Evaluating Experiences of Autistic Children with Technologies in Co-Design

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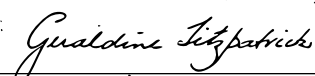Second advisor: Dr. Christopher Frauenberger

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I hereby declare that I have written this Doctoral Thesis independently, that I have completely specified the utilized sources and resources and that I have definitely marked all parts of the work - including tables, maps and figures - which belong to other works or to the internet, literally or extracted, by referencing the source as borrowed.

Vienna, 22nd October, 2018

Katta Spiel

For Sebastian

Acknowledgements

Abstract

Many technologies available to autistic children functionally focus on the medical characteristics of a diagnosis of autism. These technologies are then also evaluated according to the extrinsic motivations driving their design. Recently, though, more and more Participatory Design (PD) projects create technologies together with autistic children, albeit still mostly remaining in a medicalised view of autism. Hence, there is a lack of research into participatory design with autistic children aiming to develop technologies that reflect their intrinsic interests, holistic well-being and considers the embodied experiences they have with these technologies.

Constructive notions of experience in the research field of Human-Computer Interaction (HCI) rely on empathy as a core component of experience-driven evaluations. However, autistic individuals perceive the world differently and, hence, make sense of it differently than non-autistic researchers. This divide becomes especially pronounced when working with children, whose life worlds vastly differ from those of adult researchers. While empathy is a core requirement for the evaluation of the experience of autistic children, my work shows that researchers cannot rely solely on their empathy. Hence, evalutating these experiences requires a structured process capturing multiple views. My work makes three main contributions:

1. a concept for evaluating experiences of autistic children with technologies

2. a participatory evaluation method tailored specifically to autistic children

3. an in-depth discussion on the micro-ethics of conducting participatory research with autistic children

I give a *critical overview of current technologies* available for autistic children and the ways of evaluating them. The concept of 'Critical Experience' offers a *novel way for the evaluation of the experiences of autistic children* with technologies that are designed for their holistic well-being and enjoyment. The case studies then show *how autistic children experience these technologies* and which implications that brings for PD processes involving autistic children. I make a methodological contribution by showing how *PEACE* (Participatory Evaluation with Autistic ChildrEn) enables researchers to evaluate these technologies together with autistic children. There, the case studies present unique direct

insights into *what matters to the children.* In my discussion I further offer perspectives on the dynamics of *making micro-ethical judgements* when working with marginalised children more generally.

Not only researchers working with users who have very different life worlds, but also a community of developers and designers of assistive technologies in general are the audience for this work. This thesis argues the case for a considerate and critically informed approach when working with marginalised user groups and shows how this can be accomplished successfully.

Published Work from this Thesis

Katharina Spiel, Julia Makhaeva, and Christopher Frauenberger. **Embodied companion technologies for autistic children**. In "Proceedings of the TEI '16: Tenth International Conference on Tangible, Embedded, and Embodied Interaction", TEI '16, pages 245–252, New York, NY, USA, 2016. ACM. doi: 10.1145/2839462.
The paper discusses the interactive paradigms of the first-year prototypes. As the first author, I initiated and led the writing of the article and developed the theoretical analysis.

Katharina Spiel, Christopher Frauenberger, and Geraldine Fitzpatrick. **Experiences of autistic children with technologies**. "International Journal of Child-Computer Interaction, Special Edition on Designing with and for Children with Special Needs", 11:50 – 61, 2017. Elsevier. doi: 10.1016/j.ijcci. 2016.10.007.
The paper introduces the concept of Critical Experience, albeit without that particular name, and lays out the background for it. As the first author, I initiated, conceptualised and drafted the article.

Katharina Spiel, Christopher Frauenberger, Eva Hornecker, and Geraldine Fitzpatrick. **When empathy is not enough: Assessing the experiences of autistic children with technologies**. In "Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems", CHI '17, pages 2853–2864, New York, NY, USA, 2017. ACM. doi: 10.1145/3025453.3025785. **Honorable Mention**
The paper presents four cases studies detailing the experiences of autistic children with technologies created in the OutsideTheBox project as analysed through Critical Experience. As first author, I conducted the analysis, initiated and drafted the article.

Katharina Spiel, Laura Malinverni, Judith Good, and Christopher Frauenberger. **Participatory evaluation with autistic children**. In "Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems", CHI '17, pages 5755–5766, New York, NY, USA, 2017. ACM. doi: 10.1145/3025453.3025851. **Honorable Mention**
The paper introduces the methodological foundations of Participatory Evaluation with Autistic Children and illustrates through a few applied cases how the method can be actualised. As the first author, I initiated the article, coordinated the co-authors, developed the method and wrote a first draft.

Katta Spiel, Emeline Brulé, Christopher Frauenberger, Gilles Bailly, and Geraldine Fitzpatrick. **Micro-Ethics for Participatory Design with Marginalised Children**. To appear in the "Proceedings of the 15th Participatory Design Conference". 2018.

The paper shows in two different project case studies, one of them the OutsideTheBox project, how ethics in Participatory Design with marginalised children have to be negotiated in-situ. The paper stems from a collaboration with Emeline Brulé, which has been initiated and driven by me, but drafted jointly. However, I was mainly responsible for the theory development in the discussion section.

Katta Spiel, Christopher Frauenberger, and Geraldine Fitzpatrick. **Agency of Autistic Children in Technology Research**. *Forthcoming.* 2018.

The paper analyses a range of technologies for autistic children and how the development and use is conceptualised through an agency lens. As the first author, I have conducted the main analysis, initiated and drafted the article.

Christopher Frauenberger, Julia Makhaeva, and Katharina Spiel. **Designing smart objects with autistic children: Four design exposés**. In "Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems", CHI '16, pages 130–139, New York, NY, USA, 2016. ACM. doi: 10.1145/2858036.2858050. **Honorable Mention**

The paper discusses four case studies from the OutsideTheBox project together with design exposés. The paper has been driven by Christopher Frauenberger. My focus was on the description of the case studies and providing overall feedback.

Christopher Frauenberger, Katharina Spiel, and Julia Makhaeva. **Thinking OutsideThe-Box – Designing Smart Things with Autistic Children**. Accepted at the "International Journal of Human-Computer Interaction". 2018.

The paper summarises the work conducted in the OutsideTheBox project across the three years. My focus here was on the description of the case studies and providing overall feedback.

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Introduction

The most interesting people you'll find are ones
that don't fit into your average cardboard box.
They'll make what they need, they'll make their own boxes.
Temple Grandin

1.1 Motivation

Where modern computing technologies were once almost exclusively tied to a workplace environment, they are now ubiquitous in everyday lives. The same underlying technology is used and appropriated in different contexts, such as a mobile phone for finding a restaurant, facilitating meetings between friends or searching for animated figures on an augmented reality screen. With this diversification of contexts of use, we require evaluation strategies for interactive technologies that go beyond narrowly conceived notions of task-performance. Consequently, experience has become the dominant term of reference in designing and evaluating these technologies. However, conceptions of experience vary widely. While some aim to quantify the phenomenon as an outcome measure [e.g., Brooks and Hestnes, 2010], others rely on researchers to infer situated experiences via an empathic understanding of others [McCarthy and Wright, 2007].

When the concept of experience functions as a design goal or evaluation criterion, researchers often make assumptions about people's life-worlds to quantify or qualify outcomes. These assumptions can include the goals people might have with a device or application (such as finding food, organising social contacts or playing games; including the assumption that there is a goal), actions they might perform to achieve this goal (e.g., pressing specific buttons) and the range of experiences associated with it (for example, enjoyment and frustration). While these assumptions are helpful to understand experiences in contexts of use that researchers are familiar with, they fall increasingly short when designing with people who perceive the world around them differently.

Autistic children[1] belong to such a population. Kirby et al. [2015] have shown that sensory processing in autistic children is markedly different, leading, for example, to hyper-sensitivities for some. Beyond perceptual differences, we also know that many autistic children have unique cognitive styles that can manifest in narrow interests and repetitive behaviours or thought patterns. Thus, if allistic researchers[2] want to inquire into the experience of autistic children with technology, they cannot rely on the assumptions of a mostly shared life-world.

When evaluating technologies for autistic children, researchers rarely take their experiences into account. The design and evaluation of such technologies typically stem from a medicalised view of their condition. Examples include diagnostic tools (e.g., Westeyn et al. [2012]), or assistive technologies in the everyday life (e.g., a communication aid Torii et al. [2012] or a visual schedule Hirano et al. [2010]). Others target specific intervention goals (e.g., Bernardini et al. [2014] following SCERTS[3]), or investigate the potential therapeutic effects of playful technology (e.g., Farr et al. [2010b], Villafuerte et al. [2012] on Topobos and Reactable, respectively). It is uncommon that technologies are solely designed for experiences that are meaningful to autistic children or aim at fun and enjoyment (notable exceptions include the work by Parés et al. [2005a], where the technology centres around sensory enjoyment of autistic children).

The evaluation of these technologies is then often oriented on extrinsically defined measures of success in achieving a desired behaviour or skill acquisition. In that, the purpose of a technology matters as it shapes the questions asked and tools used when making meaning of it through evaluation. For example, technologies for diagnostic procedures are assessed based on whether they correctly identify autism [Westeyn et al., 2012]. Those aimed at everyday life are evaluated based on whether they provide the intended support and whether the children like it – as reported by parents, teachers and formal carers [Torii et al., 2012, Hirano et al., 2010]. Others, involved with intervention or therapy try to find out whether a child can do a given task more effectively than before [Farr et al., 2010b, Villafuerte et al., 2012]. Such evaluations use extrinsic benchmarks for a technology, but ignore the multi-faceted experience of autistic children and, most importantly, the children's perspective.

Within the project OutsideTheBox[4], within which this dissertation is embedded, we took a different approach and focused on positive experiences of autistic children. The technologies we developed were supposed to make sense in an individual autistic child's life without reducing them to psychosocial limitations. The only two pre-defined requirements were that the technology enables children to make positive experiences through them and that they scaffold the children in sharing those experiences with others. When

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[1]For my use of identity first language, please refer to the end of Section 2.1.4

[2]I use the term neurotypical to refer to the dominant cognitive style in western societies and the term allistic to mean not autistic as coined by Main [2003].

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

[4]Funded by the Austrian Science Fund, 06/2014 until 08/2017 under project number FWF - P26281-N23

preparing the evaluation of these technologies, we faced the challenge of qualifying the experiences autistic children have with technologies. To address this, I developed a conceptual framework for *Critical Experience*, based on Actor-Network-Theory (ANT) and Critical Discourse Analysis (CDA), to understand these experiences.

To consciously make space for the perspectives of the participants in my research, I had to support this approach methodologically. In OutsideTheBox, we used Participatory Design (PD) techniques. PD researchers include the people affected by a specific technology in the process of shaping it. Often, though, researchers' goals in PD projects define the success of the resulting prototypes, as well as the focus of evaluation [Bossen et al., 2016]. However, when the development of technology moves beyond the pragmatic evaluation of efficiency and efficacy, novel questions about what is worth evaluating come to the foreground [Harrison et al., 2011]. Expanding the role of research participants in the evaluation of technology further opens up perspectives beyond the safe space of researchers' expectations [Sengers and Gaver, 2006].

Action Research, a field in the Social Sciences [Tripp, 2005] with theoretical and moral underpinnings similar to PD [Foth and Axup, 2006], already includes testers as active research participants in evaluation [Hayes, 2011]. It allows for different stances that, when combined, deliver a more vibrant description of agendas and contexts of use than the researchers' perspective could provide on its own. Participatory evaluation (PE, see also Section 6.1), though, has received scant attention within Human-Computer Interaction (HCI) – and even less so when children are involved.

Researchers have started involving autistic children in participatory design projects more and more (e.g., Parés et al. [2005a], Benton et al. [2012], Malinverni et al. [2014], Keay-Bright [2007]). However, their participation in the evaluation regarding setting goals which define how the technology is made meaning of in these projects has been nearly non-existent; often with the argument that it is deemed very difficult to elicit actionable feedback from autistic children [Frauenberger et al., 2013]. While communication with autistic children is indeed complex, there is also a lack of concrete methods that allow them to actively participate in evaluations – even though these methods exist for design. PEACE (Participatory Evaluation with Autistic ChildrEn)– addresses this gap and, also, offers researchers working with neurodivergent populations[5] more generally a tool through which to engage them in evaluation processes.

1.2 Identity & Agency

The primary motivation for conducting this work stems from seeing how most of the technological research about autistic children is driven by a normative agenda of a predominantly neurotypical environment. While I show this in a more structured way

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[5]The concept of neurodiversity refers to different neurological conditions being seen as a variation of cognitive styles. Neurodivergent people are those with non-dominant cognitive styles in contrast to neurotypically presenting people. See also, for more information, Section 2.1.3.

in Chapter 2, I want to illustrate here, how I conceptualised identity and agency when working with autistic children. Being a queer-feminist[6] activist myself, I found it necessary to adhere to the principles of kindness and situated experience. I needed to make sure that I do not contribute to the overriding of the needs, desires and expressions of the children as happens for disabled people in most of society every day [Morris, 1991]. Being neurodivergent, but not autistic, myself, I had to ensure that my assumptions and biases were not skewing my interpretations of the children's experiences. In that regard "identity politics is both about achieving a better deal for people, but also about establishing the stories people tell about themselves, and having them listened to." [Shakespeare, 1996].

While it might be most beneficial to some disabled people to not explicitly self-identify as *disabled* [Watson, 2002], this work follows the notion of disability as a label that can be positively reclaimed [Morris, 1991]. Such an action of reclaiming comes with the concept of agency and attributing it to people who are not traditionally in positions of (discursive) power about their own lives and – relating this back to the area of Human-Computer Interaction – about the technologies in their lives.

Who can talk about it and whose expertise is valued when we discuss Autism? Pop cultural representation offers an especially intriguing example here. It seems a little paradoxical that autistic authors receive less attention than those using Autism as a fictional prop. As a literary example illustrating the problem, let me consider Mark Haddon's novel 'The Curious Incident of the Dog at the Night Time'.

> "Although Curious Incident has generated widespread interest in the autism spectrum, an interest that could foster an increased demand for autistic perspectives, the author's conclusions and the book's reception actually militate against autistic self-representation. In declaring that people like Christopher are unfathomable unless written about (...), at the same time claiming that Christopher would have trouble writing for himself, Haddon has relegated the autistic to otherworldliness while establishing a non-autistic author like himself as the necessary medium between autistic and non-autistic reality." [Burks-Abbott, 2007, p.295]

Hence, it matters who speaks about the experiences autistic children make. I am not autistic myself, so how am I qualified to conduct work and publish about how their experiences can be understood?

Writing this thesis, ultimately, contributes to a large body of work written by non-autistic authors about autistic people. Hence, I am insistent on making space for the first-person perspectives on the experiences of the children. I try to not speak *for* autistic children,

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[6]The notion of 'queer' feminism is different from classical feminism, as it critically investigates the modes of power more fundamentally. For example, queer-feminist researchers and activists critically decode a binary notion of gender. More background can be found in seminal works about queer research, e.g. Hall and Jagose [2012].

but instead, amplify and translate their experiences to make them discursively negotiable within the research community. Contrary to the novel, I underline that autistic self-representation is not only possible but needs to be explicitly attended to. There is also a personal motivation for why I chose to investigate this topic. Starting this work, I had hoped to be able to engage deeper with an autistic family member, to create something that might be ultimately useful and life-changing for someone like them who needs it. I have since then dialled back on these expectations. I learned that my notion of what is useful might be completely different from what autistic children deem valuable and life-changing does not necessarily relate to positive change.

However, as a doctoral thesis, I present the story of how I engaged with autistic children and their experiences with technologies. It tells how the children shaped the knowledge as much as me, how them being autistic and me working through a point where I could acknowledge their agency more and more led to us pushing the boundaries of what participation means in participatory research projects. It is – between the lines – a story in which I initially rejected any notion of empathy entirely, feeling ill-equipped to meet the children on an empathetic level. Only after being diagnosed as neurodivergent myself, I realised how empathy is a necessary prerequisite for participatory research, but just not good enough when researchers try and acknowledge differences as well as similarities.

1.3 Aims & Research Question

My work positions itself in the fields of Human-Computer Interaction and Participatory Design with references to Critical Disability Studies. As a neurodivergent researcher, I occasionally read publications addressing my own 'disorder' but notice a mismatch between how these works and I conceptualise my condition. As an allistic researcher, I write about autistic people and might step into similar pitfalls. Hence, I invite autistic people to challenge my work. The engagement (or non-engagement) from the autistic community ultimately determines the impact of this thesis.

In my research, I am influenced by my political and personal views on agency, democracy and participation. As a queer-feminist researcher, I advocate for appropriate *representation*, making space for *marginalised opinions* and overall *openness* to different perspectives. In that, I also believe that overall *kindness* is important to be able to understand each other better and go forward into a desirable, inclusive future.

Brought back to the topic of my research, I have the following overall aims guiding me:

- Provide a concept to holistically and qualitatively understand the experiences of autistic children with co-designed technologies.

- Methodologically and conceptually account for the agency of autistic children and their perspectives within the research about them.

- Let autistic children co-define the interaction and co-construct the meaning of technologies.

These aims are further articulated by the following research questions.

RQ 1 How can the experiences of autistic children be captured conceptually?

RQ 2 How can autistic children be actively involved in the meaning-making about technologies they co-created?

RQ 3 What are the qualitative aspects of the experiences of autistic children?

1.4   Contributions

This work contributes to the fields of Human-Computer Interaction and Participatory Design and in particular to those sub-fields focusing on an evaluation that centres on the experiences of people. Concretely, I look at the context of experiences with technologies developed in participatory design projects with autistic children. In that, my work offers three core contributions:

There is a theoretical contribution to the conceptualisation of experiences and their assessment beyond purely empathic approaches. 'Critical Experience' is based on the use of Actor-Network Theory and Critical Discourse Analysis; theories from cultural studies which I make fruitful for an experience centred evaluation context. While both approaches have been previously used within HCI, no previous work has formalised the theories into a framework for experience evaluation. The concept has been developed along four case studies and revisited in another four.

Another contribution is methodological and shows how participatory evaluation can be conducted with autistic children. Here, I show how the children can be included in evaluation along with their unique interests and abilities. Participatory evaluation seldom occurs within HCI, so the novelty of this lies in conceptualising out a process that explicitly includes marginalised users and encourages researchers to make space for their contributions. I show the usefulness of the approach in four case studies.

Finally, I detail the finer ethical judgements that were necessary for conducting this research. Drawing on my experiences, I present a complementary approach to ethics, one that focuses on discussing tacit, situated ethical judgements, both for training and research purposes. It guides future researchers in situated research projects on how to train their ethical judgement skills in-situ.

1.5   Thesis Structure

In Chapter 2, I discuss my understanding of autism, together with an overview of technologies that are available to autistic children through research projects. I complement this by an analysis of how we can extend the dominant conceptualisation of experience in HCI with the unique perceptive modes autistic people embody.

Chapter 3 presents the contextual framing of this work within the OutsideTheBox research project. It illustrates where my contribution as part of the project lies and also how this thesis is a unique part of the project. Additionally, I present epistemological groundings and introduce the background on Actor-Network Theory as well as Critical Discourse Analysis on which my experience framework relies.

All case studies relevant for my work are presented in Chapter 4. Every child is introduced together with the overall process we conducted and the resulting prototype. A total of eight case studies are described, four for design cycle within the project. This chapter provides the more concrete context for each case relevant to the thesis.

I present my framework of Critical Experience in Chapter 5. After a conceptual introduction, I show how I used it to analyse the four case studies from the first iteration of our co-design work, along with the methodological and experience-related insights the application yielded.

Chapter 6 then shows how I used the knowledge gained from the cases in Chapter 5 to create a method, I called PEACE (Participatory Evaluation with Autistic ChildrEn). It allows a more direct inquiry into the children's experiences, but also actively provides them with more agency in making meaning about the technologies they co-design. I show how I used the process in the four case studies from the second iteration and what knowledge could be gained from doing so.

In Chapter 7, I revisit the experience framework and apply it to the four second-iteration case studies. It shows how they differ between the first and the second year and illustrates whether the changes in the evaluation process created different insights when analysed through the framework. Further, I apply parts of the framework in group settings to see how it changes in different research settings.

The concept of micro-ethics for research with autistic children is detailed in Chapter 8. By focusing on the particular ethical judgements in participatory research, I illustrate how conducting my work within the project raised different ethical concerns than those that might be relevant in more conventional research with autistic children.

I discuss the implications of my work regarding the contributions I made and overall experiences of autistic children with technologies in OutsideTheBox in Chapter 9. Using agency and power as a lens, I reflect on the inclusion of participants more generally. Finally, I also revisit the epistemological implications of my research.

Chapter 10 concludes the thesis by illustrating the limitations of this work and pointing out potential directions for future work on the subject. Further, I re-visit the contributions I intended to make with this research.

CHAPTER 2

Background & Related Work

The research context of this work touches on the variations of an understanding of autism. Additionally, I discuss in more depth the role of autistic children in the technologies that are created for them (in a research context) and present approaches of how autistic people experience the world and how these experiences translate to HCI-related concepts of experiences with technologies.

Parts of this chapter can be found in Spiel et al. [2017a], Spiel et al. [2017b], Spiel et al. [2017c] and Spiel et al. [2018b]. I initiated, wrote the first draft and lead the theoretical discussion of all of these papers with supervision and conceptual as well as practical feedback by the co-authors. The note on language in Section 2.1.4 has been repurposed in Spiel et al. [2018a].

2.1 Autism as a Disability

Different strands in research define disability within a spectrum of 'internalised, individual and embodied' vs 'reinforced by society'. These two approaches have been called the *medical* and the *social* model of disability [see for example Marks, 1997]. The medical model has attracted critique claiming it promotes an understanding of disability as a deficit. The social model has been criticised for neglecting the embodied experiences and physical realities that manifest themselves for the individual [for a broader discussion, see Shakespeare, 2014]. The differences in these models matter for technological research as they come with assumptions about the agency and power disabled individuals hold over these technologies and how they might affect their lives. Subsequently, calls have been made for the inclusion of disabled people in the technological research about them, as they have unique viewpoints not only on *what* should be designed *how* but also on the way technologies shape their identity as disabled [Mankoff et al., 2010].

Especially in the area of assistive technologies, there is a further push to view the design space less with a medicalised view but rather with a critical eye on context – a critical realist perspective [Frauenberger, 2015]. I understand disability as a discourse. This understanding sees a bodily difference becoming a disability by referring to it as such and re-constructing it as a disability through language, intrasubjective actions and institutional manifestations [in reference to Foucault, 1963/2012]. This understanding is found as well in the field of Critical Disability Studies [Shildrick, 2007].

2.1.1 Medical Model Perspective on Autism

Autism as a disability can, hence, be understood and constructed along these models as well. About one in 68 children in the United States of America are diagnosed with this condition [CDC, 2015], although the recently reported increase might at least partly result from a recent change in diagnostic criteria [Hansen et al., 2015]. Along a medical model, the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) of the American Psychiatric Association sets "deficits in social communication" and "restricted, repetitive patterns of behavior, interests" as diagnostic criteria and suggests three levels of support needed [taken from Kim, 2015]. The International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO), in its 10th revision (IDC-10), requires for a diagnosis that symptoms appear in childhood, typically in the first 30 months after birth. Further, they identify "impairments in social interaction and communication accompanied by a pattern of repetitive, stereotyped behaviors and activities" combined with language delays. They distinguished between autism and Asperger's syndrome, which they identified as a 'less disabling' version of autism. Additionally, they state that "there is no cure, but treatment can help. Treatments include behavior and communication therapies and medicines to control symptoms" [taken from the `icd10data.com` website[1]. The language of these diagnostic classifications speaks of a *dis*order that appears to be diagnosed by identifying a divergence from an established norm for social interaction and how personal interests can be pursued. It positions the condition within the individual that needs medical attention and correction to fit better into the dominant society.

Alongside this kind of understanding, several theories have attempted to explain autism. Currently, the condition is assumed to stem from a combination of genetic and environmental influences [Fakhoury, 2015], but ultimately, no definite cause has been identified yet. There are several different cognitive theories available that aim at explaining differences [Rajendran and Mitchell, 2007]. A different theory claims that autistic children lack "theory of mind", the skillset to understand how other people feel and process emotion; a necessary precursor to empathy [Baron-Cohen et al., 1985, Sucksmith et al., 2013]. Further development of this theory is the "extreme male brain theory" [Baron-Cohen, 2002]. It claims that male brains are more prone to systemising whereas female brains

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[1]specifically http://www.icd10data.com/ICD10CM/Codes/F01-F99/F80-F89/F84-/F84.0

are more inclined to empathising[2]. This theory might overlook how autism presents in women and how this leads to many of them not being diagnosed appropriately despite the condition being present, with severe consequences for access to service and support [Krahn and Fenton, 2012].

A theory on executive dysfunction [Ozonoff et al., 1991] focuses on the exhibition of certain behaviours related to problem-solving and organising daily life. However, due to its lack of specificity, it fails to provide an accurate account of autism [Rajendran and Mitchell, 2007]. On a side note, the language on dysfunction also normalises a certain neurotypically presenting form of functioning as ideal.

Another account is entitled "Weak Central Coherence" theory [Happé, 2005], through which autism is explained as predominantly perceiving the world with an attention to detail instead of generalising perceptive input. The strong point of this approach is that it proved flexible enough to adapt to criticism and conceptualises as a difference without classifying this difference as a deficit [Rajendran and Mitchell, 2007]. Further, it suggests that any cognitive theory on autism might be necessarily unsuited to explain all differences for all individuals who share the diagnosis.

Another theory on autism has suggested that autistic people lack cognitive empathy, but possess a surplus of emotional empathy [Smith, 2009], which then makes interaction with other people extremely uncomfortable and exhausting. The drastic and logical consequence of the latter would be to not engage with autistic people on an emotional level too much, which would lead to further isolation. Others see in autism an account of decreased social motivation rooted in heightened fear of social rejection [Chevallier et al., 2012], where such an approach would be extremely counterproductive. This discourse shows that within a medical account of autism, it remains unclear what are generally appropriate ways to interact with autistic individuals. To this extent, preferences of individuals might be precisely that: individual.

Alternative accounts of autism can be seen in work trying to get a more holistic and embodied [e.g., De Jaegher, 2013] or phenomenological and pragmatic understanding [e.g., Sterponi et al., 2015]. According to De Jaegher [2013] different ways of processing sensory input leads to different sense-making which influences the assignment of meaning. It is then challenging when meaning-making is based on different perceptual grounds between two people interacting. It requires flexibility from allistic people and interpretation to make communication happen. Autistic self-advocates like Chew [2008] argue here for a more poetic understanding of autistic modes of communication:

> If we read autistic language with the presumption that the person saying a seemingly nonsensical phrase such as "bedtime orange" is communicating a message if we assume the responsibility of translating flavour tubes and clouds we might be able to understand some of what an autistic person is telling us.

