions requires more cognitive effort than dedicating time to an evaluation meeting. While we initially tried to tax the parents less in terms of time it appears to be more respectful of their time management and overall resources to schedule dedicated evaluation sessions and prepare these with specific questions and starting points for discussions.

During evaluation sessions with the children we found how closed contextually situated questions yielded results that require less interpretation (reproducing the findings in [14]). We also made good experiences with playing out different use contexts with the children. For the next evaluation we will involve the children directly in the definition of evaluation goals and data gathering methods. This should increase the acceptance for those methods and yield richer results.

Implications for Experience-Centred Co-Design

Our evaluation brought forward several implications for designing assistive technologies for autistic children that focus on their well-being and abilities. First of all, it is important to create a space that is individually tailored to the creative abilities of an autistic child. Freedoms and structures need to be carefully negotiated so that the design space does not become too arbitrary or too restricted [23]. Materials, methods, tools and some rituals provide conceptual flexibility to address unique preferences, whereas roles and other rituals should be pre-defined as a form of structuring the interaction.

We see another implication in the non-use we noticed among the children. The physical space in which co-design happens and the actual space for which we design should overlap – at least to some degree. Children in general view school and home environments as distinctly different spaces in which different rules are at play [24]. For some autistic children, this is even more pronounced. When designing for everyday life, designers tend to implicitly refer to the home environment (or away from school environment of a child). If a technology is supposed to be used outside of school, design sessions need to be conducted in that space as well, if not exclusively. Otherwise, the developed technologies will only be tokens of the design process, that are exhibited, but not used.

While we as researchers might be frustrated by the non-use especially because we hoped to have a tangible positive impact on an autistic child's life, we recognise there are also limits to participatory engagement. For one, autistic children are usually embedded in a rigorously planned environment with school, therapy and family events as structures and activities. Participatory design activities have to compete for attention in this space. Additionally, children's technological space is framed by parents' encouragements. We speculate that parents, who do not necessarily understand the technology and how it might be important to the child, might be less inclined to encourage its use. It appears crucial to ensure a mutual understanding of a resulting technology between a child and their social environment. Designers should make an effort to facilitate this understanding.

In the evaluation of the designs, researchers might have more success if they actively seek out interaction with the stakeholders they are interested in hearing from (be it e.g., the child themselves, their family or their teachers). Families with younger children are very busy. Regular questionnaires – even if the time used to fill them in is comparatively short – require constant reflection and mental effort to keep them in the routine. If there is no obvious intrinsic incentive for the families to provide the data, the acquisition will fail. It is easier for them to have dedicated evaluation sessions with interviews together with the child.

Ultimately, we could show how essential it is to include multiple perspectives when assessing user experiences of autistic children. Researchers' empathy is limited as it essentially assumes the researchers' perspective as privileged. We show how the children can be attributed with agency in an analytic framework that does not neglect associated difficulties.

CONCLUSION

We presented the practical application of a novel approach to assessing experience in the context of how autistic children experience their interaction with technologies. For each case we provided a detailed account about how the experiences of the children come together using Actor Network Theory combined with Critical Discourse Analysis. Through that, the assessment of experiences of autistic children does not solely rely on the empathy of researchers, instead it considers multiple viewpoints and makes sure that autistic children contribute to the construction of the experience as well.

While the case studies presented here are situated in a very specific context, we argue that our approach can initiate a wider discussion about the conception of experience in HCI. While the pragmatic perspective advocated by McCarthy and Wright [25] has meant a step forward in terms of a situated and nuanced understanding of experience, we argue that our approach can make a significant contribution towards a conceptualisation that is increasingly multi-faceted, multi-sourced and both extrinsic as well as intrinsic.

Future work includes more case studies so that we can report further on the structural aspects of the experiences autistic children have with technologies. We see additional potential for our approach to be applied in design, i.e., as a reflective tool that allows designers to reflect on their work. To this end, we have started to use ANT to document our current collaborations in OutsideTheBox and use the insights to plan participatory design activities. In order to increase the agency and discursive power the children have over the process, we intend to explore methods of participatory evaluation and how the actor-networks could be co-constructed.

With this paper we have reported on the first application of a novel concept of experience in the context of evaluating the interactions of autistic children with technology. We have demonstrated how our approach leads to unique insights, grounded in diverse data sources, most importantly including the perspective of children themselves.

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