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[2]While I understand gender as a continuum [Butler, 1999], I refer to the dichotomy here as the literature discusses it.

> Reading autistic language as we read poetry, with attention to tropes and the system behind seemingly unusual combinations of elements and images and to the music of language can offer some clues for understanding and, most of all, for communication. [Chew, 2008, p.142]

Hence, it is paramount for my research to involve autistic participants, to acknowledge potential differences in communication and being prepared to interact creatively.

2.1.2 Dis-Abled by Society?

A social model of disability proclaims that it is predominantly a lack of accommodation that disables individuals. Prominently attributed to Oliver et al. [1983], it has led to accessibility considerations being potentially mainstreamed within policymaking. It targets areas such as education, work and digital accessibility. This social model of disability has been criticised for downplaying the individual impairments and their actualised effect in the embodied experience of disabled people [e.g., Shakespeare, 2014; however, Oliver claims that this was never the intention of the social model. Instead, it is a call to step back from focusing on the individual and putting awareness on systematic changes which can help to move towards including disabled people within a predominantly able-minded society [Morris, 1991].

Practising the social model for visible disabilities, such as removing physical barriers for wheelchairs, can be reasonably straightforward. However, when the disability is invisible, as in the case with autism, disabled people can face prejudice. This comes with constant re-affirmation and necessary disclosure of needs at the risk of being ostracised. Such circumstances indicate that there is a lack of awareness regarding the needs of neurodivergent people within society. Woods [2017] suggests that the primary social barrier for autism is the negative language surrounding the diagnosis. While Holywood movies like 'Rain Man' and popular novels like 'The Curious Incident of The Dog at The Night Time' present likeable, if skewed characters on the spectrum, there are indications that powerful societal institutions like the legal justice systems are biased against autistic people—mostly due to a lack of education regarding the intricacies of neurological differences [Beardon, 2008]. Hence, the social model, while being very useful for people with visible disabilities and making their needs heard, is only marginally so for autistic people.

2.1.3 Alternative Approaches to Autism

A more critical understanding of autism (and other related conditions), *neurodiversity*, is relatively recent. The term has been coined by autistic self-advocate Singer [1999]. The concept refers to neurological conditions that afford unique requirements within a *neurotypical* society. "Neurodiversity is about rejecting the idiom of impairment. It tries to promote an understanding of alternative cognitive styles, their negative and positive sides" [Dalton, 2013, p. 74]. As a movement and theory, neurodiversity stands outside of

the dichotomy between a medical and a social model of disability; it instead opens up a discourse in which variation is celebrated and ties back to Critical Theory [Meekosha and Shuttleworth, 2016], a school of thought focused on "a theory dominated at every turn by a concern for reasonable conditions of life" [Horkheimer, 1972, p. 199]. The approach also comes with a notion of indetermination and inconsistency as well as uncertainty, which makes space for 'autistic heterogeneity' [Hollin, 2017] conceptually allowing individuals to define what autism means for them regardless of external preconceptions.

Neurodiversity does not refer to a single coherent movement, though. While the academic part of it can be referenced and discursively sharpened, in advocacy some lines are blurred. Some proponents, for example, argue for autism to be considered as a 'gift' instead of a disability. However, this ignores the genuine needs some autistic people have to be able to navigate life in a predominantly neurotypical society, in which arguments have to be made by those who are already able (albeit with difficulties) to make themselves heard [Hughes, 2015]. Hence, in this thesis, I adopt an interpretation of neurodiversity, that at its core argues for understanding autism as a neurological variation, while at the same time not ignoring the limiting effects these variations can take on—especially in a society driven by attributing worth to individuals along their ability to contribute to capitalism.

Through an understanding of different cognitive styles and attributing them equal validity[3], we can ask questions about power dynamics. Who defines what autism is and how it is constituted? Who shapes the dominant discourse? Analysing who has the power to speak and be heard about autism, allows us to see it as a constructed disability (such as any other negotiated through language).

> Perhaps Autism will always remain enigmatic, as does so much of the human condition. Thus, I [do not attempt to] locate the "truth" of autism because I suggest that there is no singular, fixed, universal biological truth to be located. Autism is articulated discursively through the nosological clustering of symptoms and through clinical practices of remediation. It is produced through the practices that materially implement the various social discourses (...). I do not deny that there are biological differences: I do not deny that genetics, ontogenetic socialisation factors, and environmental chemicals shape the emergence and expression of our embodiment. Rather, (...) I argue that Autism is an interactive kind and that individuals labelled autistic are fundamentally transformed by that labelling and the subsequent interventions that follow, thereby creating (...) a looping effect. Thus, I argue that the processes of identifying, interpreting, remediating, and performing embodied differences are cultural and historically specific. Autism is not outside of the symbolic awaiting discovery but inscribed and produced through the symbolic. [Nadesan, 2007, p.91f]

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[3]Albeit that, within the medical model, Happé [1999] argues that weak central coherence constitutes a cognitive style without the equalising tone.

This notion of autism [Nadesan, 2007] does not negate the existence of differences or even difficulties. It rather shows how these differences are categorised and how these categories inscribe themselves in the embodied experiences of those identified as 'autistic' [analogous to how gender as a constructed category inscribes itself physically into the bodies of people, see Butler, 1999]. As such, doctors who diagnose people perform a speech act through which an autistic individual is constructed [see for a general understanding of this performance Paget, 1990]. Only rarely is this power, which is firmly attached to the medical profession, questioned. Moreover, even in affirmation of self-diagnosis, this is an occurrence of where medical confirmation has not happened yet [see the analysis of online self-diagnosis by Giles and Newbold, 2011].

Within such a discursive approach, many writers conclude that the categories of disability should be resolved since they become meaningless. After all, 'isn't everyone a little autistic?' Such an interpretation rightly receives critique from authors such as Watson [2012], who states that it is "hard to see how a theory that denies the existence of basic categories can promote the development of communities of resistance" (p.198). However, Watson [2012] lumps the critique over all authors inspired by Critical Theory stemming from "Foucault, Butler, Derrida and Deleuze and Guitarri" (p.197). This move of equalising these authors with other scholars who reference them does them injustice as all of them critically engaged with the formation of the categories. They were often part of resistance movements themselves. For example, Foucault in psychiatry critique and Butler in queer feminist contexts. A constructed category does not necessarily mean it becomes unimportant and should not matter anymore, as Vehmas and Watson [2014] implies; instead, understanding how autism is constructed allows us to challenge the notions we find harmful or unjust about that construct. In that regard, discursive approaches could strengthen communities of resistance and fuel transformative research approaches such as the one in this thesis.

In my approach to working with the children, I try to see them as individuals with whom I engage in design and evaluation activities. While the diagnosis was necessary for participation in the research, in individually encountering a child, I aimed at not seeing the diagnosis alone as their defining aspect, but one characteristic next to their interests, their social environment and their relationship with me.

2.1.4 A Note on Language

When talking about autistic individuals, there are three main ways in which to formulate a reference:

- *identity-first*, also called label-first language, in which the descriptor comes before the larger group, e.g., autistic people.

- *person-first*, where the larger group comes before the descriptor, e.g., people with autism.

- a *mix of both*, which occurs when a text mixes both forms to acknowledge both versions.

Person-first language had been established within a social model of disability to counteract label-first language which was then deemed to be rooted in a medical model. The argument is that by referencing the person before their disability-related descriptor, the person would come into the foreground and the disability would become secondary [Blaska, 1993]. Louis [1999] showed that this hope for a positive change about perspectives on disabilities appears to be unfounded. According to their research, "person-first terminology d[oes] little to lessen negative beliefs and attitudes". Sinclair [2013], an autistic self-advocate, goes even further and ridicules person-first language. Their three arguments against using person-first language are:

- the language detaches the person from their condition as if it would be an additional part and not essential to their identity and being;

- it furthermore plays down the pervasive effects of the condition

- and, lastly, by separating the condition from the person, it becomes something negative, seeing that positive labels such as 'beautiful' or 'smart' are not phrased in a way that detaches them from the person they describe

Additionally, Kenny et al. [2015] established in a large study across the UK that identity-first language is endorsed more by autistic individuals and their social environment (albeit not in a majority) whereas professionals prefer to use person-first language. One way to deal with these results for one's use of language is, how Fletcher-Watson [2016] suggest, to mix both styles to value all opinions on the matter. Because of my background in disability politics, I choose not to. Using identity-first language to me is a political act that acknowledges the preferences of those who are all too often marginalised. However, when talking about a specific child I collaborated with, I acknowledge the preferences of the child and their social environment to honour their agency on the matter.

I use 'allistic person' to refer to a non-autistic person. This term, as coined by Main [2003], stems from the greek ἄλλος meaning 'other' and, hence, references the opposite of αυτός meaning 'self'. The majority of other scientific publications uses 'neurotypical' to refer to allistic people. However, doing so implicitly ignores other neurodivergent conditions such as ADHD or depression [Logsdon-Breakstone, 2013].

2.2 Participatory Design

While this work does not focus in particular on the design processes conducted with the autistic children as part of the OutsideTheBox project, it still contributes to the field of Participatory Design by addressing issues around the evaluation of these practices Bossen et al. [2016]. Hence, I briefly illustrate how my thesis relates to the context of Participatory Design approaches with children and autistic children in particular.

2.2.1   Participatory Design with Children

Starting with early work by Druin [1999], children have become valued stakeholders in participatory design processes. Consequently, a range of methods exist to systematically capture and include their input for and in design processes [e.g. Druin, 1999, Guha et al., 2004, Moraveji et al., 2007, Read and MacFarlane, 2006].

One of the main early contributions relied on conceptualising children's roles within participatory design, given the inherent power dynamics between children and adult researchers. Druin [2002] has more extensively theorised on the roles children can take on in technology research concerning them. Children can then be engaged as *users*, *testers*, *informants* or *design partners*. The order of roles also implies an increase in agency and direct participation. Yip et al. [2017b] rightly pointed out that this leaves adults in that process under-conceptualised. Matching Druin's roles for children, they conceptualised adult researchers' roles as observer, test facilitator, interpreter or design partner. Additionally, Yip et al. uncovered that these roles change over long-term engagements, meaning that sometimes the same adult might act as observer, becoming a design partner, reducing their interaction to facilitation and then interpret a child's opinion towards others. Hence, especially in long-term projects, the relationship between children and researchers is continually evolving.

Schepers et al. [2018] point out, that the agency of children as co-designers could go further than simple participation in researcher's pre-planned sessions by involving them in the design of the process directly. Different critique calls for participatory design with children to also inherit an agenda of empowerment [Ataöv and Haider, 2006]. Participatory design then bears the potential to provide children with design and technology skills they can employ confidently beyond the limits of direct engagement with researchers [Iversen et al., 2018]. One suggestion to achieve this can be to give children the role of a *protagonist* within the design process [Iversen et al., 2017]. However, not all children want to engage that deeply with researchers. Hence, Participatory Design as a field needs to further engage with methods that enable children to participate on their terms and with the amount of engagement they prefer, which might entail providing them with options for withdrawal for parts of the process or entirely [Iivari and Kinnula, 2018].

Within OutsideTheBox, children and researchers were conceptualised as *equal design partners*. My work, specifically, addresses the issue of agency over the engagement with researchers when it comes to participatory evaluation, where autistic children are actively encouraged to shape the goals and the way of achieving them together with the research team. It further provides an extension of the understanding of the role of *tester* within research engagements with children and aims at enabling children explicitly to determine the values and goals of evaluating design processes and their outcomes. As I will show, this procedure also allowed children to engage with new ways of identifying themselves and communicating that identity, following an agenda of empowerment. Finally, by focusing on the process including potential withdrawal, participatory evaluation stays open for different desires when it comes to modes of engagement by different children.

2.2.2 Participatory Design with Autistic Children

Contrary to what a medical model of autism might indicate [e.g., studies by Craig and Baron-Cohen, 1999, suggesting that autistic children have lower scores when engaging with creative tasks], autistic children exhibit creativity – just in unique ways [Best et al., 2015, Diener et al., 2014]. For example, autistic children might be stronger in visual and pattern related creativity and are often remarkably passionate about subject areas that interest them [Grandin, 2009]. Hence, including autistic children in the design processes of technologies (and other artefacts) that are present in their lives, can be beneficial to them, but also the process [see, for example, Keay-Bright, 2007, van Rijn et al., Benton and Johnson, 2015, Parsons et al., 2015, Parsons and Cobb, 2013]. However, due to the characteristics comprising a diagnosis of autism, concrete needs and preferences have to be met when engaging autistic children in participatory research. Tasks need to be presented in a structured, focus and well-defined manner but also allow for the flexibility of emerging constraints [Millen et al., 2011]. Hence, a range of methods is becoming available for researchers to do so productively [cf. Benton and Johnson, 2015, for a review], some of which I briefly discuss here.

The CiC framework (Children in the Centre) structures collaboration through nested influence layers. They specifically target multi-disciplinary participatory design projects with disabled children [Kärnä et al., 2010]. At the centre, the framework focuses on the interests, strengths and needs of a given child or group of children. At outer layers, the child's social context (made up by carers like parents or teachers) are considered. Together, this allows designers to engage with the children in a holistic manner. While this framework provides foundations for a general approach to participatory design with disabled children, it gives less guidance on methods targeting how to develop concrete tasks for specific sessions. Kärnä et al. [2010] do acknowledge this themselves.

Frauenberger et al. [2011] structured their participatory design sessions with neurotypically developing and autistic children (separately) by providing experiences with sensory objects following a narrative. Additionally, their work shows the importance of acknowledging every input as valid and not expecting specific outcomes from the process too rigidly. Similarly, in their later work Frauenberger et al. [2013] show how careful interpretation and hermeneutic engagement with participants' utterings is required for understanding and contextualising their input appropriately. Malinverni et al. [2014] suggest then to also continuously reflect on how processes were meaningful for the participating children and how they provided them with an awareness of their competencies. This might entail entirely diverging from an original plan to appropriately meet the emerging needs a child expresses during a given session.

IDEAS (Interface Design Experience for the Autistic Spectrum) [Benton and Johnson, 2014] is a design framework that bases its core structures and supports on the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) intervention programme [Mesibov et al., 2005]. The same authors also developed a concept that, more generally, provides options for researchers to include a range of neurodivergent

children in design processes, mainly through focusing on their strengths [Benton et al., 2014]. They understand Participatory Design processes as set of four tasks: gaining a solid understanding of the culture and interests of a child or a group of children, tailoring sessions to their individual strengths and desires, ensuring an appropriate structure for the environment the sessions are held in and providing necessary support in tasks and behaviour regulation.

Gaudion et al. [2015b] discuss a designer's approach to involving autistic adults in co-creation processes. They describe their methodology as being driven by their designerly, empathic understanding, rather than by preselected methods. As a lens for reflection on their activities, they used the framework for organising techniques and tools in participatory design proposed by Sanders et al. [2010].

Parsons and Cobb [2014] point out the various entanglements when it comes to participatory design with autistic children. They propose to analyse participation along three different layers: theories, technologies and thoughts. These layers correspond to particular phases in participatory design research: theories are relevant in shaping the project and finding an existing gap for design, technologies come with specific affordances and thoughts refer to participants' contributions and opinions. As an analytical approach, it allows for a deeper understanding of how decisions were formed and what the contributing factors were. However, the analysis is focused on the design and allows less flexibility when it comes to inquiring into other aspects the interaction of autistic children and technologies, such as the children's experiences.

In OutsideTheBox, we built on the work of Benton and Johnson [2014], the CiC framework [Kärnä et al., 2010] and Gaudion et al. [2015b] who all highlighted the need to adapt methods to the children and their environment, to be able to engage them in design processes. We expanded this notion on a suggestion that designers should create a *Handlungsspielraum*, a space in which there is just the right balance between freedoms and constraints to allow autistic children to express their ideas safely [Makhaeva et al., 2016]. Additionally, within the OutsideTheBox project, we identified the necessity of building repertoires of method elements that designers can readily tap into and appropriate as the collaboration unfolds [Frauenberger et al., 2017].

What is missing, however, is a structured way for inquiring into the experiences autistic children have not only with the technologies they co-create, but also the participatory processes themselves. My work targets this gap specifically by aiming at a holistic evaluation process that situatedly can take large parts of the socio-technical context of autistic children and technologies in consideration.

2.3 Technologies for Autistic Children

After establishing my understanding of autism, I will now illustrate which technologies for autistic children have been developed so far. For this purpose, I conducted an extensive literature review. The focus of the review was the purposes these technologies inherit,

how autistic children engage with them and how they can access them. I discuss different aspects concerning development and overall framing before I go into an analysis of different purposes these technologies have and how the children engage with them. Contrary to existing literature reviews, e.g. by Kientz et al. [2013], my analysis particularly focuses on the discursive contexts of these technologies and how they address autistic children and their environment through their design. I focus on the purpose of a technology and, subsequently, how it conceptualises the people using it. This focus allows me to illustrate the underlying gap in more holistic enquiries into autistic children's experiences that explicitly invite them to participate in the research about them.

To understand the work my own builds upon, I conducted an extensive search across different databases and journals. Table 2.1 shows the search items for each publication outlet and how many items the search yielded. The specific outlets were chosen with a focus to understand how the fields of Human-Computer Interaction, Assistive Technologies and Autism focused Psychology discursively conceptualise their technologies and the purposes they come with.[4] The paper search resulted in a total of 2083 initial items, of which I then read all abstracts to see how the paper fits the focus. There were several criteria for keeping a paper in this review round:

- the paper describes a technology which is supposed to be used by autistic children under ten years old.
  This choice of age traditionally includes children in primary school and younger, who might not be quite as technologically immersed as their older peers. While this is a somewhat arbitrary choice as age (measured in years) is not necessarily a good indicator for maturity, it does set a clear demarcation before teenage years.

- the paper is of sufficient depth (longer than five pages), to ensure that the system is not considered as a 'work-in-progress'.
  Focusing on full papers only made the corpus more manageable and functioned as a crude indicator for the depth of the paper.

- the paper covers either the design, system description or the evaluation process of a digital technology.
  This means I excluded papers describing early ethnographic studies for the elicitation of design requirements without a concrete design idea.

Reasons for rejecting a paper included (among others): the technology was only used as a research instrument (e.g., eye tracking, computerised task), the main topic was video modelling, no technology present, other conditions, not written in English, the paper

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[4]While, in hindsight, the results might be obvious, they were not so on the onset of my literature review. I was genuinely interested in understanding how HCI and Autism-focused Journals conceptualise these technologies. I expected to find a much more differentiated picture than I eventually found also because of the associated literature that my PhD draws on, which argues for a more nuanced understanding of autism and the consequences for engaging autistic children.

Database	Keywords	Results	Unique	Date Searched
ACM Guide to Computing Literature https://dl.acm.org/	(autism OR autistic) AND (child OR children) AND (design OR user OR study OR evaluation OR assessment)	492	485	Apr 7th, 2017
hcibib http://hcibib.org	autis* & child*	255	243	Apr 11th, 2017
Disability and Rehabilitation: Assistive Technology[+]	autis* AND child* AND technolog*	41	41	Apr 20th, 2017
Journal of Intellectual & Developmental Disabilty[+]	autis* AND child* AND technolog*	79	58*	Apr 20th, 2017
Autism[+]	child* and technolog*	140	115*	Apr 24th, 2017
Autism Research[+]	child* and technolog*	159	150*	Apr 24th, 2017
Developmental Disabilites Research Reviews[+]	child* AND technolog* AND autis*	84	75*	Apr 24th, 2017
Focus on Autism and Other Developmental Disabilities[+]	child* AND technolog* AND autis*	257	234*	Apr 24th, 2017
ingenta connect http://www.ingentaconnect.com	child* AND autis* AND technolog*	44	38*	Apr 25th, 2017
Journal of Applied Research in Intellectual Disabilities[+]	child* AND technolog* AND autis*	111	101*	Apr 25th, 2017
Journal of Autism and Developmental Disorders[+]	child* AND technolog*	624	514*	Apr 25th, 2017
Research on Autism Spectrum Disorders[+]	child* AND technolog*	208	207*	Apr 26th, 2017
Journal of Child Computer Interaction[+]	autis* AND technolog*	15	13*	Apr 26th, 2017

Table 2.1: Sources for the literature review and how many items in the corpus they yielded; [+] Journal; * Excluded Book Reviews, News, Letters to the Editors, Call for Papers, Lay Abstracts, Editorials and similar items not representing a full paper

being a review paper or the reference to autism being used off-handedly to describe a potential, but not initially intended or tested. Additionally, I removed all papers that are part of this work as they would have skewed the corpus. After this round, 314 articles were left in the corpus. All of these papers received a skim read to assess how they related to the focus. For example, not in all papers, the age of participants was clear from reading the abstract. Comparisons between two technologies were also excluded as they comprise a specialised form of evaluation. In the end, 181 papers were read in full and built the basis for further analysis.

2.3.1   Discourse Analysis

To get a handle on the amount of data, I first conducted the first five steps (Familiarisation, Initial Coding (see also Appendix 10.3), Theme Search, Theme Review, Naming and Definition) of Thematic Analysis according to Braun and Clarke [2006]. For my analysis of the corpus, I drew on Discourse Analysis as a method for making sense of themes across a range of texts [Jaeger and Maier, 2009][5]. The method originates from the works of Foucault on how norms are established within society [Foucault, 1971, 1982a]. He was concerned with understanding how knowledge is constructed through texts and language. Consequently, *statements*, *syntax* and *semantics* within a *dispositive* are in the centre of any discourse analysis [Brown and Yule, 1983]. I aim to uncover the limits of what can be said within the context of research articles describing technology research for autistic children. The form in which texts can appear is influenced by the dispositive. Hence, within this literature analysis, I limit my selection to research publications, even though I could have also included popular news outlets or app store reviews in the overview.

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[5]I will return to a more extensive discussion of Discourse Analysis as a methodological approach for understanding data beyond text in Section 5.1.3.

A discourse itself is then established by how something is constructed through language and practise. My analysis focuses on the purposes of technologies for autistic children and how these influence how the field conceptualises autistic children as users of these technologies. I provide an intertextual understanding of what is discursively established across these publications. While my work can be classified as descriptive discourse analysis [Gee, 2014], I augment this with a critical discussion on how autistic children appear as stakeholders within the technology research concerning them.

In HCI, discourse analysis has been used to understand concepts and how it constitutes its discourse about these concepts across several texts. This has lead to an increased understanding of environmental discourses in HCI as well as directions for future research [Goodman, 2009], a picture of how ageing is negotiated [Vines et al., 2015] and what the effects of the shift from 'user' to 'maker' on HCI research are [Roedl et al., 2015]. Hence, Discourse Analysis constitutes a suitable method when aiming at an understanding of how concepts are constructed through certain texts within an area of HCI.

As an interpretive method, it requires readers to understand the position from which the authors speak, the biases they come with when entering the work and their experience with the subject matter. My motivation for this review comes from trying to understand how my work differed from existing approaches with the desire to have a rigorous argument for my understanding and conceptualisation of the assessment of autistic children's experiences. Considering that both parts of my methodological approach, Thematic Analysis and Discourse Analysis build upon a constructivist epistemology, it is assumed that the knowledge is created by me as the person who engages with the corpus. Epistemologically, both methods also acknowledge that others conducting the same or similar analyses on the same corpus might construct different findings and interpretations. Hence, concepts such as inter-rater reliability as are common in a more pragmatic or post-positivist epistemology are less suitable for evaluation of the results compared to, e.g., transparency, rigour and consistency of the argument.

2.3.2 Overview of Selected Papers/Research Projects

In my final analysis, I included 181 papers across 147 research projects. Research projects, which have published their findings more than once are denoted in Table 2.2. Notably, the ECHOES project leads the table with ten publications only within the narrow search parameters of this survey. While the first mention of computing technology potentially being a suitable way to engage autistic children in tasks can be found much earlier [Colby, 1973], the first project in the corpus was published in 1990 [Repp and Felce, 1990].

As can be seen in Figure 2.1, until 2003, there were only single papers published discussing technological projects for autistic children. Around 2005, there was a slight increase in projects which took off between 2012 and 2016 and appears to be still going strong[6]. This trend shows that papers on technologies for autistic children are manifold and reach considerable interest within the research community. Hence, it is all the more important

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[6]considering that for 2017, I only took the first four months of the year into account

Project	#	%	Project	#	%	Project	#	%
Autinect	2*	1.1%	GIPY-1	2	1.1%	KASPAR	3	1.7%
AutVisComm	2	1.1%	MEDIATE	2	1.1%	Abaris	4*	2.2%
Baldi	2	1.1%	Mosoco	2	1.1%	ABCD SW	4	2.2%
CareLog	2*	1.1%	SmartBox	2	1.1%	Aurora	4	2.2%
CHARLIE	2	1.1%	Spoken Impact Project	2	1.1%	ECHOES	10	5.5%
COSPATIAL	2	1.1%	TouchStory	2	1.1%			
FaceSay	2	1.1%	Walden	2*	1.1%			

Table 2.2: Projects with more than one publication within the corpus.

to construct an overview describing larger trends about which types of technologies are in focus (to find out about those which are neglected) and how autistic children can interact with them.
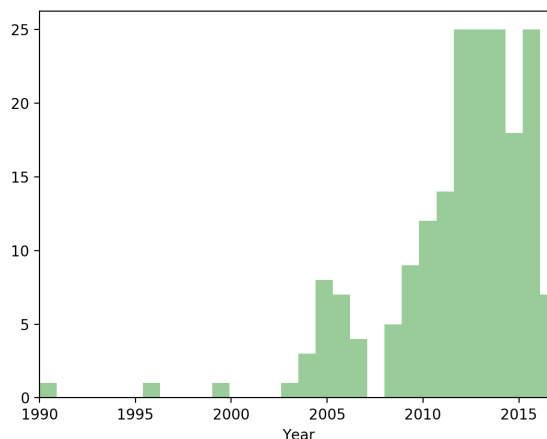
Figure 2.1: Histogram for papers along publication date

In an analysis of the author keywords (see Table 2.3), I grouped individual keywords which were similar (e.g., autism, ASD and ASC) to create a succinct description for how the papers in the corpus situated themselves. I noticed that social interaction is the most referred to keyword-class next to autism. Differences in social interaction being one of the core defining characteristics of autism, this comes as no surprise. 'Robots', as technology, is most highly ranked within the keywords. Other keywords target context of use (therapy, game), design, technology (tablet, VR, technology) or application domain (language, emotion recognition). Notably, the keyword category of 'children' (including 'autistic children') is mentioned comparatively less considering my search parameters.

Keyword	#	%	Keyword	#	%
Autism	144	79.6%	tablet/smartphone	22	12.2%
social interaction	60	33.1%	games/play	19	10.5%
robots	45	24.9%	language/speech	15	8.3%
therapy	36	19.9%	virtual/augmented reality	13	7.2%
children	33	18.2%	emotion recognition	12	6.6%
design	28	15.5%	technology	10	5.5%

Table 2.3: Prominent keyword categories that occurred more than ten times.

Subsequently, robots are one of the most commonly used technologies as can be seen in Figure 2.2. Other popular approaches are game-based or rely on screens (either stationary or mobile). About a fifth (32, 17.8%) of the papers deal with technologies affording more intuitive use, such as ubiquitous technologies, interactive environments or tangibles.
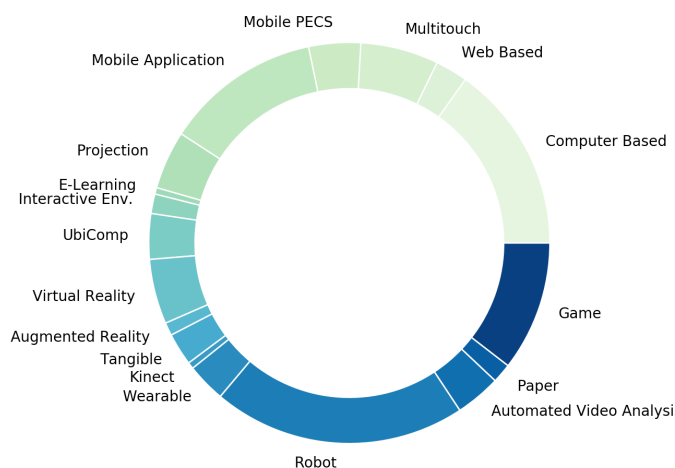
Figure 2.2: Technologies used throughout papers in the corpus

Table 2.4 presents the list of publication outlets that occur five or more times within the final corpus. About 10% of the papers come from two psychological journals (ten from *Autism and Developmental Disorders* and nine from *Autism*). Only 24 of the 65 (36.9%) papers in the most commonly represented journals are from Psychology; the others stem from general (13, 20.0%), children-related (14, 21.5%) or accessibility-oriented (14, 21.5%) HCI. However, technology for autistic children is discussed most prominently in Psychology and Computer Science and less so – as one might have expected – in the field of Education or in a concentrated way at publication outlets primarily targeted by scholars within Robotics.

Publication	Name	#	%
Journal	Journal of Autism and Developmental Disorders	10	5.5%
Journal	Autism	9	5.0%
Conference	ACM Interaction Design and Children (IDC) Conference	9	5.0%
Conference	International Conference on Universal Access in Human-Computer Interaction	8	4.4%
Conference	ACM CHI Conference on Human Factors in Computing Systems	7	3.9%
Journal	Personal and Ubiquitous Computing	6	3.3%
Conference	International Conference on Computers for Handicapped Persons	6	3.3%
Journal	Research in Autism Spectrum Disorders	5	2.8%
Journal	International Journal of Child-Computer Interaction	5	2.8%

Table 2.4: Prominent publication outlets (five or more times listed in the corpus).

As design processes give an indication whose expertise is relevant to the design of a given technology, I analysed which were used how often among the corpus. A vast majority of the papers (138, 76.2%) base their designs on existing literature without direct stakeholder participation. These authors reviewed the associated topic to their subject of interest and then designed and developed a technology based on their reading of what appears to be necessary. In 9.4% (17) of all papers, a Participatory Design approach is described.

Of the 17 (9.4%) projects involving stakeholders in design (as in User-Centred Design, Informant Design and Participatory Design), seven (41.2%) involved the autistic children directly in the design processes (AutVisComm [Sampath et al., 2012], CAPES [Braz et al., 2014], Pico's Adventures [Malinverni et al., 2017], ECHOES [Frauenberger et al., 2013], MyCalendar [Abdullah and Brereton, 2015], COSPATIAL [Alessandrini et al., 2014], Responsive Dome [Brown et al., 2016]). Other stakeholders included teachers (9, 52.9%), therapists (6, 35.3%), family members (9, 52.9%) or various other professionals dealing with autism from a researcher or practitioner perspective (4, 23.5%). Note that one project might involve more than one type of stakeholder. However, about a third of the projects actively allowing non-researchers to participate in the design processes did not consider involving the perspective of the children themselves in the design of their technologies (see for a more extensive review on this issue, Benton and Johnson [2015]).

I listed common evaluation methods in Table 2.5. 37.2% (67, 52.9%) of the papers used observations as their main source for determining the validity of a given technology. In 27 (or 14.1%) there was no indication for planned or given evaluation. Hardly any projects investigated directly into the children's perspectives on an artefact or software[7], but rather inferred their perspective either from observations, via proxies (e.g., parents or teachers) or not at all. Hence, autistic children have little direct say in how technology for them is made meaning of.

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[7]Exceptions are discussed in more detail below.

Evaluation	#	%	Evaluation	#	%
observations	71	39.2%	questionnaires	9	5.0%
learning outcomes	21	11.6%	questionnaires with adults	5	2.8%
task performance	15	8.3%	expert heuristic	4	2.2%
usability	13	7.2%	other	22	12.2%
proof of concept	11	6.1%	planned	14	7.7%
interviews with adults	10	5.5%	no indication	27	14.9%

Table 2.5: Forms of evaluation in projects involving technologies for autistic children

Across the 181 papers in my corpus, I find a diverse range of projects, technologies as well as design and evaluation methods. I now show how I analysed them along the purpose and technological conceptualisation of systems for autistic children as well as how the discursive power in such projects is distributed.
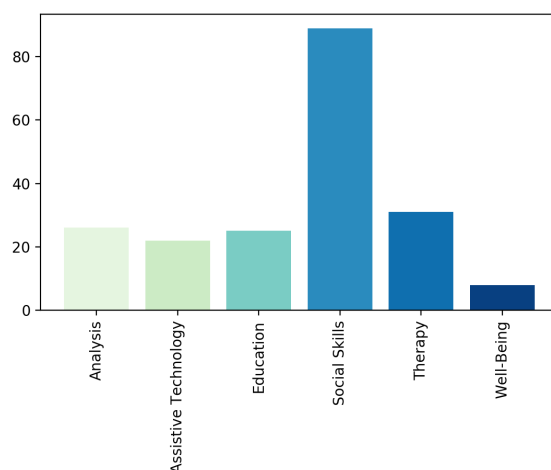
Figure 2.3: Distribution of purposes of technologies for autistic children; x-axis depicts the counts of paper sorted into a certain category

2.3.3 Purpose of the Technologies

I analysed the given purpose of each technology-related paper in my final corpus. Figure 2.4 shows all final codes and subcodes in relation to each other. I aimed to make the codes abstract enough to cover a core concept expressed in a paper. Even so, some of the concepts (e.g., 'Educating Classmates' [Bratitsis, 2016]) only have one reference. These papers have a unique purpose not seen in other papers within the corpus and through that offer an opportunity for further development in that area.

If the technology itself has a different purpose, the paper has been coded for the technology and the overall aim of the paper. For example, a technology might have a purpose of being a communication aid while at the same time structuring daily activities as a visual aid as is the case with Garrido et al. [2006]. Hence the overall sum of purposes (196) exceeds the number of papers within the corpus (181).
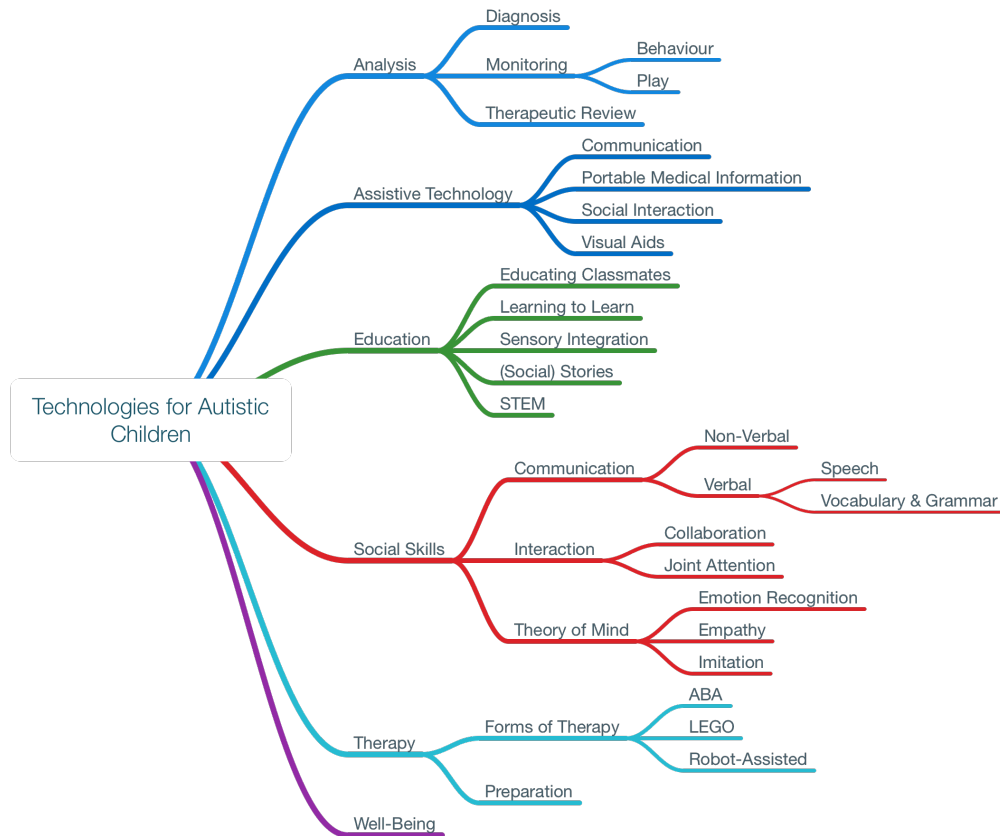
Figure 2.4: Purpose of technologies for autistic children

In this section, I discuss how different purposes shape the resulting technologies and how the meaning of said technologies is subsequently established. My aim is not to cover all of the papers in detail but to provide a critical overview of the space in which technologies for autistic children are created.

Categories: Analysis

I have categorised technology as having an analytical purpose if it records data on aspects, analyses the data and presents its interpretation in the form of results for people to review. Out of all papers in the corpus, 13.6% (or 26) follow this goal. In the context of autistic children, analysis consistently means video analysis or wearables which record movement patterns. These technological observations then classify behaviour to infer a

potential diagnosis, monitor progress (with a particular focus on behaviour during play activities) and reflect on therapy sessions for continuous improvement. 80.8% of papers classified as 'Analysis' papers monitor the behavioural response of autistic children.

Technologies in that space (see Table 2.6) analyse different aspects of the lives of autistic children with different agendas driving the analysis. Some aim at providing *diagnostic* information through a computer-based game [Sehaba et al., 2005]. Others try and support therapists in reviewing their work and the children's therapeutically defined progress in the form of an automated capture and access application consisting of a webcam, a microphone and an Anoto-Pen as well as a computer-based program for analysing the data [Kientz et al., 2005]. Monitoring technology can be focused on aspects such as behaviour or – more specifically – behaviour during play activities. However, some of the technologies more generally aim at monitoring the children's development, e.g. through a portable audio/video recorder [Vosoughi et al., 2012]. When focusing on the behaviour of children, the resulting technologies use, for example, sensors in smartphones [Chuah and Diblasio, 2012] or cameras embedded in computers to analyse the children's attention while they interact with a program [Mohamed et al., 2006]. All projects monitoring play behaviour use social robots to do so, indicating that robots can be conceptualised as play partners [Wong et al., 2012, Boccanfuso et al., 2016, Francois et al., 2007].

These technologies are, by default, more on the periphery of the lives of autistic children. Especially the part that is focused on analysing is hidden and ephemeral as it does not require active engagement by the children. Instead, the children are passive and provide input to the systems as data sources. These technologies are then used to make meaning about the behaviour and condition of the children. An exception – to some extent – is the monitoring of behaviours during play as facilitated by social robots. However, the monitoring part is not necessarily apparent or even transparent to the children; they play with the robots and focus on playing whereas the purpose of the robot is to monitor and analyse the behaviours the children exhibit during the activity. While the child interacts with a play partner, they do so for an external purpose, namely monitoring their behaviour during play.

Hence, autistic children are *secondary users* when it comes to analysing technologies as they are primarily directed at their carers. Even when interacting directly, e.g., with a robot, they have limited power over initiating the setting or choosing the specific activity. For example, Wong et al. [2012] envision robot interaction be constrained by special needs education, Boccanfuso et al. [2016] embed play in a diagnostic procedure, and Francois et al. [2007] similarly suggest an educational and therapeutic setting outside of self-guided play. This does not mean, that the children might not exhibit innate desires to engage with a robot when presented with the opportunity, but that the dispositive and setting are primarily dominated by their allistic environment. Following this passive interaction paradigm, it also becomes clear, that the act of analysing autistic children's behaviours usually comes with an additional *classification* of what autistic children do. They are not viewed as individual people by the technologies and – by extension – the adults using them, but rather as generators of classes of behaviour which then lead to

Purpose	References	#
Analysis		**25**
Diagnosis	Sehaba et al. [2005]	1
Therapeutic Review	Kientz et al. [2005], Artoni et al. [2011b], Repp and Felce [1990], Bartalesi et al. [2014]	4
Monitoring	Kientz et al. [2005], Walczak et al. [2012], Vosoughi et al. [2012], Xu et al. [2009], Bartoli et al. [2014], Hayes et al. [2004], Kientz [2012], Karaboncuk and Ersavas [2008], Kientz et al. [2006, 2007], Nazneen et al. [2012, 2010]	12//20
Behaviour	Alhalabi et al. [2014], Nazneen et al. [2010], Mohamed et al. [2006], Kong et al. [2016], Chuah and Diblasio [2012]	5
Play	Wong et al. [2012], Boccanfuso et al. [2016], Francois et al. [2007]	3

Table 2.6: Occurrence count of purposes of technologies for autistic children along instances of references in the corpus that are categorised as Analysis

further actions towards the children. The technologies act here as mediators for the adults' interpretation of the children's behaviour and facilitate further decision making that impacts their life.

Categories: Assistive Technology

Assistive technologies aim at functionally supporting autistic children in specific contexts. They are intended to alleviate perceived deficits autistic children are assigned to have. Among all technologies in the corpus (see Table 2.7), 11.5% (22) are of this traditional class of technology, with 40.9% of these being communication aids (falling into a class of Augmentative and Alternative Communication (AAC)). Another eight papers assist in social interaction, 18.2% offer visual aids for structuring daily activities, and only one provides a system for portable medical information. It should be noted, that more publications and research projects concern similar technologies. However, they do not necessarily explicitly concern autistic children.

Following a more classical notion of assistive technologies as mitigators of functional limitations, AAC devices prominently use pictures and associated audio output (e.g., in Torii et al. [2013]) to enable nonverbal children to communicate in a way the adults around them can comprehend. Existing physical devices with buttons can be expanded with more options when implemented as a virtual layer. Visual aids (e.g., Zamfir et al. [2012]), on the other hand, allow carers to communicate tasks and events in the near future in a structured way to autistic children. Technologies aiming at general social

communication are used to guide the children in behaviour that is deemed appropriate (e.g., Zakaria et al. [2016]), to understand more about the current social-emotional context as established by others and oneself (e.g., Rosenbloom et al. [2016]) or prompt them to initiate social interaction, for example, through vocalisations (e.g., Hailpern et al. [2009b]). Finally, the application providing portable medical information to autistic children [Jiam et al., 2017] can communicate individual needs to those assisting in crisis situations, where a child might not be able to express them otherwise.

From the perspective of autistic children, the technologies extend them much in a Heideggerian understanding of a tool [Heidegger, 1927] or function as a lens into their environment. They use them whenever their own body and modes of expression do not get something across or cannot make sense of what the environment is telling them when it fails to communicate in ways that autistic children understand. As the technologies are conceptually tied to a notion of inadequacy, they inherently symbolise an understanding of an autistic child as one that lacks something, misses out and is not able to do certain things that are expected of children. While this might be inherent to the purpose and, in extension, to all assistive technology at least to some regard, it also depends on *who* defines assistive needs *how*. Within the given projects here, I found that researchers, often in cooperation with other adults, identified the need and how it should be addressed. A different approach would be to work with the children to create assistive technologies, similar to what can be seen below in Section 4.3. However, refusing to use the technologies can be a revolutionary act of defining and conceptualising the self as a powerful, but different entity.

Purpose	References	#
Assistive Technology		**22**
Communication Aid (AAC)	Garrido et al. [2006], Leo et al. [2011], Sampath et al. [2013], Boesch et al. [2013], Gevarter et al. [2014], Torii et al. [2013], Schlosser et al. [2007], Abdullah and Brereton [2015], Voon et al. [2015]	9
Visual Aids	Barros et al. [2014], Abdullah and Brereton [2015], Hirano et al. [2010], Zamfir et al. [2012]	4
Social Interaction	Yin and Tung [2013], Tentori and Hayes [2010], Yee et al. [2012], Hailpern et al. [2009b], Tartaro and Cassell [2008], Mower et al. [2011], Rosenbloom et al. [2016], Zakaria et al. [2016]	8
Portable Medical Information	Jiam et al. [2017]	1

Table 2.7: Occurrence count of purposes of technologies for autistic children along instances of references in the corpus that are categorised as Assistive Technologies

While autistic children are the *primary users* of assistive technologies, the use of these technologies happens out of a shared desire for understanding between autistic children and allistic adults/environment. However, the communication is limited to aspects that

designers of these technologies have implemented. As autistic children are sometimes included in the design of these technologies (for example, Abdullah and Brereton [2015], Hirano et al. [2010]), this could be a non-issue; however, for autistic children, who use these technologies in their everyday life, the range of assistance is limited to the needs of an outside world or what that world assesses and prioritises their needs. Regardless, augmented communication or visual aids can be useful tools in specific contexts. However, the aim is to make autistic modes of communication more accessible for an allistic environment instead of putting similar efforts into the reverse.

Categories: Education

Educational technology provides autistic children with knowledge content that supports them in learning. Overall, 25% of the papers in the corpus had an educational purpose (see Table 2.8), where seven of them address more general learning skills not related to a specific topic. Only one of them is not directly targeted at autistic children but aims at eliciting empathy for autistic classmates from allistic classmates [Bratitsis, 2016], which embeds the paper chiefly within the social model of disability. About a third concerns the contextual setting for learning and assists autistic children in acquiring meta-skills that are essential to learning. Content-wise the papers focus on sensory integration (3), storytelling and social stories as a way to understand narrative and social interaction (7) and topics of science, technology, engineering and mathematics (STEM; 6).

Most technologies that have been categorised as generally educational discuss different forms of content provision (e.g., Konstantinidis et al. [2009]) or show how different therapeutic principles can be adapted (e.g., Artoni et al. [2011a] for Applied Behavioural Analysis (ABA)). To elicit empathy for autistic peers Bratitsis used digital storytelling Bratitsis [2016]. Supporting autistic children in learning to learn is based, for example, on Internet-of-Things (IoT) devices [Sula et al., 2013], augmented reality [Escobedo et al., 2014a] or uses a visual game for generalisations skills [Gruarin et al., 2013]. As integrating the input from different senses seems to be notoriously taxing for autistic children, some technologies target that skill specifically through virtual reality applications [Bekele et al., 2014b], tangibles [Jung et al., 2006] or body capture on a projected screen [Ringland et al., 2014]. Narration and storytelling also receives extra attention, especially when it comes to social stories (e.g., Davis et al. [2007]. These technologies are all screen-based. Finally, several papers focus on STEM-topics by providing learning environments (e.g., Santos et al. [2016], Sula et al. [2014]), interactive e-books (e.g., Hulusic and Pistoljevic [2015]) or robots (e.g., Lindsay and Hounsell [2017-10-03]).

Educational technologies potentially offer autistic children new opportunities to learn more about the world and the social contexts they live in. While this might allow them to feel safer and more sure-footed in an environment that is tailored to neurotypical needs, encountering new things comes with the associated cost of stepping outside a comfort zone of known parameters and adding others. Hence, the technology and its context might be associated with anxiety, especially, if they are not part of a routine, but instead singular in use.

Purpose	References	#
Education	Artoni et al. [2011b], Alessandrini et al. [2014], Vidakis et al. [2014], Artoni et al. [2011a], Lányi and Tilinger [2004], Buzzi et al. [2013], Konstantinidis et al. [2009]	**7//25**
Educating Classmates	Bratitsis [2016]	1
Learning to Learn	Sula et al. [2013], Porcino et al. [2015], Vullamparthi et al. [2011], Doenyas et al. [2014], Strickland [1996], Bhattacharya et al. [2015], Gruarin et al. [2013], Escobedo et al. [2014a]	8
Sensory Integration	Bekele et al. [2014b], Ringland et al. [2014], Jung et al. [2006]	3
(Social) Stories	Sula et al. [2014], Dillon and Underwood [2012], Alessandrini et al. [2016], Browder et al. [2017], Davis et al. [2007, 2006], McKissick et al. [2013]	7
STEM	Lindsay and Hounsell [2017-10-03], Sula et al. [2014], Santos et al. [2016], Hulusic and Pistoljevic [2015], Escobedo et al. [2014b], Sitdhisanguan et al. [2012]	6

Table 2.8: Occurrence count of purposes of Educational Technologies for autistic children along instances of references in the corpus

The children directly engage with these technologies as *primary* users in that they are supposed to learn from what they provide. However, they do so with limited agency as the content is either given by the system or set by teachers around them. I am not arguing that autistic children should not be educated or that these technologies are not appropriate for them. However, I want to point out that there is a lack of educational technologies with which the children can engage in a self-driven manner. They are more tied to curricula and external learning goals than supporting the children's potential exploratory curiosity. Essentially, carers set the topics of interest and choose the time and place for interaction with one of these technologies.

Categories: Social Skills

Most of the technologies for autistic children concern social skills (see Table 2.9 and 2.10). They target areas of acquiring social skills, facilitating social situations or supporting the children during these moments. Contrary to the subcategory of 'Social Interaction' that is part of Assistive Technologies, these technologies eventually become obsolete through their use. 48.1% of papers fall into this category; no surprise considering the conceptualisation of autism as a disability that becomes apparent in social situations. The skills concern communication (25.8%), non-verbal and verbal, where verbal aspects are again split into formal (vocabulary and grammar) and informal (speech) elements.

Further, the papers discuss parameters of interaction (34.8%), concretely collaboration and joint attention. Finally, 23.6% of papers concern themselves with Theory of Mind. In this subcategory, most technologies aim at emotion recognition, followed by imitation and only two concern empathy directly.

Purpose	References	#
Social Skills	Tartaro et al. [2014], Agarwal et al. [2013], Hopkins et al. [2011], Fletcher-Watson et al. [2016a], Frauenberger et al. [2011], Giusti et al. [2011], Bamasak et al. [2013], Chuah et al. [2014], Escobedo et al. [2012], Kim et al. [2013], Zancanaro et al. [2011], Ben-Sasson et al. [2013], Didehbani et al. [2016], Volioti et al. [2016]	14//**89**
Communication	Sampath et al. [2012], Porcino et al. [2015], Fletcher-Watson et al. [2016b], Alcorn et al. [2013], Hetzroni and Tannous [2004], Hajela et al. [2013], Holt and Yuill [2017], Hailpern et al. [2009a], Signore et al. [2014]	9//23
Non-Verbal	Palestra et al. [2016], Tsai and Lin [2011], Robins et al. [2012], Suzuki et al. [2016]	4
Verbal	Wadhwa and Jianxiong [2013]	1//9
Vocabulary & Grammar	Bosseler and Massaro [2003], Ganz et al. [2014], Whalen et al. [2010], Massaro and Bosseler [2006], Hulusic and Pistoljevic [2015]	5
Speech	Silva et al. [2014], Rahman et al. [2011], Wojciechowski and Al-Musawi [2017-02-01]	3

Table 2.9: Occurrence count of purposes of Social Skills Technologies for autistic children relating to Communication

The technologies used to facilitate social skills learning and actualised behaviour according to those skills are manifold. For example, Didehbani et al. use a virtual reality platform to provide social cognition training elements to autistic children [Didehbani et al., 2016]. In one of the rare cases of Participatory Design in the context of social skills acquisition, Porcino et al. [2015] created a game through which autistic children can engage more with communication. On the other hand, robots are used to teach the more nuanced aspects of nonverbal communication (e.g., Palestra et al. [2016]), whereas verbal components such as vocabulary [Ganz et al., 2014] and speech patterns (e.g., pronunciation in Wojciechowski and Al-Musawi [2017-02-01]) tend to use more classical forms of screen-based interfaces – on either mobile or stationary devices. Interactive technologies tend to be mobile (e.g., Ahmad and Shahid [2015]), or – as it is the case for most cooperative technologies – facilitated via large displays (e.g., Herrera et al. [2008]) or physicalised technologies (e.g., tangibles Villafuerte et al. [2012]) or robots [Robins et al., 2009]. Whenever joint attention is the subskill autistic children should acquire, technologies facilitate this in different ways, e.g. combining rhythm and robotics [Srinivasan et al., 2016b], embedding robots within a larger technological system [Bekele et al., 2014a] or, again, using screen-based methods [Zheng et al., 2015]. Technologies addressing theory of mind use narration [Galitsky, 2013] and – chiefly when focusing on emotion recognition – virtual or realistic facial representations (e.g., Moore et al. [2005], Sauvain and Szilas [2009]. Rarely, the concept of emotional expressions on the entirety of a human body is conveyed (examples include Alcorn et al. [2011]). Empathy is taught only (through virtual reality [Muñoz

et al., 2012] and computer software [Cheng et al., 2010]) and not facilitated in action. Finally, robots are often used to encourage (and observe) autistic children imitating others (e.g., Fujimoto et al. [2010]).

Purpose	References	#
Social Skills		**89**
Interaction	Villafuerte et al. [2012], Hagiwara and Smith Myles [1999], Porayska-Pomsta et al. [2013], Bernardini et al. [2012], Ahmad and Shahid [2015], Porayska-Pomsta et al. [2012], Lee et al. [2014], Robins et al. [2006], Bernardini et al. [2014], Giannopulu [2013], Zancanaro et al. [2014], Bernardini and Porayska-Pomsta [2013], Robins et al. [2005]	13//31
Collaboration	Battocchi et al. [2009], Brok and Barakova [2010], Gal et al. [2009], Boyd et al. [2015], Huskens et al. [2015], Farr et al. [2010a], Wainer et al. [2010], Herrera et al. [2008], Robins et al. [2009], Wright et al. [2011], Farr et al. [2010b]	11
Joint Attention	Zheng et al. [2015], Bekele et al. [2014a], Sharma et al. [2016], Alcorn et al. [2011], Srinivasan et al. [2016b,a], Warren et al. [2015]	7
Theory of Mind	Galitsky [2013], Holt and Yuill [2017]	2//21
Emotion Recognition	Piana et al. [2016], Palestra et al. [2016], Lacava et al. [2010], Moore et al. [2005], Rice et al. [2015], Matsuda and Yamamoto [2014], Lorenzo et al. [2016], Sauvain and Szilas [2009], Christinaki et al. [2013], Costa et al. [2013b], Schweiger et al. [2014], Alves et al. [2013], Kaliouby and Robinson [2005]	13
Empathy	Muñoz et al. [2012], Cheng et al. [2010]	2
Imitation	Chevalier et al. [2017], Duquette et al. [2008], Fujimoto et al. [2010], Holt and Yuill [2017]	4

Table 2.10: Occurrence count of purposes of Social Skills Technologies for autistic children for Interaction & Theory of Mind

As it is debatable, which social skills autistic children might have and how they might socially express themselves differently, these technologies are a source of learning and encountering new aspects about how to interact with others. They can, similarly to educational technology, at the same time be a source of social anxiety [Kuusikko et al., 2008] or enable them to learn strategies that allow them to engage with a predominantly neurotypical environment. However, different from education, these technologies are very one-sided. The children are required to learn the modes of interaction that are deemed appropriate by neurotypically presenting adults. However, it could also be imaginable that those adults inform themselves more on how autistic children might want to engage or reflect on the notion of withdrawal as social interaction. As it stands, interacting with the technologies happens in a space where autistic children are required to engage with

something that they might feel uncomfortable with as first-person accounts of autistic people indicate (e.g., for eye contact Grandin [1995b]).

While autistic children are the *primary* users of this type of technology, allistic people around them are secondary users. The content of these technologies is driven by the perceived functional deficits that comprise a diagnosis of autism and the social aspects of the condition. Hence, the efforts are at teaching autistic children how a neurotypical society expects them to engage instead of (also) teaching neurotypically presenting people about the many ways in which autistic children might prefer to communicate and how to be attentive to a specific child. While learning contexts and disciplining technology for facilitating social interactions in-situ are very dominant, I also found a lot of games and play scenarios aimed at improving the social skills of autistic children. However, in such a context play is always associated with an extrinsic purpose. It is not conceptualised as positive experience by itself but is embedded in an agenda. Hence, play for autistic children – as conceptualised by this corpus – is a necessarily extrinsically productive activity, that results in behaviour a mostly neurotypical society deems as appropriate.

Categories: Therapy

Within the corpus, 16.8% of papers discuss technologies for therapeutic settings (see Table 2.11). Most of them target a specific therapy, even though 'robot-assisted' therapy is not a formalised approach, but instead includes robots in medicalised therapy, whereas Applied Behaviour Analysis (ABA)[8] and LEGO-based activities[9] consist of formal paths. Only three papers explicitly assist carers in preparing therapeutic sessions.

The technologies which are just generally subsumed under 'Therapy' show no orientation on a cohesive therapy or commonalities on a technological level. For example, Alessandrini et al. [2014] suggest the use of audio-augmented paper for therapeutic sessions, whereas Caro et al. [2017] created an exertion game engaging in motor coordination exercises and Pickard et al. [2016] again discuss how a physically absent therapist can be enabled to guide parents through an intervention. When it comes to ABA, most of the technologies are computer-based and support either structured learning (e.g., Bartalesi et al. [2014]) or constant monitoring of therapeutic efforts (e.g., Kientz et al. [2005]). Both papers concerning LEGO therapy [Barakova et al., 2015, Huskens et al., 2015] use robots as well as all papers concerning robot-assisted therapy[10] (e.g., Mazzei et al. [2012], Yun et al. [2016]). Hence, the most considerable opportunity space for technologies in therapy use is seen in incorporating robots. For the preparation of content in technologies used in therapeutic contexts, an authoring tool for social stories [Constantin et al., 2013] and a game engine for serious games [Schweiger et al., 2014] are available.

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[8]A rigorous approach of analysing and reinforcing desired behaviours [Baer et al., 1968].

[9]Largely based on structured play with LEGO blocks as developed by LeGoff [2004].

[10]This is not a structured or well-defined approach, but instead, robots assist more generally within therapeutic settings that are defined otherwise. The expectation there is that autistic children might find it easier to interact with a robot and then be able to transfer skills acquired in such a setting towards more complex interactions with other humans [Cabibihan et al., 2013].

Some of these technologies have already briefly been discussed under an analysis angle as only peripherally relevant to the children or, for the educationally relevant technologies, as only partly intended to be interacted with by the children. However, I found it notable to see how many of these projects try to involve robots in therapy. Mostly, this stems from the notion that autistic children appear to appreciate structure and predictability [Colby, 1973]. Hence, incorporating robots might be a gateway for interaction with allistic humans, and ultimately preferable from the viewpoint of autistic children. The context in which these technologies are embedded in might ultimately be more relevant than potential differences in experiences with different technologies.

Purpose	References	#
Therapy	Harris and Summa-Chadwick [2005], Yan [2011], Alessandrini et al. [2014], Caro et al. [2017], Friedrich et al. [2015], Pickard et al. [2016]	6//**31**
Preparation	Constantin et al. [2013], Schweiger et al. [2014]	2
Forms of Therapy		22
ABA	Repp and Felce [1990], Bartalesi et al. [2014], Artoni et al. [2011b], Buzzi et al. [2013], Venkatesh et al. [2012], Kientz et al. [2005]	6
LEGO	Huskens et al. [2015], Barakova et al. [2015]	2
Robot-Assisted	Huskens et al. [2015], Boccanfuso and O'Kane [2010], Boccanfuso et al. [2017-03-01], Yun et al. [2016], Giannopulu and Pradel [2012], Goodrich et al. [2012], Dautenhahn et al. [2009], Barakova et al. [2015], Bonarini et al. [2016], Kim et al. [2015], Costescu et al. [2015], Stanton et al. [2008], Mazzei et al. [2012], Ranatunga et al. [2012], Kim et al. [2013], Costa et al. [2013a]	15

Table 2.11: Occurrence count Technologies for Therapy for autistic children along instances of references in the corpus

The notion of dedicated therapeutic interventions and using technology in them comes from a medicalised view of autism. While even autistic self-advocates do not deny that there is a place for therapeutic interventions in working with autistic children [for example, Grandin, 1995a], the therapies these technologies focus on are highly debated. A popular therapy addressed by technologies in this space is ABA, probably because the structure and demand for documentation lend itself to automated processes. However, first-person accounts of adults who experienced ABA [Sparrow, 2016] and even former therapists indicate that it is a very stressful procedure for the child, which in parts can be deeply traumatising – potentially leading to Post-Traumatic Stress Disorder (PTSD) [birdmadgrrl, 2017]. Seeing as the approach requires up to 36 hours of weekly intervention [Eldevik et al., 2010], the children are expected to have therapy to the extent of a full-time job. The relevant papers in this space do not engage in the controversy of this therapy [Raeburn, 2016]. This emphasises a change in the autistic child at such great expense that it presupposes that the child is implicitly conceptualised as an entity which is in need of 'correction' and 'improvement', without including a notion of acceptance of different ways of being in the world.

Categories: Well-Being

Finally, 1.7% (3) papers can be subsumed under the category 'Well-Being'. Here, we grouped papers concerning themselves with fun, engagement or, more generally, the facilitation of positive experiences uniquely tailored to the needs and interests of autistic children. Due to the low number of papers falling into this category, I deemed it not feasible to add subcategories here. Two of those projects are very similar: MEDIATE [Parés et al., 2005a,b] and Responsive Dome [Brown et al., 2016]. Both are sensory installations spanning up a large space for exploration.

Purpose	References	#
Well-Being	Parés et al. [2005a,b], Brown et al. [2016]	**3**

Table 2.12: Occurrence count for Well-Being Technologies for autistic children along instances of references in the corpus

Autistic children rarely encounter the sensory installations and only with limited access to them. Large spaces are required to install them. Hence it is not feasible to incorporate this type of technology in the home environment of most children. To the children, this is an exceptional experience, which appears to be positively connoted.

As *primary* audience, autistic children are often in control of these technologies. They can decide whether to engage with them and regulate time and mode of interaction – within reasonable boundaries. However, as the sensory installations are particular event technologies, the children rely on the adults around them to enable access. Whereas refusing to engage with technologies is a practical option to the children, asking for engagement is complicated and cannot be achieved in a self-driven fashion. Ultimately, though, these technologies allow the most self-determined use within the corpus.

2.3.4 Evaluation of Technologies

As these technologies are mostly driven by the conceptualisations of autism and requirements to deal with them of a neurotypically dominant environment, they are in their majority not actually for autistic children but instead alleviate the needs for interaction from the primarily neurotypically presenting people around them. In that regard, it seems to come to no surprise that most of these technologies are evaluated along extrinsic measures, such as therapeutic success (as defined by therapists, parents and researchers), interaction rates or classical usability.

The experiences of the autistic children are then only secondary for the technology to achieve the desired outcomes. It follows that they then are also second in the evaluation of these technologies. Inquiring into these experiences, hence, means asking radically new questions about autistic children's perspective, their meaning-making and their agency in use. Seeing which technologies are predominantly developed for autistic children and that they do not necessarily target the needs of the children, but those deemed worthy

and relevant by a neurotypical, adult society, it comes to no surprise, that a systematic approach for questions into their experiences has been missing so far. With my work I, hence, implicitly also challenge the current space of technologies for autistic children and point to a gap full of so far missed design and evaluation opportunities particularly with a focus on the experiences autistic children make with technologies in their lives.

2.4 Experience

In my research, I am interested in the experiences autistic children have with the technologies that were co-created within OutsideTheBox. To provide context for this, I now present work on the experiences autistic children have in general, how experience has previously been conceptualised in HCI and how the predominantly qualitative approach should be extended to go beyond empathy as the primary guiding strategy for elicitation.

2.4.1 Experiences of Autistic Children

According to De Jaegher [2013] different processing of sensory input of autistic people leads to different sense-making which influences the assignment of meaning. For example, a preference for listening to the same set of music in only one order, while potentially tedious to allistic people, can be an essential indicator of stability to autistic people. Repetitive behaviour, a preference for sameness and a focus on detail help structuring the environment and create a feeling of safety. Sharing experiences in a mode De Jaegher [2013] calls *participatory sense making* becomes challenging when the basis on which participants assign meaning is different between them.

Autistic individuals have strategies for dealing with heightened sensory input, which include repetitive behaviours and self-stimulatory actions (also known as 'stimming'). Repetitive communication is often meaningful for an autistic person, but not necessarily in a way an allistic person might expect. For example, the repetition of a fact like 'the door is open' can indicate distress (e.g., 'I want it closed'), worry (e.g., 'What if the cat runs out?'), an attempt to share something that pleases them with others or something that allows them to block out other sensory inputs in a stressful environment. Whenever allistic people interpret autistic behaviour and communication, they need to tread carefully and consider the context appropriately [De Jaegher, 2013].

Autistic children are of special interest to researchers, because early intervention and acquiring coping strategies can help establish harmless ways of emotional regulation[11]. However, interacting with autistic children can be challenging. Many researchers tend to avoid gathering self-reported data directly from autistic children due to the lack of shared modes of communication. Instead, assessments are most often via proxy, e.g. through parents and caretakers [e.g., in Baranek et al., 2006], who are limited to giving their

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[11]I want to point out that, personally, I do not see the onus simply on the side of the autistic individual, but also on a society that should learn to accept harmless, albeit unusual ways of emotional regulation, such as stimming (self-stimulatory behaviours).

interpretations of the children's experiences or through observation and ethnography [e.g., in Alper, 2018]. I define this as an *indirect* perspective. Alternatively, researchers also conduct interviews with autistic adults [e.g., in Volkmar and Cohen, 1985, Cesaroni and Garber, 1991], who can provide a hindsight view on their experiences as a child; I define this as a *reflective* perspective.

Allistic researchers often shy away from explicitly including autistic people actively in their research, since it is challenging for them to ensure that they interpret and handle communication appropriately. This conundrum is even more present in the case of autistic children, as allistic researchers tend to possess more relative power in societal hierarchies along several axes, such as age, social status, attributed agency and so on. It is only recently that the experiences of autistic children have been more directly assessed: Kirby et al. [2015], for example, talked with autistic children about their everyday experiences and gathered previously unconsidered perspectives, which showed, e.g. how autistic children acquire coping strategies to deal with situations that are overwhelming to them. As an alternative approach to eliciting first-person perspectives Satchwell and Davidge [2018] co-created stories that allow insight into how a person might understand their autism for themselves. I define this as a *direct* perspective. These findings support De Jaegher [2013]'s theory about sense-making of autistic individuals and are relevant to describing a *felt* experience.

Each perspective – indirect, reflective and direct – is limited if used only by itself [see for example, for the differences in first-person reports in HCI, Doherty and Doherty, 2018]. However, if we combine the three ways of reporting, we can arrive at a more holistic view of the everyday experiences of autistic children than any one of them individually. However, to date, there is no concept available that methodologically combines these perspectives when assessing experience in an HCI context.

2.4.2 Experience in HCI

Investigating diverse experiences people have with technologies has been a long-standing interest within HCI, albeit with a multitude of labels [Ibargoyen et al., 2013]. Here, the concept of 'user experience testing' is most dominant – especially in industry. Enquiring into experiences then becomes a measurable endeavour, focused on quantifying what is there. Common strategies are questionnaires, log data, alpha-beta testing and lab studies [Albert and Tullis, 2013]. However, designing along the information yielded by these investigations means designing for a majority – which is predominantly neurotypical. Hence, these approaches are less helpful in trying to find out about the experiences of marginalised people such as autistic children.

A large body of qualitative research focuses mostly on how to assess experience without necessarily providing a theoretical background to that assessment. Despite the very general work by McCarthy and Wright [2007], which I discuss in more depth below, most theoretical work is limited to certain contexts (such as Battarbee and Koskinen [2005] for joint experience between multiple users, or Giaccardi and Karana [2015] for experiencing

materials). The most common use of the term user experience is as a concept to design with [Hassenzahl, 2014] e.g., through experience prototyping [Buchenau and Suri, 2000, Yasar, 2007], or focusing on designing for a subset of experiences, such as playful ones [Olsson et al., 2013]. Very few approaches use the notion of experience in the sense of acquiring knowledge through the interaction with technology [Malinverni et al., 2016a].

One of the most prominent and general theoretical understandings of experience in HCI has been developed by McCarthy and Wright [2007]. They established a notion of *felt* experience that puts the user in the centre instead of focusing on designers' goals. By giving space to subjective truth, they acknowledge the user as a *social actor* [in reference to Suchman, 1986] and their interactional situatedness as relevant. With that, they created an adaptable concept that applies to a wide range of everyday contexts and experiences of neurotypically presenting users.

Experience according to McCarthy and Wright [2007] spans across four threads: sensual, emotional, compositional and spatiotemporal. They rely on the shared processing of these threads; however, autistic children's sensual perception is profoundly different [Kirby et al., 2015]. Emotional processing and compositional meaning-making are subsequently not always obvious to allistic people [De Jaegher, 2013] and spatiotemporal information is handled differently as well [Bertone et al., 2005]. These differences again manifest differently in individuals with the same diagnosis (cf. Section 2.1) and influence aesthetic and ethical experiences. While the four threads are present in the experiences of everyone regardless of cognitive style, they might be constructed very differently, which is why we cannot rely on assumptions of our own sensual, emotional, compositional and spatiotemporal processing.

McCarthy and Wright's concept heavily relies on the notion of researchers' empathy with users [Wright and McCarthy, 2008]. 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 neurotypically presenting people 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 through the limits of empathy between researchers and autistic children can be addressed [Gaudion et al., 2015a, Smeenk et al., 2018]. However, I deem the gap between the life worlds of allistic researchers and autistic children so fundamental, that I require an approach that does not solely rely on researchers' empathy, even though I am acutely aware of how necessary empathy is in my research context. However, an approach singularly relying on researchers' empathy limits itself in unnecessary ways.

2.4.3 Limitations of Empathy

A vital part of the notion of experience is the concept of empathy. As a concept, empathy was of interest to HCI researchers in two ways in recent years: firstly, when trying to design technologies that increase empathy of their users for others [e.g., Hailpern et al.,

2011, Ando et al., 2012, Huck et al., 2015]; secondly, when discussing how to design with empathy in circumstances where different assumptions about users' lifeworlds clash [e.g., Lindsay et al., 2012]. When referring to empathy, I refer to the latter understanding, where researchers and developers are required to have empathy with their users.

Because their concept of experience relies on a shared understanding of users' lifeworlds, Wright and McCarthy [2008] consequently lay out how, in practice, they require researchers and designers alike to be empathetic. Kaye [2009] shows how this can be achieved by combining more traditional data gathering approaches, such as questionnaires with ethnographic and auto-ethnographic approaches as well as interviews. However, most of these methods require participants and observers to have a shared mode of meaning-making and expressing this meaning to each other to make sense of the collected data.

I deem the empathy of allistic researchers as necessary but not sufficient to capture the experiences of autistic children as they process sensory input differently. It has been shown that they pay attention to different areas in movies [Klin et al., 2002] and that thinking in autistic people can itself follow unique cognitive styles, such as purely visual thinking, math and music thinking or verbal logic thinking [Grandin, 1995a]. If an allistic researcher attempted to simulate such traits, their experiences would be limited to the simulation context (in, e.g., time, severity, consistency) and not integrated into daily life.

While different life worlds always exist between researchers and the people they design for or, in fact, any human being and another, the differences in overall sensory and emotional processing between allistic researchers and autistic children can be profound. Gaudion et al. [2015a] made initial steps to bridge this empathy gap from a design perspective, but still rely solely on the designers' empathy without a further conceptual grounding.

I argue here for a differently grounded understanding of experience that is multi-faceted, both conceptually and methodologically, that is open to various data sources, encourages us to be critically reflective and flexible in the construction of the assessment.

2.5 Summary

In this chapter, I have discussed different perspectives on autism and contextualised them with each other. I provided a thorough overview of existing technologies for autistic children to show how investigating their experiences has not been of interest before due to a systematically dominant design approach in which neurotypically presenting adults define the limitations and needs of autistic children. I showed how technologies conceptualising children as something other in need of correction are not interested in their experiences with these technologies. Hence, with the advent of new technologies addressing these experiences, new evaluation concepts and methods are needed to address them adequately. Finally, I also detailed how experience and empathy are discursively constituted for autistic children and within HCI and how previous conceptualisations of experience fail us with this population.

3

Context & Epistemology

This chapter presents the project context for OutsideTheBox and discusses my epistemological background guiding my work. Some of the details have been published previously by Frauenberger et al. [2016a]. Part of the section on ethics I have published in Spiel et al. [2018a]. In the first paper, I have participated in the discussion of the project phases and the writing of them, but they are chiefly a team effort.

3.1 The Project Context – OutsideTheBox

Within the three-year long research project OutsideTheBox (OtB; 2014–2017) we co-designed technologies with autistic children that targeted their holistic well-being. The resulting technological artefacts ranged from small tokens to large body interaction devices. Throughout at least one full school year, we met each child about every fortnight for an hour-long session, usually at their school. The primary purpose of the technologies we individually developed with the children is that they made sense in their lives and enabled them to share the positive experiences they had with those technologies.

3.1.1 Project Parameters – Goals and Cycles

OutsideTheBox has three goals of which two align with this thesis. We planned to a) create a theoretical framework as the basis for the participatory approach with the children, to b) describe the design space and evaluate the design methods and to c) conduct a series of case studies resulting in functional prototypes we would then evaluate. With my work, I contribute to the first and third goal of the project. I show, how we can *conceptualise the evaluation of the technologies through an experiential lens* and also *practically evaluate the case studies together with their resulting prototypes.* Additionally, I also developed an approach for participatory evaluation with autistic children.

We worked with a total of eight autistic children aged six to nine years. The first year, we interacted with four children, the second with another set of four and in the third, we continued working with three of the second four to have the chance to create more robust prototypes. One of them had to cancel the collaboration due to personal reasons. Five participants (Blaine, Claude, Quentin, Mia and Yvan[1]) were recruited through the mentor system of the city of Vienna. Every autistic child has a mentor who mediates between school, therapy, families and other stakeholders (like OtB). We introduced the project to them, and they suggested participants to us. In one case, the parent of a child with autistic perception[2] (Dean) asked to participate, and we could accommodate the request. They had encountered information through an advocacy group. Hence, it can be quite relevant to the start of a research project to disseminate it publicly from the beginning. The two remaining participants (Andy and Oliver) were – sometimes temporary – classmates of other participants (Dean and Yvan). Since we worked with each child individually, two individual projects within the same class did not interfere with each other.

Phase	Description	Sessions
Ideation	familiarising ourselves with the child and their context	2-4
Conceptualisation	exploring potential ideas and converging on one	4-6
Prototyping	developing low- to mid-fidelity prototypes	2-4
Refining/Testing	improving on the prototypes towards functional objects	2-4
Evaluation	reflecting on the final object and the design process	1-4

Table 3.1: Cycles within OutsideTheBox along the five phases established in Frauenberger et al. [2016a]. Overall, we worked with eight autistic children in two cycles, spanning over one or two years.

As described in more detail in Frauenberger et al. [2016a] and shown in Table 3.1, each cycle consisted of several phases. During the *ideation* phase we got to know the child and their social context, made ourselves familiar with the working environments, immersed ourselves in the interests of the child and got a feeling for their talents and abilities. In this phase, we also decided on which design method we would use for the conceptualisation, prototyping and refining/testing phases. In the *conceptualisation* phase we developed, expanded and drilled down on a set of ideas until we converged on a concept for a smart object. This was followed by a couple of sessions for *prototyping* in which we first used low-fidelity material like paper and cardboard to make our way through more high-fidelity ones built to last longer and with functional electronics inside. These high-fidelity prototypes were then subject to *testing and refining*. During this phase, we fixed bugs, improved on the interaction and made the objects more durable.

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[1]To protect the children's privacy, I changed the names of the children for publication purposes (including this thesis).

[2]This is a direct translation of how the parent referred to the diagnosis (German: Autistische Wahrnehmung).

Finally, during our *evaluation* we consulted the children and core-actors of their social environment on their experiences with the prototype and the design process. In the second year, we additionally conducted the participatory evaluation with the children.

3.1.2 Academic Members

OutsideTheBox consisted of three core academic members: Christopher Frauenberger as principal investigator and Julia Makhaeva and me as project assistants. Every academic member had clear roles within the project and their unique research angle which will lead to comprehensive pieces of research. Associated members were Florian Güldenpfennig and Barbara Werzer, who both focused on prototyping and object finishing. However, Florian also took part in some of the sessions with Oliver as well as Yvan and Hank.

Christopher was responsible for the overall organisation and the management of the project. Whenever press, advocacy group or institutions, such as the Viennese Stadtschulrat, requested dissemination from us, he represented the project and our work. In his habilitation, he discusses assistive technologies and their roles in the lives of people using them more generally. He argues for a critical realist perspective combining aspects of the medicalised and the social model of disability. Doing so, he uncovers new avenues for assistive technologies more generally and implicit ideologies within current approaches.

The participatory design sessions were conducted jointly by Julia Makhaeva and myself. For each child (or a pair of children), we separated our roles into Active Observer (AO) and Play Partner (PP). For every cycle, I was the Play Partner for two children and the Active Observer for two other. How my roles align with the individual children can be seen in Table 8.1 in Section 4.1. In the first year, the Active Observer was responsible for recording and planning the sessions and overall leading of the sub-project. They also hand out tasks during the sessions, give out appropriate materials and provide feedback. In the second year, we added 'communication with social network' to the Active Observer's tasks. This task was previously assigned to the Play Partner but had lead to confusing situations when the children were together with their parents, and the Play Partner had to switch tone too often and became somewhat inconsistent in the role. The Play Partner is the design partner of a child and as such artificially put under the authority of the Active Observer as well. That way the design team consists of more people and the child is supported in finishing given tasks by having the skills of the Play Partner available to them. For example, if a child was not able to write quickly yet, tasks entailing some writing were done by the Play Partner under the instruction of the child. We have detailed our conceptualisation of researchers' roles in Spiel et al. [2018c].

Julia Makhaeva's work focuses on the creative contributions of the children and how those can be fostered by careful planning. She developed the concept of 'Handlungsspielraum' [Makhaeva et al., 2016] in which she shows how an interplay of structures and freedoms has to be carefully curated to facilitate a creative environment in which the children feel safe to contribute.

When creating the objects, we had a loose division of tasks between us: Julia had the primary responsibility for the object design, which entails the look and feel, and the overall object properties. Christopher dealt with the hardware aspects of the electronics and soldered connections, where necessary. I was concerned with the software side of functionality. We came together in design meetings to catch up on each other's activities and decide on tasks and how to distribute them. There are exceptions to this procedure and where they become essential, I flag them in the descriptions of the case studies in Chapter 4.

The evaluation sessions were conducted mostly by Julia and me. It was my responsibility for all cases, to make decisions on how to evaluate and which sources to additionally collect data from. However, this being a group project and the evaluation, of course, being up for discussion among the team members, I acknowledge that Julia and Christopher had a substantial influence on how the evaluations were conducted. The conceptual framework for analysis and the methodological approach for participatory evaluation were initiated by me, and I did the core theoretical and planning related work.

Seeing how my work is embedded in a team effort, I try to reflect that throughout the thesis by the use of pronouns. Whenever I refer to 'we' as doing something I refer to concrete things that have been done by two or more people in the project including me. For work that I conducted on my own, I refer to myself in the first person.

3.1.3   Ethics

Historically, participatory design aimed at reinforcing democracy, by acknowledging and supporting a diversity of voices [Halskov and Hansen, 2015]. It is often framed as inherently attentive to values and ethics [Steen, 2011]. Research on ethics in this body of literature may take very different perspectives, around four central questions: Who do we engage as participants? How do we engage with them? How do we represent them? What can we offer in return [Robertson and Wagner, 2012]?

Many approaches co-exist to answer these questions, each at different levels of generality. Some scholars apply theoretical ethics to participatory design [Gram-Hansen and Ryberg, 2016]. Others have investigated the effects of participatory design outside of the research project itself (and found them limited [Ehn and Badham, 2002]). Finally, there is a body of literature on the researchers themselves, and on how they shape the research outcomes. For instance, Toombs et al. outline researchers as care-receivers, rather than just care-givers [Toombs et al., 2016], or outline the importance of continuous reflection on how our judgements of value shape the research [Malinverni and Pares, 2017].

My work belongs to this latter strand of research. However, in contrast to previous work, I focus on articulating how different approaches to ethics contribute to my work. I do so by focusing on the moral *judgements* guiding actions of researchers, and on how these influence the research partnership rather than the research outcomes–as well as the under-investigated topics they may reveal.

While neither the funding body nor the institution of OutsideTheBox and, subsequently, this thesis required a formal ethics approval, it was nevertheless crucial to all participants of the project to conduct ethically sound research. For this, we have written our own ethics guidelines, which can be reviewed in Appendix A. Christopher had initially developed the guidelines, but they were expanded and continuously refined by Julia and me as well. We collected consent forms at the start of every collaboration from the legal guardians of the children and sought assent for every session from the children directly, albeit sometimes through continued negotiation (see Section 4.2).

These guidelines were based on the UK Economic and Social Research Council (ESRC) framework of ethics, written upfront and modified throughout. They do include continuous reflection on what is going on but set the basics for us to conduct our research with ethics in mind. However, as stated in the guidelines, we could not predict everything that happened up front. As also described further in Frauenberger et al. [2016b], we had to adapt to situations as they arose and come up with new procedures for specific contexts. Such decisions included deliberately stepping back from the pre-defined guidelines and acting ethically precisely through that in the moment. These occasions are further described in the case studies, whenever they occurred (Chapter 4) and picked up on again with a more general lens to ethics in participatory research within the discussion in Section 8.

While Frauenberger et al. [2016b] describe a continuous reflection process during the research as an in-action approach along the distinctions of 'in-action' and 'on-action' established by Schön [1987], our continuous reflection on ethics had aspects of both. During the sessions, Julia and I reflected in-action by making microdecisions that were necessary in the moment. For example, we would quickly adapt planned activities to the child's current mood. Hence, we were required to have a mutual understanding that put the interests and well-being of the child above all else. We further reflected on-action immediately after each session and further in-between; even before the sessions we briefly discussed potential upcoming issues for that session and how to encounter them. Procedurally, we did this by travelling to and from the schools together, or, where that was not possible, in preparation for the sessions or the office afterwards. Further, we noted down ethical issues and relevant observations in shared and co-authored field notes after every meeting. While we did not have institutionalised external ethical supervision, we adhered to a more pragmatic concept of ethical research.

3.2 Epistemology

This research endeavour comes with a constructivist approach to knowledge creation. While still empiric, the underlying philosophical grounding has consequences, when it comes to quality assessment and reliability, as these notions are more fuzzily defined than in post-positivist research paradigms. In this section, I will briefly introduce the underlying philosophy and detail the implications for quality assessment these stances bring with themselves.

3.2.1 Knowledge Production and Care

I situate my work within the field of Human-Computer Interaction (HCI), which is a core part of Computer Science [Denning, 2005]. Even for Computer Science the debate on whether it constitutes a *science* and if so, which type, is hotly debated (ibid). So it happens, that the occasional seminal books on the history of Computer Science even leaves out HCI as an area of investigation (e.g., Tedre [2014]). Where there is agreement, though, is that the field thrives on a multitude of different knowledge contributions.

HCI itself is not a consistent field either. Different paradigms are alive and well within the area, each of them conceptualising knowledge differently. Harrison et al. [2007] consider three different paradigms: One stemming from engineering and ergonomics, a cognitive era focused on modelling and a situated approach aiming at an understanding of the complexity of the individual and collective interactions between humans and computers. While these paradigms have historically grown sequentially, all of them build the basis of different work within the field up to date. My work belongs to the latter paradigm (within their conceptualisation). It is interpretive and (co-)constructivist in its approach.

The situatedness of the resulting knowledge stemming from such work constitutes a core problem within feminist theory [Stacey and Thorne, 1985]. Especially in fields with dominant (post-)positivist paradigms, interpretive and 'subjective' points of view are more difficult to articulate as they are contrasted with the notion of absolute and objective scientific truth. One can argue (and many have done so) that every scientific endeavour is in itself deeply situated within a paradigm, an ideology, the people, the tools and methods associated with the fabrication of the resulting knowledge (see, Latour [2010]). However, if this assumption is not accepted across the research community, such knowledge is constructed as inferior. Constructivist stances are dangerous in that they put knowledges into relation to each other and the powers that be and distinctly embrace the uncertainty and incompleteness of their 'results' Foucault [1970]. Understanding knowledge as situated causes 'epistemological trouble' [Harrison et al., 2011] as it questions the very foundations of paradigms relying on absolute facts [Haraway, 1988]. That does not mean, however, that there are no criteria for the quality of the work (see Section 3.2.2).

While I pre-dominantly associate my work with HCI, I heavily draw on feminist disability studies when it comes to acknowledging the experiences of disabled people themselves [Garland-Thomson, 2005, Morris, 1991]. Situating myself within such a frame makes my work additionally vulnerable to the interpretation of the people involved in my research as it very likely differs. I partly address this by acknowledging that this thesis represents a snapshot in time and does not make any permanent statements pertaining to the children's current or future identity constructs.

Heron and Reason [1997] conceptualised a participatory paradigm, that is explicitly co-constructivist and directly acknowledges that there is expertise, which necessarily remains outside of the academic realm, but uniquely contributes to it. Participatory research is a process in which power is explicitly shared and distributed [Bratteteig and Wagner, 2016], and in which this power is also continuously re-negotiated.

Coming from natural sciences via critique to matters of concern [Latour, 2004], the work I do is a matter of care [de la Bellacasa, 2011]. I *personally* care about the topic and the people I interact with conducting my work, the results and how other researchers use them. Ultimately, though, I care about the impact it might have into society at large for what I consider to be a better future, one where people are given the power to participate in the research about them if they choose to do so. This does not imply that other researchers with a different epistemology do not particularly care about their participants, but rather, that I pro-actively selected this stance as a frame for the engagement with the children I co-designed with.

3.2.2 Quality Assessment

Since there is no clear-cut agreed upon mathematically defined criterion for quality assessment available in qualitative and interpretive research, the soundness of conducted research has to be judged differently. Seale [1999] suggests a triangulation of methods and people using the methods. This work has triangulation in its core, as one of the leading advantages of using my conceptualisation of experience is, that it considers different perspectives which often require different data sources. Further, I have pro-actively discussed my work (mostly with internal and external co-authors) to triangulate individual viewpoints we might have as researchers. While there was a definite hierarchy for this work in that I am judged as an individual PhD student, I also had the final say in how results are reported; I aimed at getting a well-rounded picture that acknowledges different viewpoints.

Further, Seale [1999] also indicates how important the integrity of the researcher conducting the work is. They come with personal and professional experience in research methods and approaches and each research endeavour they are involved in shapes their knowledge and informs future approaches.

Specifically for participatory research projects, Frauenberger et al. [2015] proposed a framework to assess rigour and reflect on research through four lenses: Epistemology, Values, Outcomes and Stakeholders. In that, they argue, researchers can evaluate their work and in peer-review processes also consider the rigour of other participatory research.

Another option for quality assessment of *inclusive* research[3] is provided by Nind [2014]. They state that for inclusive research to be deemed of high quality, it needs to answer relevant questions that cannot be asked without including a particular participation, access participants' knowledge in unique ways, reflect on the culture of participants, be recognised as valid by the people involved and make an impact in their individual lives.

Epistemologically, I position myself within feminist research traditions. Hence, the values of self-disclosure, a mixed methods approach to support dialectic information gathering and knowledge production, co-construction of knowledge and an empathic relationship with research participants focused on an understanding of their experiences combined

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[3]A term coined for all kinds of collaborative research by Nind [2014].

with reflexivity on processes, outcomes and communication are aspects, my research has to address (see Bardzell and Bardzell). I disclose my stance on Autism and neurodiversity especially in Section 2.1. My work *requires* the use of mixed methods and radically contributes to the co-construction of knowledge through participatory evaluation. I try to go beyond empathic relationships with my researchers and try to establish relationships of mutual care [Toombs et al., 2016]. Finally, I discuss the ethical implications of working with marginalised children more generally to reflect on the convoluted problems that come with a research project such as mine. The analysis and evaluation of outcomes and stakeholders are the main focus of my work.

While I concretely tried to address issues of quality assessment, I am aware, however, that the final judgement lies in the hands of the research communities and – even more so – the autistic community in particular as represented by all of my participants.

3.3   Summary

In this chapter, I illustrated the project context of OutsideTheBox to discern how it relates to my work. Further, I detailed my epistemological standing on constructivism and feminist care and provided the theoretical background on core theories used throughout my work. These sections build the basis on which further chapters are organised.

CHAPTER 4

Case Studies

In the OutsideTheBox project, we had eight case studies with nine children. This chapter introduces the design processes we conducted with them as well as the resulting technologies. As such, it provides the full context for my work.

This chapter is partly taken from Spiel et al. [2016b], Frauenberger et al. [2016a], Frauenberger et al. [2017] and Spiel et al. [2017c]. I have driven and theorised the content in Spiel et al. [2016b]. While Christopher Frauenberger is the main contributor behind Frauenberger et al. [2016a] and Frauenberger et al. [2017], Julia Makhaeva created the visual representations whereas my main responsibility lied in the description of the case studies. Spiel et al. [2017c] has been mainly driven and written by me (see also Chapter 6). Additionally, parts of these case studies can be found in Frauenberger et al. [2018].

4.1 Overview

Table 4.1 provides an overview of the names of the participants as referred to throughout this thesis, their age, the diagnosis to the detail it was shared with us in the initial Contextual Inquiry phase [Holtzblatt and Jones, 1993], the name of their objects, the number of overall sessions and my particular role with that child. I distinguish in this thesis between first-year (Andy, Blaine, Claude and Dean, see also Chapter 5) and second-year (Quentin, Mia, Yvan, Oliver, see also Chapter 7) case studies.

I have altered the children's names to protect their identity. In the first four cases, I looked for appropriate names along the alphabet. In the second four cases, I either took the names we used in other publications of the project for consistency across cases or used a random rotation algorithm to change the first letter of their name and find an appropriate name starting with that letter.

I refer to the children with gendered pronouns. These reflect their gender identity during the time we worked together. However, in more than one case, a child questioned

Name (Age)	Diagnosis	Method	Object name	#	Role
Andy (8)	PDD-NOS	CI	ProDraw	10	PP
Blaine (6)	AS	FW	ThinkM	14	AO
Claude (6)	AS	CI	Adaja	13	AO
Dean (8)	Autism	FW	DSmart	14	PP
Quentin (9)	AS	Makers	Sound Boxes	15	PP
Mia (9)	Autism	Drama	RattleC	20	AO
Yvan (8) & Hank (6)	Autism	MD	TimeM	20	AO
Oliver (6)	Autism	MD	Öxe	20	PP

Table 4.1: Research Partners in OutsideTheBox together with age, diagnosis, design method used, name of the finished object and number of meetings; separation is by year (first-year, second-year case studies); FW: Future Workshops, CI: Co-Operative Inquiry; MD: Makers & Drama; AS: Asperger Syndrom, PDD-NOS: Pervasive Developmental Disorder - Not Otherwise Specified; AO: Active Observer, PP: Play Partner

traditional notions of gender identity and seeing how gender variance appears to occur more often in autistic than allistic youth [Janssen et al., 2016], I see them as temporary and subject to change.

4.2   Andy

Andy had officially been diagnosed with 'Atypical Autism', a diagnosis particular to the German diagnostic spectrum of autism, which can be best compared with the English 'Pervasive Developmental Disorder – Not Otherwise Specified'. He did not express himself much verbally, but instead preferred communication through interactive play and, primarily, drawing. During our initial meetings, one of his teachers was present until we all decided that he felt comfortable just being with the research team. The meetings were also held in a playroom adjacent to his classroom, so that in a potential crisis or whenever he wanted to share something with them, his teachers could join us.

As his Play Partner, I often had to encourage him to work with us at the beginning of each session. Andy was somewhat shy and did not like meeting new people. It took him a couple of sessions to feel safe enough to interact with us directly. Moreover, even then, there was a pattern for each meeting: During the first ten minutes or so, he refused to work with us. We had to rebuild our relationship anew each time for him to be able to trust us and feel safe. Even though he signalled at the start of each session that he did not want to work with us, we convinced him to interact with us every time. Since after each session, he would run to his teacher and tell her about the positive experiences he made, we judged this decision to be appropriate.

Figure 4.1: Andy's drawings from the second session, a set of different animals

Figure 4.2: Andy's cat at different scales

Consequently, it was also challenging to engage Andy in shared activities. He preferred working by himself or delegating tasks he did not feel he could complete. As an example: he would take over sketching whereas I was commissioned to use the play-doh as he was not that familiar with the activity. As a design method, we re-interpreted Co-operative Inquiry [Druin, 1999], because it offers a flexible frame to engage a child according to their interests and abilities. As a starting point, we used a set of elaborate drawings he made in one of the initial sessions (see also Figure 4.1). We explored them at different scales of size and observed his interactions with them (see also Figure 4.2). He augmented the cats with little attributes which gave them different characters and personas. There was a princess cat, a grandpa cat and so on.

His incredible drawing skills combined with his need for feeling safe and, hence, controlling social situations inspired us to give his object two modes: a drawing surface and an animation mode together with different modes for private enjoyment or public display using a touch screen for interaction and a projector for sharing.

After initial mockups using a combination of a projector and a trackpad for drawing and Scratch[1] for animation, we found that Andy cared more about the functionality of the object rather than the aesthetics – with one exception: he was adamant about having his key colours available: pink and purple. Hence, most of the decisions around the look and feel have been driven by researchers in the project, whereas the functionality was co-developed in following Andy through his interaction with the material we provided.

In its final iteration, ProDraw (see Figure 4.3) consists of a touch surface that can switch between a drawing mode and an animation mode. ProDraw is implemented in Python on a Raspberry 2 using an 8" touch-enabled display as a drawing and interaction surface, that also comes with a touch-enabled pen. Furthermore, there is a DBPOWER 2.4 LCD

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[1]https://scratch.mit.edu
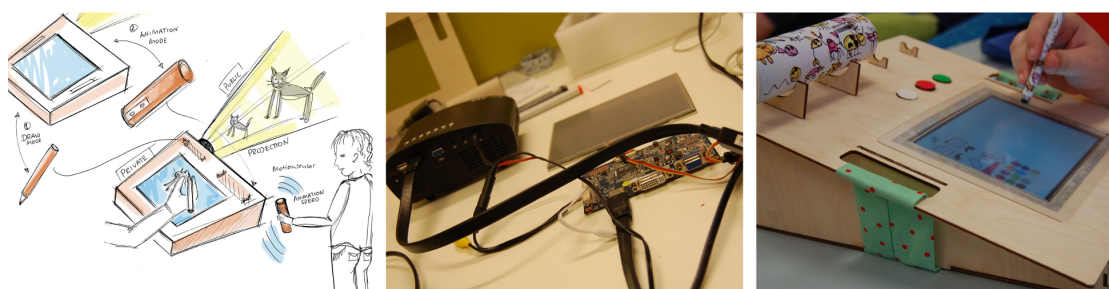
Figure 4.3: ProDraw showing self-created animations with embodied control

TFT display projector for displaying pictures to a broader audience and a Wii Remote Controller [2] for controlling the speed of an animation. In the drawing mode, images can be drawn and saved. They will be automatically grouped for later animation. In the animation mode, a folder is chosen and the animation loops through the pictures in that folder to create the animation – quite like a flipbook works. The sensor data received from the Wii Remote Controller determines the speed of the animation. The faster the controller is shaken, the faster the animation plays. Potential projection of what happens on the touch surface is independent of the mode.

While the drawing mode of ProDraw does follow paradigmatic standards of touch interaction, the animation mode forces Andy to take a step back and interact with the technology using his own body. Hence, the drawing experience is more private than the animation experience, which is addressed towards a potential surrounding audience. While it is technically possible to continually project what happens on the touch surface or to turn the projector off during the animation, having the animation react to the input of the Wii and how fast it is shaken, it lets Andy step away from the technology and open himself up to a public. This gives him full embodied control over his sharing experience. It opens up new spaces for interaction between himself and a potential audience that would not be possible by a static or non-embodied mode of interaction.

Andy presented ProDraw in front of his class and earned praise and envy – according to his teacher for the first time since he entered school. He was acknowledged for his skills rather than singled out for his perceived deficits. While he likes to share his finished drawings with others, he only rarely includes them in the process.

4.3 Blaine

Blaine has been diagnosed with High-Functioning Autism. He engages animatedly in verbal discussions about his favourite topics – science, technology and inventions –, but is quickly overwhelmed by demands of social interaction which, for example, repeatedly leads to stressful situations in class with his classmates or his teachers. We met with

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[2]http://wii.com

Figure 4.4: Blaine using his Play Partner as an extension of his own abilities.

Blaine in a separate room inside his school building, down the hall from his classroom. During the very first session, one of his teachers was present but was not required for further meetings. He was very animatedly interacting with us and seemed excited to conduct a series of science-related workshops with us.

In this partnership, I had the role of an Active Observer, which meant, I planned out the sessions with Blaine and had the primary responsibility of structuring and recording them. He took me as a slightly more authoritative figure than his play partner and was eager to get positive feedback from me. Since he had only just started school and was in the process of learning to write throughout the year, he used his Play Partner Julia reasonably consistently to extend his capabilities in recording and drawing (see also Figure 4.4). He also did not expect us to know anything about his favourite topics, probably mirroring what his everyday experience in school was. To me, it was also interesting to see that he was surprised anytime, we did show knowledge about technical aspects and that he started seeing us as a design team once we began to prototype. On several occasions, he displayed pride of results obtained in collaborative work and indicated that he felt like being part of a research/design team.

From the start, Blaine identified himself as a researcher. Therefore, our working space was framed as a research lab, which he divided into designated areas for brainstorming and prototyping. We initially inquired into his interests through drawing activities and by discussing objects he liked.

Re-interpreting Future Workshops (cf. Vavoula and Sharples [2007]) as our co-design

Figure 4.5: Playing out a use scenario with the second low-fidelity prototype of the Thinking Machine

method, we started to investigate current tools for research, before projecting them into future scenarios. Blaine focused his interests on two main ideas: a machine to better concentrate with (Thinking Cap) and a machine to remind himself of forgotten events (Remembering Machine). We decided to combine both ideas.

Initial paper prototypes allowed Blaine to test possible forms for the head mounted part of his object working simultaneously as a Thinking Cap and as a recording device for the Remembering Machine – ThinkM. He also specified certain interaction modi, e.g., data transmission had to be wireless and directed to a specific screen device. He stated that he could not remember events in which he became aggressive or very excited, which led us to frame ThinkM as a device to capture and reflect on such situations in a calm environment. We thus decided to introduce Blaine to the possibility of using a pulse sensor and included this data in the visualisation of captured events. When trying out a pulse sensor, Blaine quickly linked the data with his emotional state through self-paced experiments. The more he understood that ThinkM would be a functional device in the near future, the more he was able to compromise between what his skills allowed him to do, what was technically feasible and his perfectionism.

ThinkM in its final version consists of a wearable device – headphones – and a base station (see also Figure 4.6). The wearable device holds a camera and a pulse sensor as well as two Arduino Mini Pro microcontroller to control them; both record data when being put on. The camera is right at the eye level of the wearer and records an image for every ten seconds of wearing. The pulse sensor is located on the inside of the headband
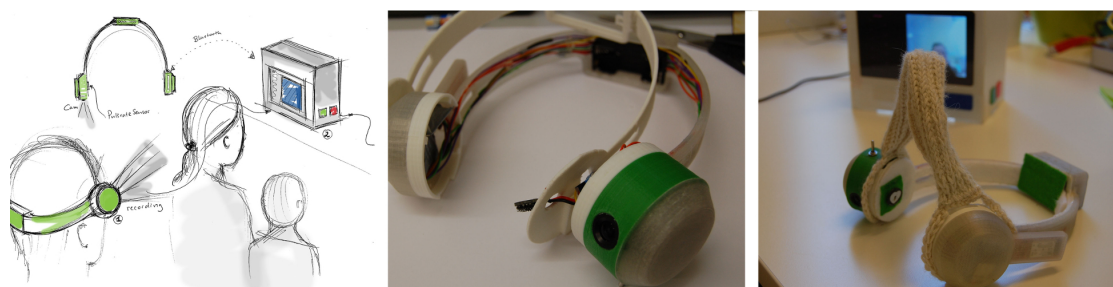
Figure 4.6: ThinkM providing opportunities for embodied reflection of situations

and connected to a roller switch. This way, recording starts as soon as the headband is worn. When the base station and headphones meet, pictures and pulse data are transferred via a Bluetooth connection and shown in a loop on the base station. Other parts of the base stations are a Raspberry Pi 2 and a 7" display. Over time, ThinkM loses some of its memory to mimic the behaviour of a human brain – an analogy, Blaine introduced. Hence, after a week, half of the pictures in a folder are deleted, after another week, only a quarter of the pictures remain and so on. With such a procedure we could address the privacy issues that occurred during discussions with Blaine, not just about his privacy but also that of others, he might incidentally record. Hence, the data never leaves the system. Due to the combination of a static device with a wearable component the machine works in two phases: the recording phase and the reflection phase.

As well as its function as a stylish enhancement, ThinkM also gives back control that was lost in certain situations. It provides Blaine with a way to make sense of them at the time and helps him to reflect on his behaviour in what he sees as a 'scientific' activity.

While it was not possible to present Blaine's invention in front of his whole class, the special educations teacher, an individual therapist and one parent were an audience he could share unpacking the final prototype with. They praised him for his invention, and he explained in detail how the different parts work together and what they do. He stated: "I invented this, and you built it.", which indicates that he felt ownership of the design, but less so of the actualised machine.

4.4 Claude

Claude was diagnosed with High Functioning Autism shortly before entering school. At the time, he was already able to read and write in two languages, despite his young age, but was quickly distracted from tasks and had short attention spans. With Claude, we worked initially in a narrow room that usually hosts the school nurse, but had to change to a larger playroom after a few sessions. During the first meeting, a special education teacher was present to provide a stable point of social safety; however, their presence was not required in further meetings. During our first meeting, he seemed engaged and interested in colourful things. That we brought letters to play with in the form of the logo
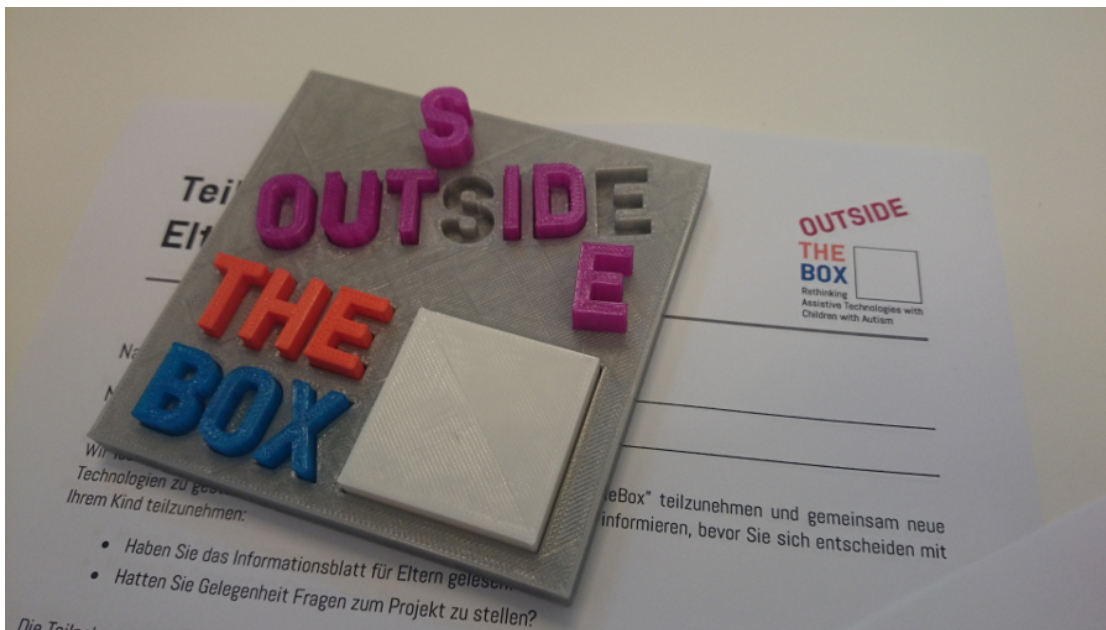
Figure 4.7: The OutsideTheBox logo as a 3D puzzle

seemed to entice his interest in us. While he inspired the development of the 3D puzzle, we used it as a present for all of our first meetings with children (see also Figure 4.7).

For Claude, I was the Active Observer. It was especially important with him to limit the materials he had access to and enforce rules that were given. This became a lot harder when we moved into the playroom, which was full of distractions and even when we tried hiding the available toys, he knew very well how the room was structured and was less interested in working with us than finding his at this time favourite toys. Julia as his Play Partner often suggested team compliance to him – with different rates of success.

Claude was very curious and had many interests. He used writing to emotionally regulate himself in moments of distress. He also liked playing with letters or words and was obsessed with cars. The structure of the sessions was soon clear to him, and he accepted the roles of his play partner and the active observer early on. When we changed our setup from working on a table to working on the ground, the sessions became much more lively and interactive. In some of the sessions, we were joined by one of Claude's friends.

The surrounding toys in the playroom challenged Claude's interest in the sessions. At the same time, we were bound to not merely creating a toy for him, even though our design brief is deliberately open. While the name of a potential smart object, Adaja, was set early on, we found it difficult to establish a longer-lasting interest besides cars. However, as the design brief of the project was inclined to create technologies that target well-being of the individual children more holistically, we decided against making a toy that we deemed having a reasonably isolated purpose. Using Co-operative Inquiry (cf. Druin

Figure 4.8: Different materials we used with Claude during the Ideation and Conceptualisation phases: bricks and modelling paste

[1999]), we determined that the finished object would have to offer flexibility to capture Claude's attention in various contexts continually. After trying different materials to understand more about the collaboration (some of which are depicted in Figure 4.8), we explored his use of a digital camera, electrical components for a smart car and his view on hidden letters in pictures – all to no avail. Finally, when he interacted with a Kinect, we found that he was interested in exploring his surroundings whenever there were visually intriguing effects. After that, we decided that Adaja should visualise surrounding sounds and be a shareable device for exploration with peers.

We then experimented with different forms of visual representations of sounds on variable display sizes using wall projection, smartphones and bracelets. We noticed that Claude preferred to interact with the prototypes in an ambient manner to calm himself.

The whole setup for Adaja consists of an Arduino Mini Pro in combination with a microphone and a 1.5" OLED-screen as shown in Figure 4.9. It is arranged into a wearable ambient device that continually updates its screen according to the intensity of noise it records via the microphone. With Adaja, Claude can explore the sounds of his environment. He can share the display exhibiting a visualisation of the loudness of incoming sounds with others or tilt it so that he alone can interact with it. Whenever a pre-defined thresh-hold is reached, Adaja displays the words 'too loud', to help him regulate his voice.

We established three use case scenarios: First, it can be used as a passively acting ambient companion, which gives constant visual feedback of the noise level surrounding it and, by extension, to Claude. He can choose to look at it and investigate further or decide not to do that. However, the display is ambient in that it pushes itself into the foreground occasionally because of its location on the wearer's chest.

Second, Adaja can be actively used as a sound lens through which to discover a user's
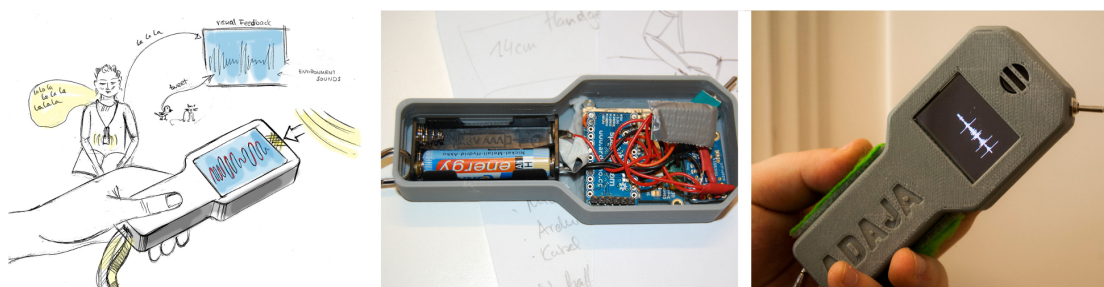
Figure 4.9: Adaja, an ambient companion for exploring sounds of self and others

environment. Different visualisations of different sounds can be investigated and experimented with. It is, hence, imperative that the visualisation of the acoustics stays flexible and can change to create new visual patterns with different sounds.

Third, Adaja can also be used socially. It affords showing the screens to others and makes it possible for Claude not only to investigate himself but together with others or show them something he finds exciting either by showing what is (still) available on the screen or going to the place in his environment where it happened. He can also make sounds individually or together to see how the visual patterns change.

In all three scenarios, Claude has full control over Adaja. He can decide when he interacts with it at all and when he lets others interact with it. In classroom situations, we could observe how this led peers to ask Claude to share their experiences with Adaja, which opened up new options for spaces of negotiation. The visualisation itself is dependent on surrounding noises. All the while it privileges Claude's voice as the one who is wearing the device. Having a clear hierarchical structure where the control is always given to the wearer. However, in its final realisation as well, Adaja was only briefly interesting to Claude to the point that he even returned the object to us in the end.

4.5 Dean

Dean has been diagnosed with autism at a very young age and subsequently received Applied Behavioural Analysis Therapy. He had excellent verbal skills in two languages and appreciated structures and being in control while also being considerate of other people he interacts with. For our sessions with Dean, we were able to use a playroom adjacent to his classroom. During our first, brief meeting in the classroom, his mother and two teachers, as well as other classmates, were present, as we just quickly got to know him briefly before an interview with his teachers. The actual design sessions were conducted without any other adults present. Through initial tasks for contextual enquiry (such as sampling audio), we learnt that he is very enthusiastic about movies and storytelling.

Being Dean's play partner was a very intense relationship, even though it had rough starts. In the beginning, he seemed very focused on trying to say the 'correct' things and

Figure 4.10: Closeness shown in the interaction between Dean and me as his Play Partner in one of the later sessions

fulfilling tasks to our satisfaction, which limited the expression of his creative potential. Throughout the year, we grew closer (see also Figure 4.10), resulting in occasional outings outside of a clear research context, where I went to the cinema with him. However, this interaction stopped after the summer holidays. He needed time to feel safe to 'fail' with us and to start exploring ideas and being silly. Later in the process, he started being very interested in social play with me. I was also helping him in trying out new activities by trying them first. For example, he took up finger painting after I showed him what it does and how it worked. Julia was the Active Observer to our design team.
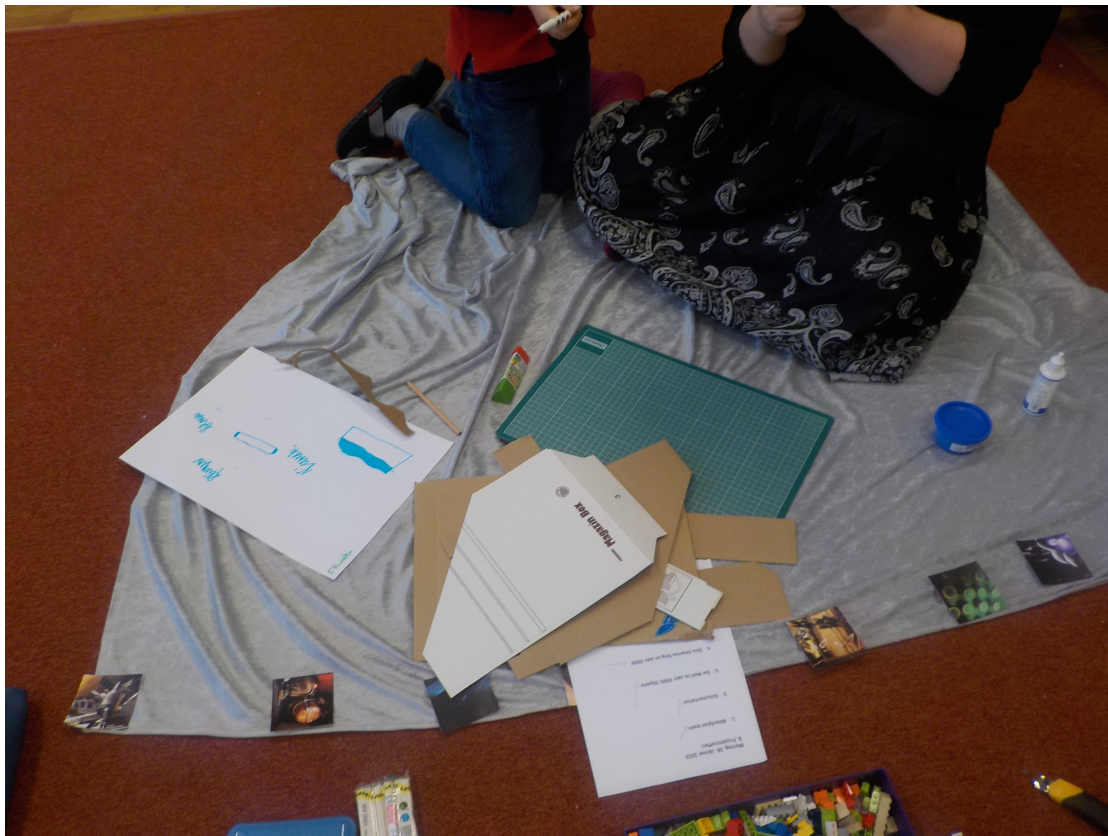
Figure 4.11: A magic silver carpet transporting us into the year 3000

For the conceptualisation phase, we adapted Future Workshops (cf. Vavoula and Sharples [2007]) with elements of Fictional Inquiry (cf. Dindler and Iversen [2007]). We started by planning the second episode of his favourite film, "Brave", set in the future. That made it possible for us to explore future everyday activities in the movie and in general. We also added a 'magic' silver carpet (see also Figure 4.11) that transported us into the year 3000. This creative object assisted us in thinking outside of our known technological environment. The fundamental concept of DSmart combined watching trailers of upcoming movies and supporting Dean in telling his own stories by providing appropriate prompts.

During the prototyping phase, we first had to develop the concept of prototypes as stand-ins for a functional object. For example, we experimented with forms for DSmart using cardboard, but it was conceptually tricky for Dean to also incorporate electronic materials in the cardboard prototype – elements he had previously understood as finished products. However, he frequently used prototypes as props for storytelling.

In the form of a kaleidoscope, DSmart is a smart companion that not only informs about upcoming movies but can also support Dean by giving prompts while telling someone a story (see also Figure 4.12). It functions as a facilitator between him and his environment
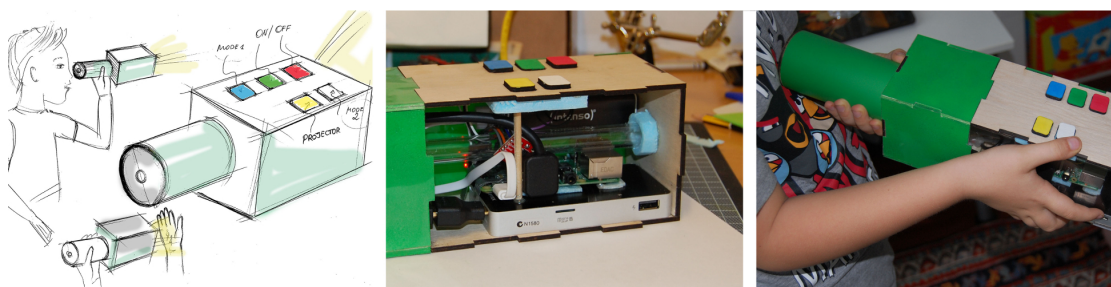
Figure 4.12: DSmart, a smart companion for telling stories and investigating upcoming movies

in certain situations, making these more controllable and, hence, predictable for him. DSmart is implemented in Python on a Raspberry Pi 2 and displays its visual content using an Aiptek Mobile Cinema Q20 projector. Both of them are visibly located on the inside so that Dean could investigate the different components and explain to others how their object works. Next to using an on/off switch, Dean can switch between the video mode displaying up to three movie trailers, one after the other, or the story mode, which shows up to ten pictures of agents or backgrounds that inspire him to tell/continue a story using them. Another button advances the pictures/movies. When the limit of movies or pictures is reached, DSmart enforces a pause to avoid a narrow focus on single activities – as per Dean's suggestion (!). He wanted his object to be able to do several things which are unrelated to each other. Accordingly, the story mode and the movie mode function independently from each other.

DSmart works in many ways via a standard interaction mechanism: buttons. However, its contextual setting makes it facilitate embodied interaction between a storyteller and their audience. It is very much not a tool to be used alone but instead requires a partner to explore content and *potential* content together. Hence, if charged, DSmart is portable and can be shown to others and moved around.

In observation of Dean's interaction with the object, we could see that he showed *Reactive Embodiment* in that he physically reacted to what happened with the object which on the other hand influenced how the object presented its content. For example, they were investigating, how the story changes when pointing the projector on different surfaces, reacted gleefully to how things changed, moved DSmart in his hands, creating a new picture by accidentally moving it to a new surface, which again made him explore more or react again.

Since Dean was sick on the day we could hand over the object, we visited him at home. He later held a talk about it in front of his class to which we were not present. When conducting a small design workshop with the whole class a year later, he was happy to have me by his side as a design partner again.
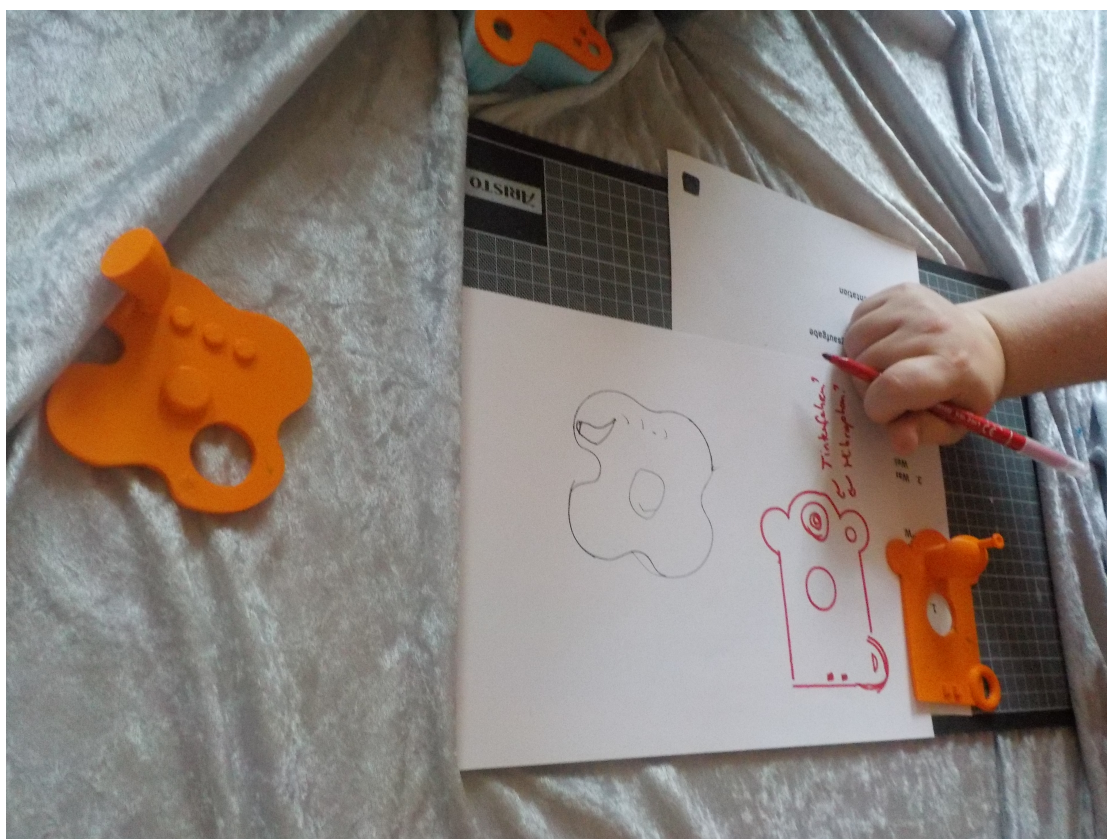
Figure 4.13: Experimental Objects we Used for Inspiration

4.6 Quentin

When we first met Quentin, he was nine years old and went to a mainstream school. He was diagnosed with Aspergers when he was in pre-school. Tinkering and crafting were well-loved activities, but only to create a finished object that has a use (even if it is not necessarily evident to outsiders). For our collaboration, we had an empty classroom around the corner from his classroom to our disposal. Our first meeting was held at a side room to the classroom, which was much smaller. All meetings were unsupervised; however, during the first meeting, we ensured that we were in earshot distance from the teacher. Two sessions were conducted at the university.

As Quentin's Play Partner, I was sometimes disregarded. While he was happy to delegate tasks to me, my contributions regarding ideation or design work were given little consideration. Quentin tried more to create a partnership with Julia as the Active Observer. We modified the roles slightly so that I would be able to bring in materials and ideas that would intrigue him as well to create more of a partnership. However, we ultimately had limited success with this.
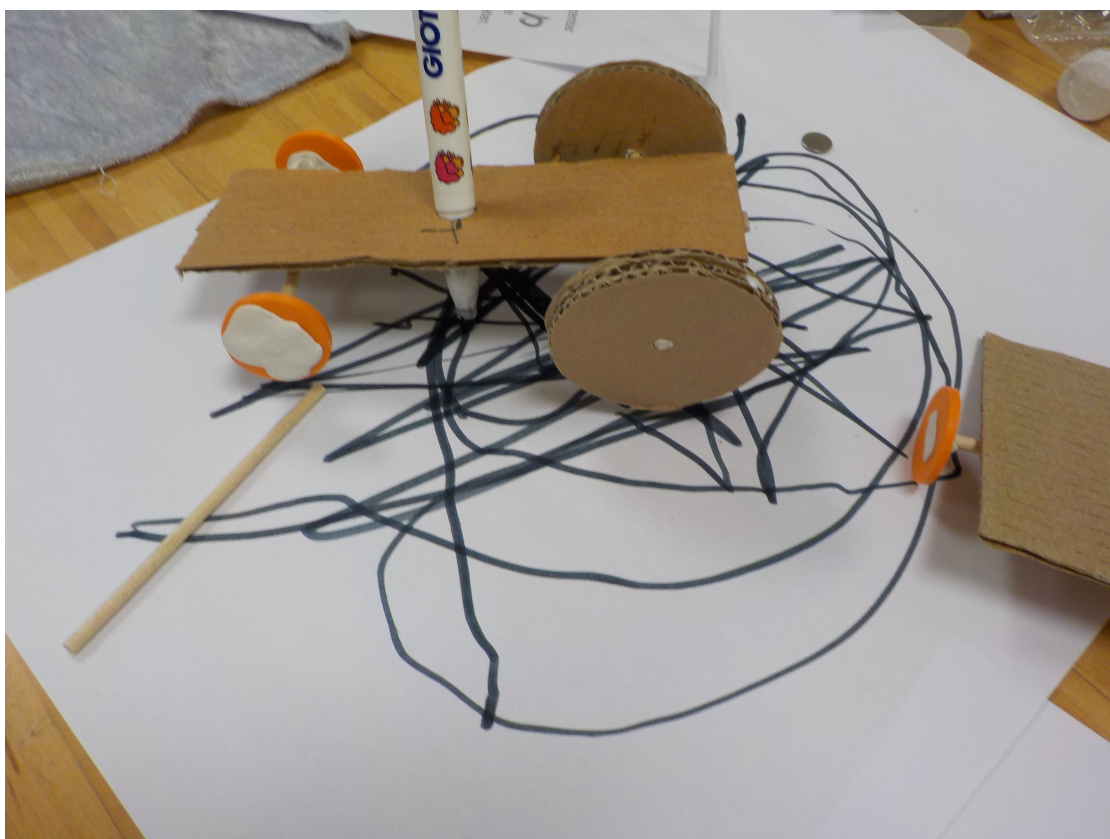
Figure 4.14: A Drawing Car, one of the low-fi prototypes coming out of the ideation sessions with Quentin

After a phase of Contextual Inquiry [Holtzblatt and Jones, 1993], we decided to use Digital Fabrication [Frauenberger and Posch, 2014] as our design generating method. Quentin was very caught in the ideation of things he already knew or got to know via his science club. Hence, we also tried out experimental objects (see Figure 4.13) to tease out new ideas. On our design journey, two sessions were conducted at the university, where 3D-printers, a laser printer, a CNC machine and several smaller fabrication tools are available. Inspired by the potential of these machines and a prototype for exchanging sound messages from a different research project [3], we dove into the development of Sound Cubes.

Due to the chosen design method of digital fabrication, prototyping was our primary activity. In every session we created a small object, for example, the Drawing Car in Figure 4.14 until we settled on the idea of the sound cubes. Hence, Quentin expected from our sessions to always bring something home, which made the iterative development of the final prototype a bit tricky to negotiate. Of all children, Quentin was involved

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[3] http://igw.tuwien.ac.at/sparkling
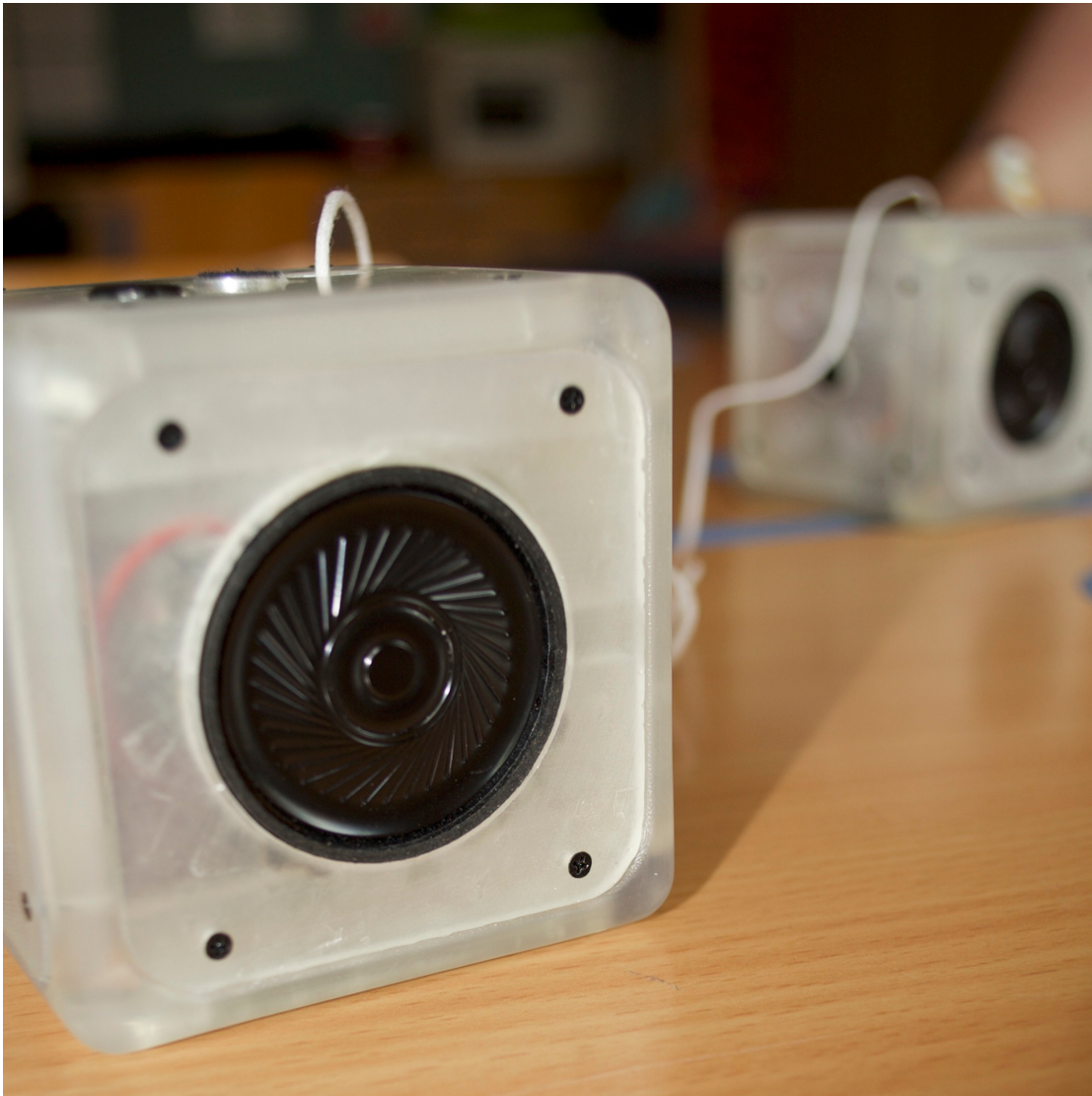
Figure 4.15: Sound Cubes – developed together with Quentin

the most in creating his final object. He was very enthusiastic about using a soldering iron to connect the different parts. However, it was hard for him to understand, that the object was sufficiently complex that there were further steps to do in a separate session. The fidelity of an object was secondary as long as he could take it home immediately.

Each Sound Cube consists of the same interior: a Teensy 3.2 with an Audio Shield, a microphone sensor, a speaker and a conductive mechanism for the I2C transfer between the cubes. The shells have been 3D printed with high resolution and given a professional finish. The Sound Cubes were realised as a pair. However, it is technically feasible to create additional cubes such that any cube could function with any other. The cubes

can record a sound message, replay it or move it to another cube. Each side of the cube is dedicated to a different function: one for the speakers, one for the microphone and recording, one for message replay, one for receiving messages, one for dropping a message (via direct contact) and finally, one to place the cube on. The last surface can also be used to individualise the cube so that, e.g., each family member has their own, or opened to tinker with the technical components of the cube. Quentin was the primary driver behind the shape, functionality and aesthetic design of the object. However, researchers made several suggestions, e.g., concerning the potential use cases of sending messages between the cubes.

During our last session, we gave the Sound Cubes to Quentin, and he experimented with them. He also was engaged when we explained the final functioning to him and carefully folded the short manual so he could show it to his parents. While he did not want a classroom presentation, we could observe him later coincidentally, when he showed the cubes to three other peers. They seemed interested and impressed, although Quentin could not explain the functionality as the cubes were not turned on and he did not at that moment remember where he put the manual.

4.7   Mia

Mia had recently been diagnosed with Autism Spectrum Condition when we met her. The nine-year-old was aware of her diagnosis, but she and her family were still figuring out what it meant to them and their daily life. Mia's school acted as a supportive anchor in that it provided dedicated, additional teaching staff for her class on some days during the week. She loved everything related to the Super Mario games, with Toad and Yoshi being her favourite characters. She also likes playing outdoor sports and drawing (see Figure 4.16) but dislikes handwriting. Our meetings were held in a classroom adjacent to her own with the teacher nearby or at the university.

Being Mia's Active Observer was a very intense role. While during the sessions it was just like expected, for Mia's mother, I was a kind of confidant with whom she could discuss the recent diagnosis of her daughter to someone who also has an autistic family member. This relationship went even so far as she discussed personal problems with me as well. She said that her reason for this was a lack of outspoken feminists in her social circle and that she found the empowering perspective we took with Mia refreshing. Hence, we also ended up being involved to points where we deliberately set clear boundaries. However, this was also an advantageous collaboration that had the characteristics of an ideal design partnership.

In each of the sessions, we had to make a picture of Mia and Julia grimacing into the camera (see Figure 4.17). She introduced this activity, and we made it quickly part of our shared routine. There were lots of opportunities for her to design our interaction and whenever we brought something to the table, she consistently made it her own. That way, she reinterpreted methods we introduced and used them in interacting with others as well when she felt this was appropriate. She had a strong sense of social rules or rather
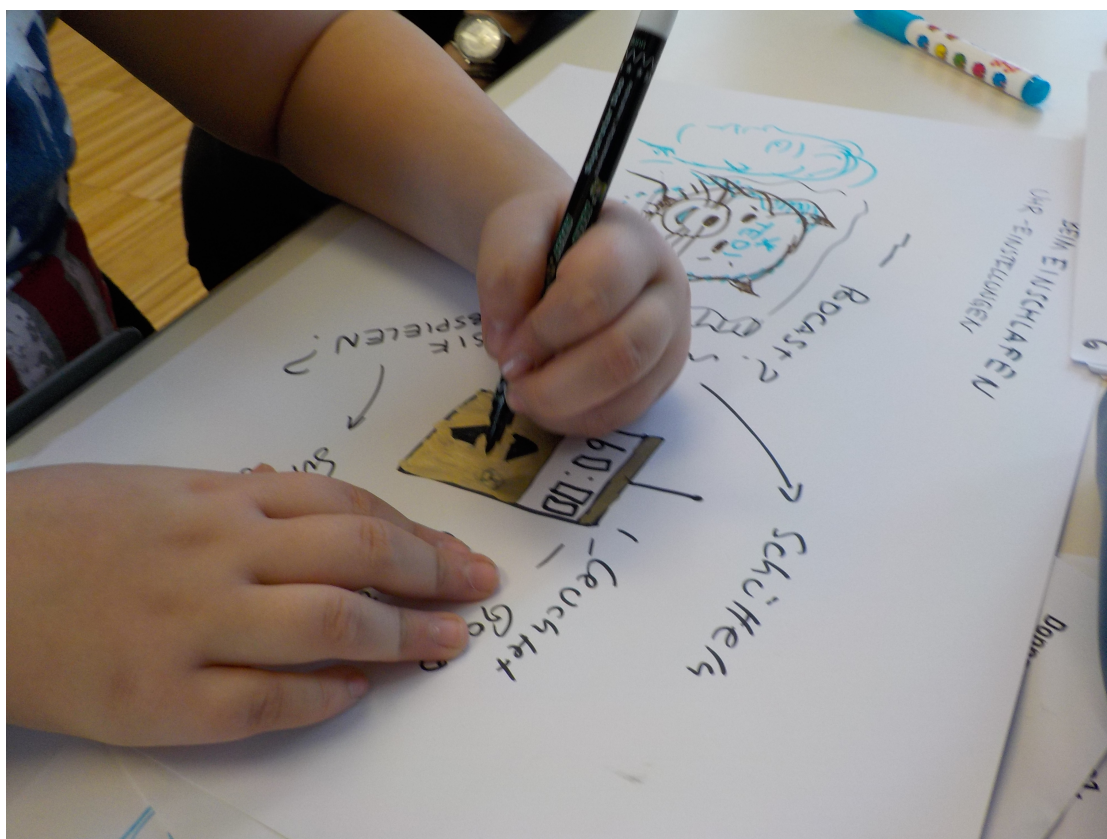
Figure 4.16: Collaborative drawing between Mia and her Play Partner Julia

that she was breaking them consistently, which led to her letting plush toys speak for her. During our collaborations, she used Yoshi, Bowser, Super Mario and later Link (whom she called 'Right' in opposition of the German 'Links', meaning left) to communicate things she did not necessarily feel safe to express in her voice.

Using the semantics of a Super Mario game world, we used theatre methods [Sato and Salvador, 1999] and augmented them with playful elements to learn more about Mia's life context [Spiel et al., 2016a] . We established that she finds getting up in the morning incredibly annoying and painful – so difficult that already during our second of 17 meetings, she suggested that we create a cushion that wakes her up by vibrating next to her instead of the disturbing sound made by her then-current alarm clock. Once we understood how important first impressions of a day are in creating a good mood, we also recognised the potential positive impact of such a technology.

During our prototyping phase, we tried to involve Mia down to co-constructing parts of the alarm system. However, she did not seem very interested in the minutiae of technology development and was more engaged when she gave feedback and developed new ideas. A further one, she brought up several times after it was clear to her that the
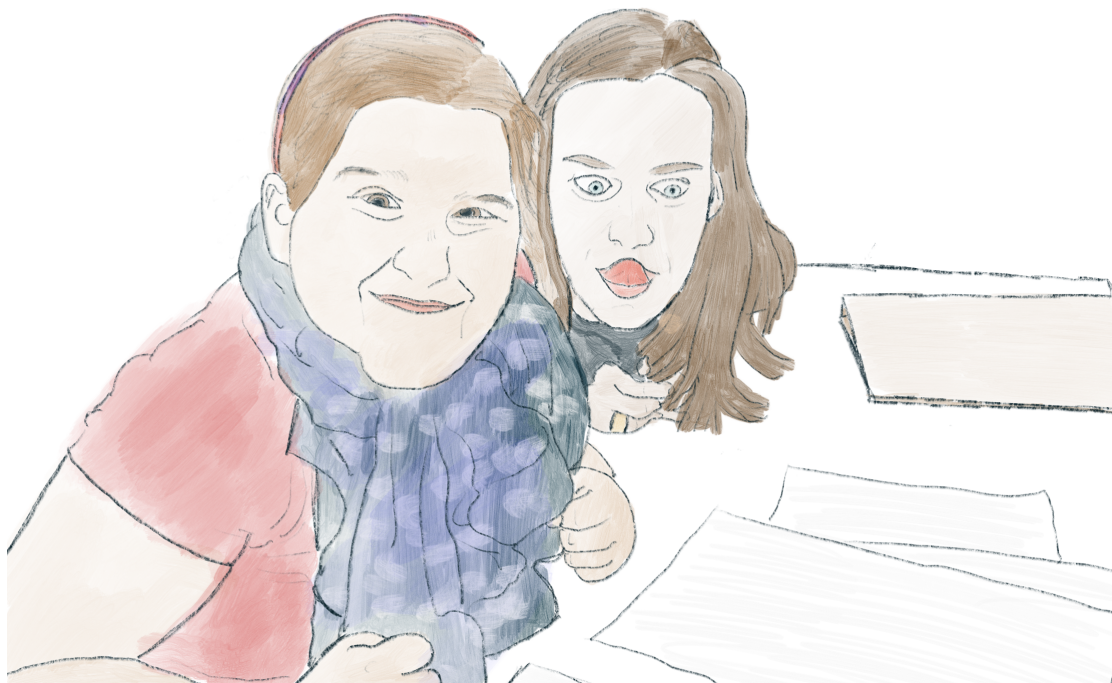
Figure 4.17: Mia and Julia grimacing at the camera as ritualistic part of our routine

alarm system would be developed as a functional prototype, was a nose warmer. It was so important to her that she even brought it up in summer.

The Rattle Alarm System (see Figure 4.18) consists of three parts. The alarm clock module – modelled after Toad's head – displays the current time through blue lights on a NeoPixel light ring with 24 LEDs. The alarm time can be set through a touch on top of the module and is displayed with a green light. When the alarm goes off, the Super Mario theme song plays in an endless loop, and the cushion vibrates. The alarm can be stopped by stepping on the pressure mat. Shortly after the alarm turned off, the clock plays a unique melody which sets the mood of the day as a stand-in for a horoscope.

When the rattle cushion starts vibrating to the Super Mario theme song, it suggests a cheery person, waking you up with a gentle touch. 'Getting up' itself also becomes embodied by having to stand on the map to turn off the alarm. There is no snooze functionality. The horoscope melody sets the tone for the day. We made sure it always ends on a positive note even though a more mellow tone can be set before. Sharing becomes much more implicit in this context as the positive experiences with this technology would not be explicitly shared, but influence Mia's interactions with others for the whole day.

Figure 4.18: The Rattle Alarm System – Developed together with Mia – left: cushion, middle: alarm clock, right: pressure mat

When we presented the object to Mia's peers, they all came from their usual classroom into the room we had our sessions in. Mia then competently presented her object and interacted animatedly with her peers. She had prepared a 'newspaper' about the object, that she read to them and answered curious questions like "When can I have something like this?" or "Is this going to be for sale?". She only referred to us, when she was unsure about an answer – but she always did so confidently regarding us as her associates.

4.8 Yvan

All things related to geography, planets and space travel are of great interest to Yvan. The eight-year-old, diagnosed with Autism Spectrum Condition, talked at length about these topics whenever he could; not always considering whether his audience was interested in listening. At the beginning of our cooperation, which spanned overall 13 sessions, Yvan

Figure 4.19: Several materials for guiding design Ideation with Yvan: a map, a globe, brainstorming about different countries and a lego tower for traveling between places

was educated in a special needs class but transitioned into a multi-age classroom later. We always had a small room to ourselves for the collaboration which was self-guided from the start.

During our collaboration, I mostly held the position of an Active Observer. Overall, my authority as the person setting the rules, structuring the session and managing the available material was respected, and often Yvan took me more seriously than Julia because of that assumed authority. That means, that practically, it was sometimes more important for him, to explain something to me than to Julia to receive the feedback, I provided through my role.

At the first couple of design workshops, we conducted a Contextual Inquiry [Holtzblatt and Jones, 1993]. That way, we not only learnt more about Yvan's core interests but also how essential his five-year-old brother Hank is to him. During our ideation phases, he always envisioned his brother in potential contexts of use. We used several objects and methods related to his interests during to create design ideas (see Figure 4.19). He was always focused on developing something that allowed him and his brother to explore

faraway places – preferably in space even. Once we settled on the idea of a Time Machine, with which we could travel through time and space to different temporal stages and different planets, we explored the actualisation of this idea through means of Digital Fabrication [Frauenberger and Posch, 2014]. While the Time Machine initially had the form of a pyramid and later followed the concept of a travel tower, we eventually decided that it would consist of two parts: an immersive light blanket and a navigation interface.
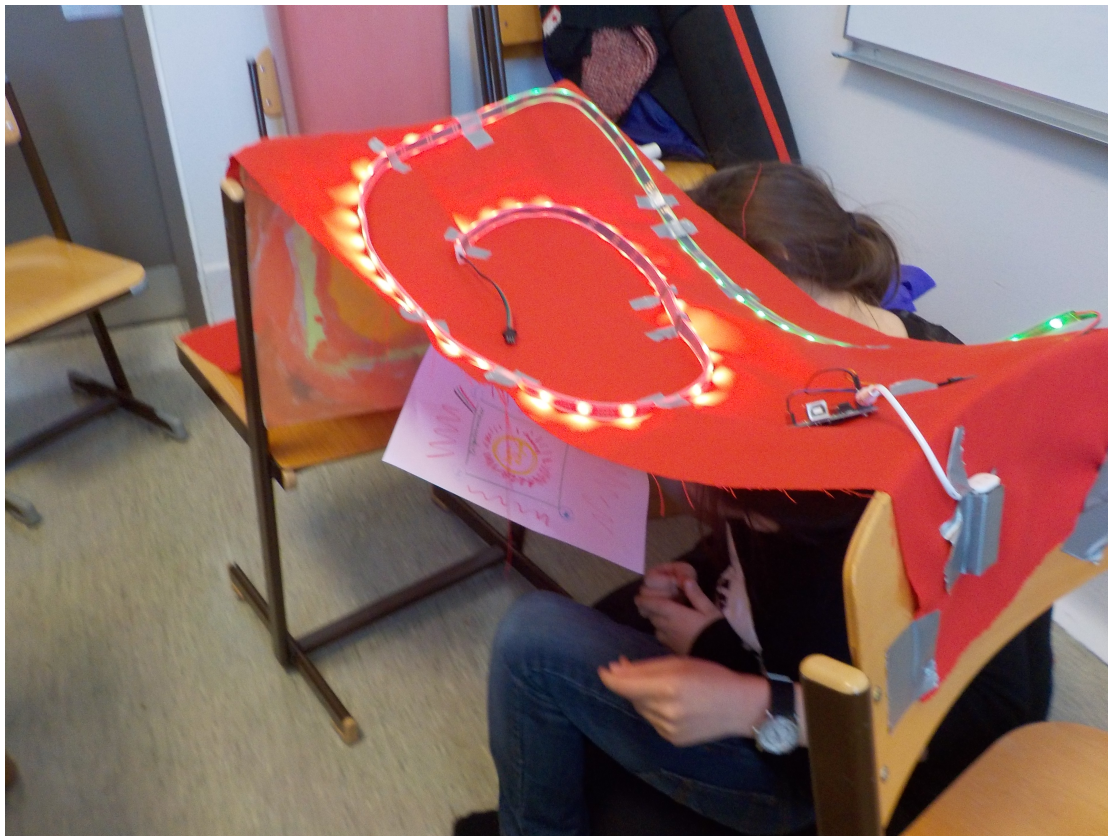
Figure 4.20: A mid-fidelity prototype of the Time Machine for use case exploration

Yvan was quite enthusiastic when it came to prototyping his ideas. While other children had issues with conceptualising cardboard prototypes as stand-ins for later, more finished objects, Yvan had no problem interacting with them as is (see also Figure 4.20). Still, he did not see them as stand-ins for later, but rather as finished pieces that he could show his brother and play with. He expressed disappointment when we moved into more iterative developmental steps with the time machine, that he could not take them at home anymore and play with his brother but was instead referred to a later point. Still, he enthusiastically provided design critique and suggested alterations to the design that would improve it from his point of view. Even when we presented the first final version and it broke down and had to be repaired for him to take home, he then was okay with it and trusted us to keep our promises.

In its final version, the time machine consisted of a red blanket with three LED Neo-Pixel strips sewn on that moved in different light patterns and were connected through a LilyPad Arduino. The light patterns could be activated by buttons on the navigation interface (yellow in Figure 4.21), which was connected to the blanket via radio modules and also had an Arduino for processing inside. The different buttons took on a new meaning during each playthrough of a journey through time and space.

Figure 4.21: Time Machine in the foreground, the navigation interface, in the background, the immersive light blanket

While the technological parts of the Time Machine are comparatively simple, the smartness of the technology emerges in use. Through the navigation interface, a user can control

different light patterns on the blanket. They only become meaningful through the narrative established between users. Yvan then tells elaborate stories in which he travels to different planets at different points in time. Once he 'lands', he steps out of the machine and grabs different things in the environment, but gives them a different meaning, appropriate to the time and place he travelled to, even though pretend play is thought to be notoriously difficult for autistic children [Jarrold, 2003]. However, the Time Machine introduces just enough structure for Yvan to do so cooperatively. Another effect of the Time Machine is that it becomes a productive release for Yvan's specialised knowledge that engages the other person as well. They experience the immersive space together and can both shape the narrative. The specialised knowledge becomes part of a joint adventure instead of a one-sided lecture.

Yvan presented the first version of the blanket in his classroom as well. His teacher was very supportive and explained to the other children the nature of iterative development, trying to explain that sometimes things do not work at first try. Seeing as the blanket did not exhibit any lights at this show and tell, the majority of the children was wondering what was there to see, when Yvan referred to fantastic places he visited with them under the blanket. Only one of his classmates joined in in the imaginary play and told others how fantastic his trip to outer space was. While Yvan found it not to be a problem for himself, that the blanket had broken down and could still use it for imaginary play, he was acutely aware of the reactions of the majority of his classmates and was later not interested anymore in presenting a better functioning version to them.

Yvan and Hank

After the first working prototype, we continued our collaboration and also included Yvan's neurotypically developing, six-year-old brother Hank. Hence, we held our sessions in a separate area within the workplace of their parents. We noticed that Hank, being the younger brother of the two, also often needed encouragement and a partner, so we made sure, he got the support he required from either one of us as convenient. Therefore, we sometimes left our assigned roles; especially me as Active Observer. While I still was the person who set the rules and had the power over materials, I was also willing to engage more playfully with the children once Hank was involved. Partly, my role was taken by another researcher (Florian Güldenpfennig) during a temporary leave of absence. However, this meant also, that my authority seemed flexible enough for Yvan to challenge it more. While the spirit of this is something we supported in children more generally, in this specific case, it partly kept us (including both children) from doing the more structured design activities, essentially allowing too much freedom. Hence, the explicitly separate roles we had initially defined work best in collaboration with only one child and have to be adapted when working with two or more.

While we investigated options that could help the brothers resolve conflicts and work together, we ultimately created a new and more robust version of the Time Machine. The refined implementation came with two navigation elements, each of which was explicitly assigned to one of the brothers through colour choices following their preferences (see

Figure 4.22). The setup combines a Philipps Hue Lightbulb in a lamp with a microscope and a gyroscope in each of the navigation elements. One of them also holds an RFID reader, whereas the other contains an RFID tag. The intensity of the light changes with sound input whereas the colours change along the data coming from the gyroscope. When both navigation elements are put together at a certain point (where the RFID reader and chip are located), they activate a rainbow light show, where the lamp circles through several colours. Both children interpreted that as the travel part of their adventures.

Figure 4.22: The Time Machine in its latest iteration. The two navigation elements, all elements and appropriation of the light through a fidget spinner

When we handed the final iteration over, only Yvan was present. However, he was once again enthusiastic to show the setup to Hank and experimented with the different input modalities; for example, he put his fidget spinner on top of his navigation element (the red one) and found out that the sound it makes results in the light intensity pulsating in an exciting rhythm. The accompanying parent was also impressed by what came out of the process with the two children.

4.9 Oliver

Oliver was six years old and in a mixed abilities pre-school classroom when we first met him. Our collaboration span was over two years. During that time he transitioned to an integrated classroom. He was very interested in building and construction work as well as elevators and drawing. Additionally, he developed a core interest in maths number games. Our first meeting was held in a classroom adjacent to the pre-school classroom. Later, we also met in an adjacent classroom; incidentally, the same room in which we worked with Andy and Dean two years prior.

Oliver was a very physical child. He continuously climbed on me and sat on my lap. Even when that was not the case, he stood very close to me when we worked together. At one point he even said to other children, pointing at me: 'This is mine!' (sic!). He seemed very comfortable in our interaction and was happily leading the design work with me as his helper and play partner. When we conducted a design session with all children in the pre-school classroom, he automatically grabbed me to assist him and seemed to have difficulties with the notion that in this case, I would also support other children.
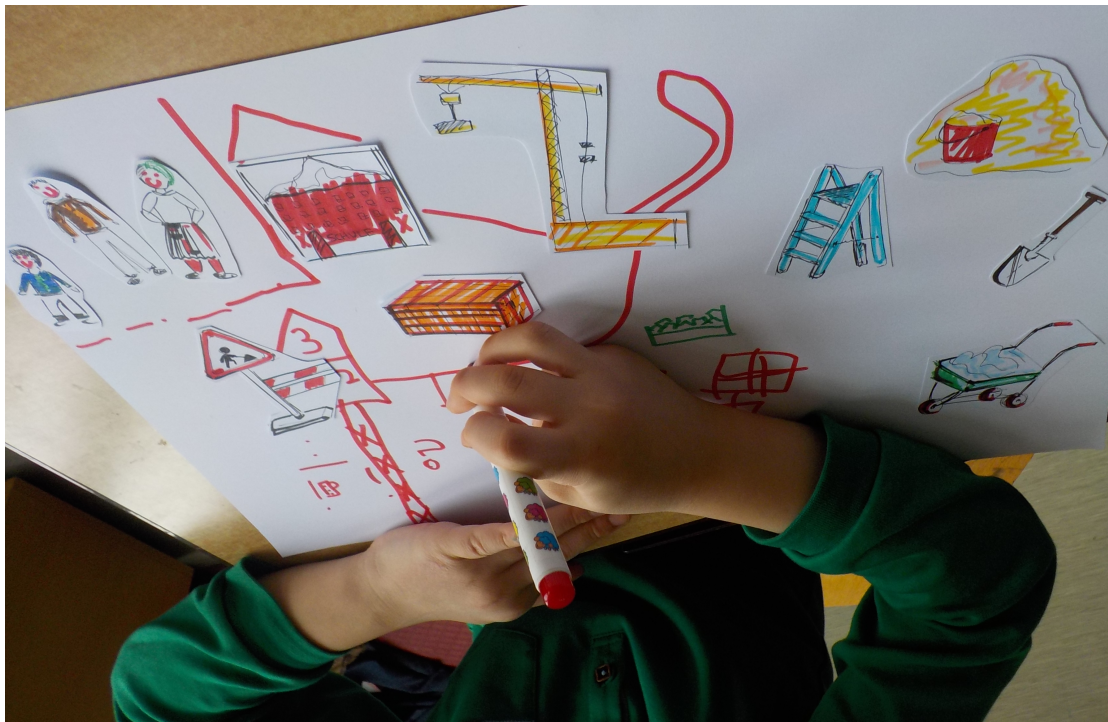
Figure 4.23: Oliver drawing around construction elements

With Oliver, we conducted a series of narrative-driven maker-workshops during which we investigated ideas and built prototypes hands-on [Frauenberger and Posch, 2014]. We started by creating a 'construction site' for his smart object. He could sort, alter and expand on construction elements and tell a story (see Figure 4.23). Incorporating mixed media, such as Lego or modelling clay was effortless for him. Finally, we also incorporated ourselves into the assemblage, by having Lego elements with our pictures attached to them. Oliver indicated great joy in being able to 'walk us through' the construction site.

Oliver's fascination with traffic lights guided our first idea. We were wondering whether we could take this idea and make it a mood light showing how Oliver felt or trying to map external things on the lights to explain Oliver his surroundings. However, we got more captivated by his mathematically inspired games with me and his interest in drawing and creating stories. We focused on the idea of an interactive light table on which he could create images with tokens representing the alphabet, numbers or animals.

Oliver called his object Öxe when he encountered the first prototype; a name, which – to our knowledge – does not mean anything specific or concrete. He happily interacted with the prototype and handled it with great care. The little bits and pieces, as well as the electronic wiring, intrigued him (see Figure 4.24), but he was genuinely fascinated by the fast animations of the drawings, which could move left and right and up and down at different speeds. While we were determining the specifics of the functionality and
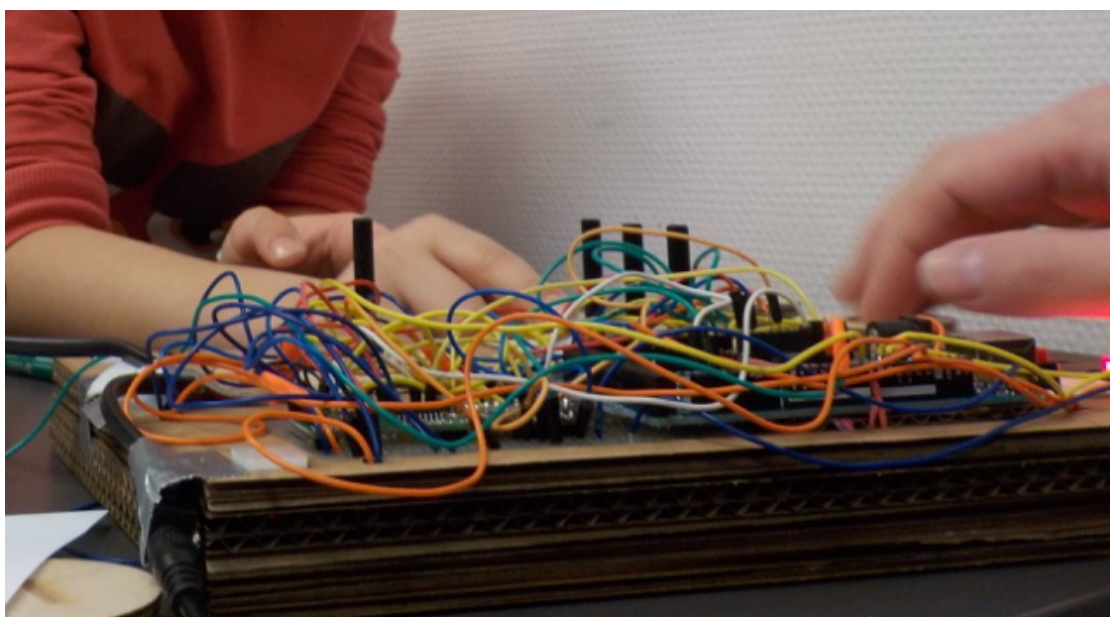
Figure 4.24: An early prototype of Öxe, the Light Table, fully with insight into the intricacies of the electric wiring.

aesthetics for several sessions, we could also observe how he appropriated specific modes, such as moving the number games with his play partner towards the table. This way, we could support these appropriations during development.

As can be seen in Figure 4.25, Öxe consists of two core elements: a table with a 16x16 NeoPixel LED Matrix and a control table with which Oliver can move the drawings on the table, animate them and undo previous steps. Additionally, there are tokens to create numbers, letters and animals on the light table. We also provided a set of pre-formulated games and tasks that can be solved individually or collaboratively (with peers and other adults, e.g., teachers, parents) with Öxe. With Oliver being the core expert in Öxe, he animatedly shows others how it works and what you can do with it, but he also guides them through the interaction with the object. Being so familiar with it, also enables him to come up with ideas for further games and tasks. We were also able to use the object itself to evaluate our design process with Oliver as it is so open for all kinds of purposes.

There was no chance to present Öxe to Oliver's classroom; however, one of his teachers joined in for the last session. Oliver explained the elements of Öxe diligently to her and even brought her to tears because she was so impressed by what he designed and co-developed. In the end, Oliver decided that Öxe should remain in the classroom so that other children can play and learn with it as well.
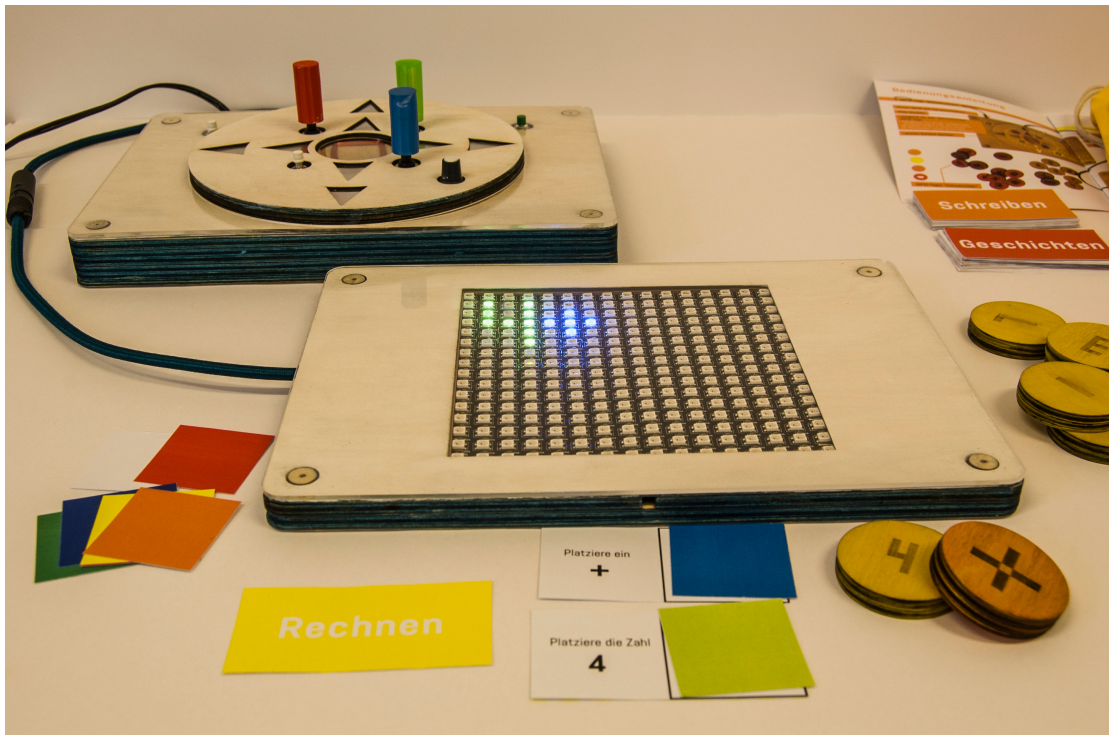
Figure 4.25: The light table Öxe in its final form with elements for math games, writing and storytelling

4.10 Summary

Within the empirical work presented in this thesis, I worked with nine children in eight case studies. In each of the case studies I worked closely with Julia, but they provide the context for my evaluation work, which I lead on my own. The collaboration with every individual child resulted in a unique object specifically tailored to their interests and needs. Hence, the parameters for evaluation changed with each case as well, as the technologies ranged from occasional interaction (Sound Lens) via intervention modes (ThinkM) to everyday use (Rattle Cushion). To try and understand how these technologies function in the context of each child, I needed a conceptual and methodological approach that accounts for the situatedness of the technologies in the children's lives and offers an insight into how these technologies are meaningful to them as well. Hence, I developed Critical Experience as an evaluation framework which I present in the next chapter.

5

Critical Experience

The work presented in this chapter has been previously published in Spiel et al. [2017a] and Spiel et al. [2017b]. I mainly drove both of these papers and conducted the data analysis in them; however, the data gathering was performed conjointly with Julia Makhaeva and Christopher Frauenberger. It was my responsibility to plan and conduct the evaluation of the final objects. The co-authors of the papers, Christopher Frauenberger, Geraldine Fitzpatrick and Eva Hornecker provided feedback in shaping the presentation and asking questions to identify holes in the work.

5.1   Theoretical Background

In the following, I explore how Actor-Network Theory (ANT) and Critical Discourse Analysis (CDA) help grounding a holistic understanding of experience that is open, multi-faceted, and allows for varied kinds of data sources. It contains relational as well as interactional modes of analysis while being critical towards its results and how they are constructed. Within its framework researchers identify a range of human (such as users and researchers) and non-human actors (such as the technological artefact or different concepts of disability) and analyse their relation to each other. Drawing from this actor-network (AN), they gather discursive statements for actors and connections of interest. By identifying similarities and differences across the discursive statements, experiences are presented and constructed from different angles.

5.1.1   Motivation

When dealing with autistic children, we face the issue of having multiple stakeholders with a vested interest. Autistic children often have different people speaking for them – legally as well as pragmatically (parents, carers, etc.) – and those are often neurotypically presenting people. However, this means that the opinions of autistic children should

be explicitly attended to [see also for a discussion regarding children Britzman, 1989]. However, every individual is also embedded in social contexts and autistic children particularly so. Social actors such as parents or teachers play critical roles in enabling the children to make experiences. Identifying these stakeholders is a crucial task in the evaluation [see for an example of stakeholder analysis for development Carmien and Fischer, 2008]. The diversity of perspectives considered together give a more in-depth grounding in our assessment of the experience. In that context, researchers provide their viewpoint on this as well.

Thus when talking about experience, my concept should allow for *multiple viewpoints* and needs to be *flexible* in the ways it allows to obtain data. The flexibility is two-fold: it has to be flexible regarding the source data, allowing for different communicative ways an autistic child might prefer and additionally, it has to be flexible and tentative when interpreting statements that might be nonsensical to researchers at first. Additionally, I wanted to be able to consider the *ecology* of the children's lives in a structured way akin to the work by Forlizzi et al. [2004]. Thee children's social and physical contexts made up by parents, institutions, conceptions on disability as well as important objects in their lives need careful consideration in the assessment of their experiences.

The toolset to gather data requires a range of different methods so that researchers can choose an appropriate one (according to the abilities of the user group) at any point. Where modes of communication do not differ too radically, classical methods [such as observations, interviews or questionnaires, see O'Reilly and Parker, 2014, Markopoulos et al., 2008] might be used. When children are limited in their verbal skills, photos, videos or drawings might be informative [see Fasoli, 2003, Dockett et al., 2011]. Alternatively, artifacts often help in eliciting responses from children [Riekhoff and Markopoulos, 2008, Nicol, 2014]. In other cases dedicated instruments for neurodivergent children are available [such as Read and MacFarlane, 2006, Feldhaus, 2015].

When allowing for multiple viewpoints, there is also a risk that of contradictory positions. To deal with this I suggest to be *open* to such contradictory positions [Sengers and Gaver, 2006] and initially treat them all as equally valid. As a further sense check, I also suggest that where researchers want to disregard particular statements or views, it could be useful that they are asked to argue for doing so and make this decision explicit.

While I acknowledge the importance of a variety of data sources, I particularly want to provide enough space for the autistic child's own opinion and not let them be drowned out by a cacophony of other voices. Hence, I suggest that researchers need to be *critically reflective* about who is involved in constructing the understanding of autistic children's experiences. Researchers are not only part of the experience, but also in charge of assessing it and often have a higher social status in society than their users, which brings along tensions in the roles that researchers assume. This conundrum is hugely pronounced when working with autistic children due to, e.g., age and difference in cognitive styles. There are implicit power hierarchies that researchers can address and even overcome by reflecting on their influence and that of others during analysis.

From my conceptual stance, I see one critical theoretical challenge arising: integrating the multiple angles and data sources into a coherent whole that allows us to construct knowledge about the experiences of autistic children with technology. In doing so, we need to pay attention to who makes the contributions and be critical of the statements extracted. We will show how Actor-Network Theory (ANT) and Critical Discourse Analysis (CDA) help to accomplish these goals.

5.1.2 Actor-Network Theory

One of the challenges noted above was the multiple perspectives and the risk of not giving the child their equal voice in the process. Actor-Network Theory (ANT) can provide an approach to deal with this. Latour [2005] presented a new understanding of networks that are neither purely technical nor purely social, but rather socio-technical. Through this, ANT acknowledges that technical components are not free of social elements. As an example, a smartphone has been developed by people, consists of hardware and has societal discourses inscribed in it.

As a theoretical and methodological approach in the social sciences, ANT was developed in the 1980s by a group of scholars which notably included Latour. The approach stems from the observation that prior studies of things and the social world framed things solely as resources which determine or reflect social position, or constitute a mere background for social interaction. By arguing for a symmetry principle understood in ontological terms, ANT emphasises the agency of these things and the interdependent relationships between humans and things: they show themselves in use, practice, maintenance, development, invention and so on, rearranging themselves into networks of relationships [Latour, 2005]. These networks always remain in a state of continuous malleability. ANT is based on highly detailed observations and stories of the series of interactions necessary to sustain a network [e.g. Latour et al., 1999]. Indeed, the goal is not to explain why a network has taken a particular shape—but rather how it has come to take this shape through the delegation and translation of powers from one actor to another.

As much as technology is not free of social influences, societal actors do not interact in a technology-free space either. For example, if someone owns a smartphone they might have organised an appointment with it, it might disrupt a meeting, or more generally serve as a status symbol. Actors within a socio-technical network are made up of their sub-actor-network (AN). We can combine the actors around the smartphone and the actors around the user and create a simple AN consisting of user and smartphone. ANT does not privilege one view – social or technical – over another. It instead puts different human and non-human actors in a 2D ontology (cf. the simple network in Figure 5.1).

There are three main strands of criticism of ANT. Winner [1993] argues it ignores social factors in artefact-human relationships. The premise of ANT is, however, that sociology has been too focused on social factors and ignored its components. Different approaches then yield different insights into socio-technical configurations. Whittle and Spicer [2008] argue that ANT has limited usefulness to articulate a social critique because the account
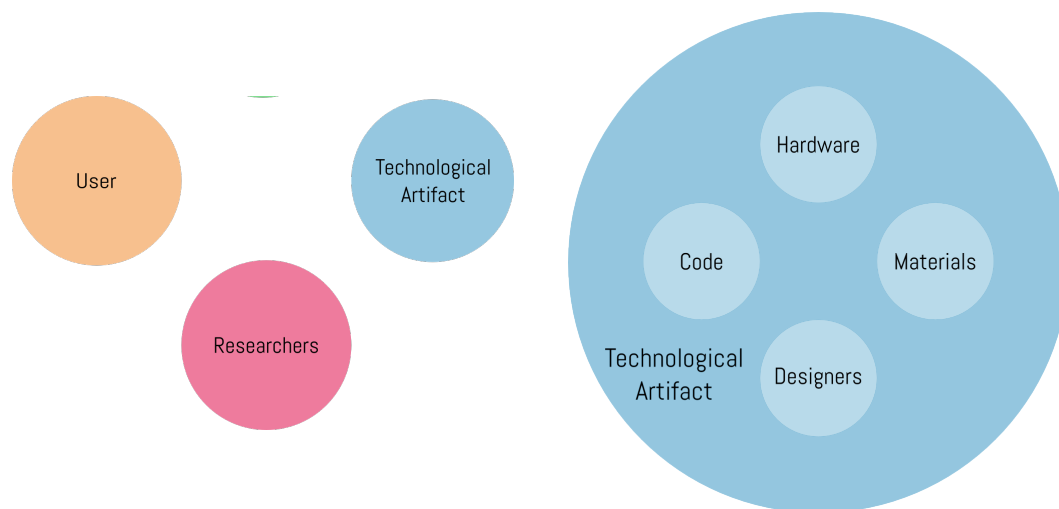
Figure 5.1: Examples for actor-networks within ANT

delivered remains in a purely descriptive state. I tend to agree with this, which is why I use ANT in combination with Critical Discourse Analysis (CDA, see below). Shapiro [1997] notes that there cannot be perfect symmetry between objects and humans, which led Kaptelinin and Nardi [2006] to proclaim that the approach is inadequate for HCI research and instead proposing *Activity Theory* as an alternative. As human goals heavily drive this approach, though, it does not, for my purposes, adequately reflect the agency and subsequent effects of inanimate objects and concepts on the experiences autistic children have during the design process and with the resulting technologies. Further, while ANT aims at conceptual symmetry, there is no value assigned to actors. For example, children and technologies are conceptually on the same level in my work, but I am much more focused on the children's perspectives because I value those more.

However, ANT is not a theory; rather it provides a flexible set of terms and concepts that can be appropriated in specific contexts: "It does not seek coherence. It does not build a stronghold. Instead of crafting an overall scheme that becomes more and more solid as it gets more and more refined, ANT texts are out to move—to generate, to transform, to translate. To enrich. And to betray." [Mol, 2010]. As such, ANT can act as an initial step into understanding more about the objects' perspective which can then be augmented with further analysis to make the insights productive for critical approaches to design.

In an HCI context, ANT is considered by some as a powerful tool for analysis. It has also inspired new forms of capturing design processes [Frauenberger et al., 2016a], starting from initial explorations concerning PD [Storni et al., 2012], to explorations into the aspects of use or non-use of technologies [Fuchsberger et al., 2014], to reflections about participation in PD processes [Andersen et al., 2015]. ANT provides a useful heuristic for articulating multiple perspectives on the same situation of interaction, with the goal of deepening the understanding of this interaction. In the cases above, it allows us to

nuance and complete users' reports—and, more broadly, to identify relevant connections between different actors that would otherwise remain hidden.

While ANT is a static and *relational* tool for analysis, it is also instrumental in exploring potentially informative connections. It helps in levelling out social hierarchies between connected parties and through that enables researchers to consider every actor's viewpoint equally. However, at the same time, it also hides existing and more implicit power dynamics between actors. This is where Critical Discourse Analysis can come in, as a critical point of qualifying actor-networks, and contributing a more holistic understanding of experience.

5.1.3 Critical Discourse Analysis

While not formally laid out by Foucault [1970], Critical Discourse Analysis (CDA) emerged as a theory from their approach to dealing with the topics they investigated—most notably on how norms are established within society [Foucault, 1971, 1982a]. It relies heavily on the concept of *statements*. While these are predominantly available as texts, a statement can have many forms. For example, this: ♡ is a statement. All actors, be they human or non-human, produce statements in different ways. While human actors can communicate their statements via language or drawings, technological artefacts tell us about their use through their general physical look, signs of deterioration or via logs. Researchers employing CDA are concerned with understanding how knowledge is constructed through texts and language. Consequently, *statements*, *syntax* and *semantics* within a *dispositive* (the fixed situational context) are in the centre of any discourse analysis [Brown and Yule, 1983].

Jaeger and Maier [2009] show how CDA defines statements within data and how it enables researchers to assess the contribution of individual data points to the knowledge about a discourse. This is accompanied by continuous reflection on what constitutes *valid* knowledge within the discourse. I showed above (Section 2.3), how autistic children are marginalised and consequently excluded from making valid statements when knowledge about their technological experiences is created. By analysing the position of these users within the actor-network and making actors' contributions explicit, my framework counteracts these normativities and gives *power* to marginalised voices.

CDA also offers the option of qualifying the relationships between actors. Although all actors have *agency* within the network, with CDA those with and without *intent* can be distinguished. In this context, *agency* refers to the inter-dependencies of influences between different actors. A technology has agency where it, for example, complies with the use or where it does not by, e.g., giving unexpected feedback. *Intent*, on the other hand, refers to a cognitive process of decision making, e.g. through design. With this, we can distinguish human and non-human actors on a qualitative level, while still considering statements from both.

According to Haig [2004], there exist three core strands of critique on CDA: Lack of specificity in philosophical grounding, inherent tie to researchers' values, and lack of

actual critical impact. However, in my work I use the notion of statements and texts for CDA and analyse them in relation to each other, basing the identification of actors on Actor-Network Theory, which philosophically stems from a longer tradition. While my values impact the work, throughout, I try and make them transparent so that readers can judge it with an understanding of my perspective on the subject matter. Lastly, requesting actual, tangible critical impact from an analytical theory might be asking too much of a research approach. Even so, by merely asking questions about the experiences of autistic children, this work is critical in that at its core it also questions how autistic children are seen and met in research and society.

Within HCI literature, Bratteteig and Wagner [2012] show how power relations in participatory design processes can play out differently according to small-scale decisions researchers and participants make. They also pointed out the crucial power differences between participants and designers, considering the latter tend to initiate projects, plan the encounters and guide through them. With autistic children, such power dynamics are even more pronounced, considering the age difference and presumptions around functioning following the diagnosis.

CDA has also been used to qualify the participation of children in interaction design [Iivari et al., 2015]. Specifically through a Foucauldian lens on discourses surrounding children's participation in design projects, they could uncover that these discourses are filled with contradictory statements which at the same time conceptualise the children as design partners, but also effectively hindering the design process. Their participation is discussed in an idealistic and a problematising way. Hence, I aim to reflect on the children's agency with an agenda to increase their participation in the process of making meaning for technologies, without demanding or requiring them to but instead taking any given input or lack thereof as a valid choice.

The concept of a discursive *dispositive* – the circumstances around a discourse – provides an understanding of experience as created between individuals and the relations between artefact, user, environment, the interactions between them and the arising statements.

By making sure that all actors can contribute equally, CDA helps to identify holes in data. Through reflective practice, it encourages the gathering of missing data points without requiring comparability of data sources. If the hole can be identified as a limit of what can be said, the functions of the discursive limits can be made visible and critically reflected upon. In the words of Jaeger and Maier [2009], researchers determine *collective symbols* or statements within an AN.

In contrast to the *relational* knowledge ANT produces, CDA analyses *interactional* aspects. Where ANT maps out the space of relevant actors contributing to experience without qualifying the relations between them, CDA provides us with qualitative descriptors of the connections between actors. Were we to only use ANT as a basis for our understanding of experience, we would have no way to interpret the modes of interactions between single actors meaningfully. CDA describes what happens in the static actor-network and with it, researchers can critically investigate what is desired and by whom.

The combination of ANT and CDA does not result in readily comparable statements or numbers that make definitive assertions about users' experiences, but it allows for a nuanced analysis that highlights *agency*, *intent* and *power* of single actors and how they contribute to the experiences autistic children have with technologies.

5.2 Evaluation Framework

Within the nine case studies of OutsideTheBox, we required a contextual understanding of the individual experiences each child made with their technology. As every child created their own artefact, the experiences were not expected to be comparable; instead we were interested in the quality of their experiences. As there was no conceptual or methodological approach available that would centre the experiences of autistic children appropriately, I developed Critical Experience as an evaluation framework for qualitative inquiry into experiences that goes beyond a purely empathetic approach.

5.2.1 Creating Actor-Networks

To establish which viewpoints are informative about the experiences an autistic child has with technologies, these viewpoints first have to be gathered and grouped in an actor-network. When researchers are simultaneously involved in the design as well as the assessment of a given technology – which is often the case in PD projects – they also have to be considered a core part in the creation of these experiences. Figure 5.2 shows core aspects of a schematic for an actor-network depicting experiences of autistic children with technologies in PD projects as a result of abstracting from the range of actor-networks I created in my work (see also Appendix 10.3).

The three main actors in the schematic are an individual autistic child, the technological artefact and the researchers. When these three come together, they make up central parts of the experience. The autistic child and the artefact mainly meet through interacting with each other. In PD projects, the skills of researchers (either directly or indirectly via resources) shape the artefact, but also the artefact might require skills that the researchers have to acquire. The child and the researchers meet in design processes.

Each of the core actors, as well as their overlaps, are colour coded. Subactors are then depicted in the same colour, and further sub-subactors are encircled around the relevant subactor (see, for example, Figure 5.3). While distance does not matter per se, subactors belonging to the same actor or intersection of actors are grouped.

Autistic children are also tied to their social environment consisting of, amongst others, their family (parents, siblings, other relatives) as well as their school with teachers, peers and friends. Their diagnosis and daily routines influence their experiences. For each child in a project, their actor-network looks different according to their circumstances. The social network of the child is made up mostly of their micro-system but can encompass every systematic level as they might influence the experience with the technology [Bronfenbrenner, 1992].
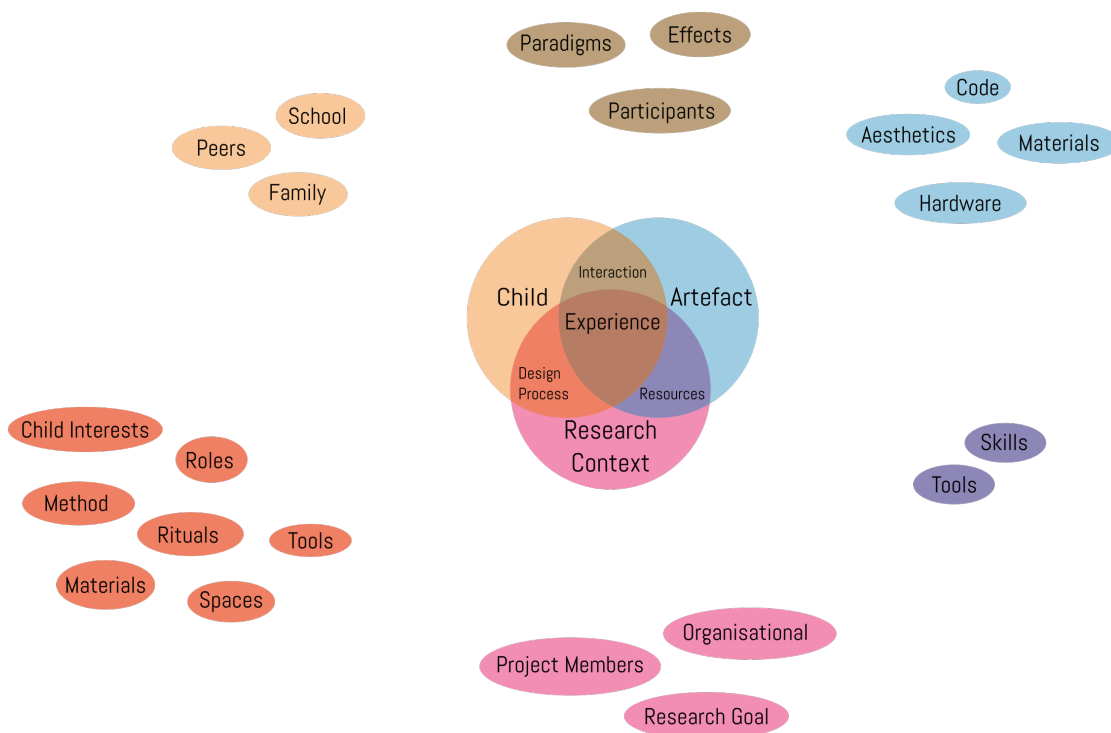
Figure 5.2: Actor-Network schematic describing experiences of children in PD projects

Artefacts have a history that describes how they came to the state in which they are evaluated, e.g. through a series of prototypes. They are culturally embedded in a techno-society. Their aesthetics and materials shape the experience as much as the used hardware (and its reliability) and the implementation in code (and its reliability) [Tholander et al., 2012].

Researchers have their motivation, ethics and morals that influence the questions asked about the experience and, hence, shape the experience in return. Those questions are often tied to their career, abilities and funding.

The schematic constitutes an initial starting point for evaluating the experiences autistic children have with technologies. It can be adapted to individual circumstances and provides an example template for the first step in the evaluation strategy. The core points of any evaluation consist of a user, the technological artefact and the researchers evaluating the experience since they are part of constituting what is accepted as a valid experience [for the relationship between observer and observed cf. [Chataway, 2001]. However, merely creating Actor-Networks, while informative about the components that might contribute to experiences, does not suffice to understand *how* these components contribute. To critically embed the network within the context and to analyse the power relationships explicitly, I use CDA (see below) to situate these actors meaningfully within the network.

I use the example of the story of one autistic child, Gus, using Siri as an everyday companion, to illustrate [Newman, 2014]. The article is written by Gus' parent. In this case, I am not personally involved as a researcher and have no other sources than the published article. However, the article itself provides a small unit of analysis that I can use to exemplify the key points of my approach and show how they can be mapped out in an actor-network schematic.
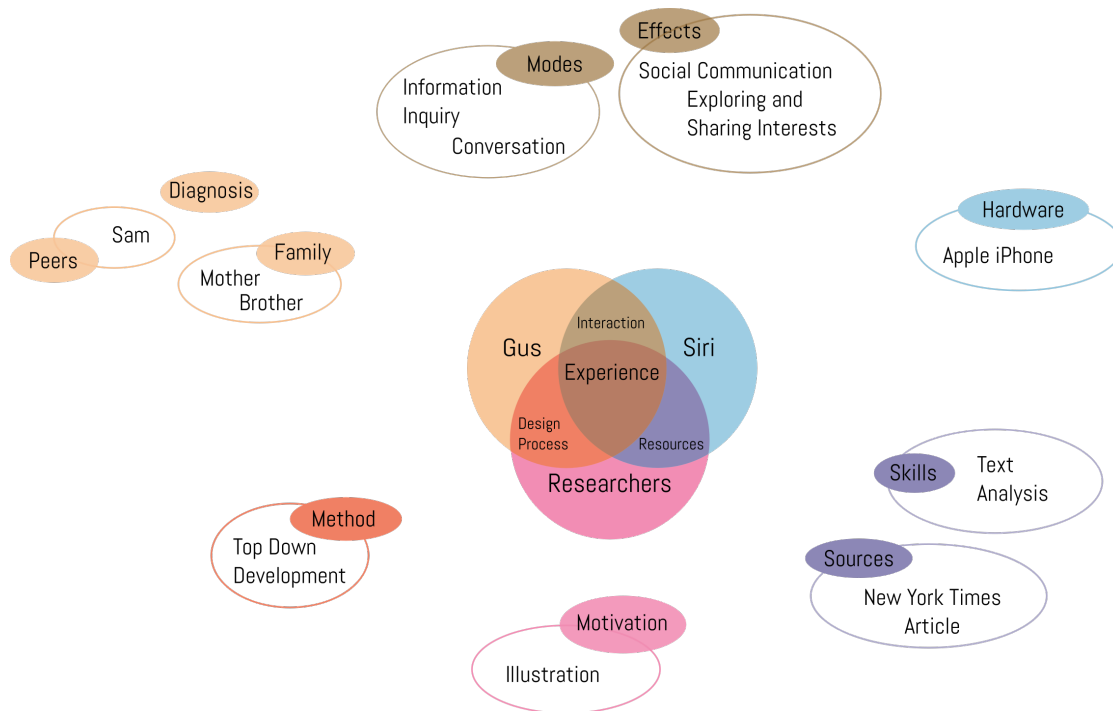
Figure 5.3: Actor-Network for Gus' interaction with Siri

Even though I only have access to a limited single perspective I can establish a basic description of possible angles that influence this interaction. Gus' peer Sam, for example, another autistic child, as well as Gus' neurotypically developing brother interact with Siri as well. The development process and specific hardware of Siri, while known, becomes less important in this context. Researchers are involved in that they have a certain motivation to present this case. Regarding interaction, I could extract modes and effects that appear to be meaningful – at least to the author of the article. Figure 5.3 illustrates this for the story of Gus and Siri [Newman, 2014].

As a side note, since I originally created the actor-network, Newman has published a full book on her autistic son [Newman, 2016]. The book has received criticism from the autistic community for speculating with sterilisation [Rhywiol, 2017] or invading Gus' privacy [Frazier, 2017]. The discussion around the book shows how limiting an actor-network to one data source provides a very biased outcome and, hence, exemplifies the limitations of a single perspective.

5.2.2 Combining ANT and CDA

Having set up a schematic understanding of the network, it is then possible to start the further analysis, which is comprised of five steps that can be repeated until no new findings occur. Based on an initial actor-network (as above) the steps are the following:

1. ⊕ Define Discourse and Context (Dispositive)
   Through a context analysis establishing the dispositive, researchers can find out which actors and relationships might be relevant for answering their research question, e.g., by an expanded stakeholder analysis [such as in Carmien and Fischer, 2008] that includes non-human actors.

   - For the example case, we could establish all actors other than the subactors in interaction modes and effects (see Figure 5.3).

2. ⚔ Gather Data to Populate Actors and Relationships
   In this step, researchers establish suitable data gathering methods for individual agents and relationships. It is important first to identify the main stakeholders and systematically make sure they all can contribute appropriately via data gathering methods. In this way, it is more likely that otherwise hindering power relations can be circumvented. For example, if parents always tend to answer for the child when questions are posed to their child, researchers can aim for other modes of data acquisition to get the child's direct opinion.

   - In the Siri case, it is the perspective of the mother. Every other perspective is mediated through her writing.

3. 🔍 Analyse Data and Identify Statements
   Depending on the data sources, researchers now perform suitable data analysis and attribute statements to the connections and individual agents with the actor-network. I stay deliberately abstract on data sources here to allow for different modes of data analysis that might be less common (such as object speculation Bogost [2012]) or not known to us as well. A statement is data-driven, but interpreted and abstracted, for example, if a log file is empty but functional, then a statement might be: "I have not been used at all." For the discourse analysis in the next step, every statement is in text form but can be derived from a variety of data sources, such as observations, prototyping history or phrasings in interviews. While there is no clear cut-off point to stop identifying statements, researchers can do so when they have reached a saturation point, i.e., where further extracted statements mostly repeat what has been established previously.

   - Statements from Gus might be: "You're a really nice computer." (mediated utterance), whereas a statement from the mother can be (abstracted from the article): "My son's interaction with Siri changed our communication patterns for the better."

4. ⚭ Put Statements in Context to Each Other
   With the established statements, researchers analyse context, content, discursive position and other peculiarities individually and about each other. This way, they can identify contradictions and actors whose statements could be informative, but might still be missing. For example, it might become clear that a sibling used a technology more than the intended user due to the parents' statements, but the sibling was not part of initial considerations.

   - With the two extracted example statements for our Siri case we see that the interaction is differently meaningful for Gus and his mother. While he sees Siri as a companion to interact with, his mother values the interaction between herself and her son when Siri is not present more, because Siri covers modes of interaction the mother is uncomfortable with.

5. ↻ Rinse and Repeat
   During the last step of the iteration cycle, researchers reevaluate their existing actor-network and add missing links or actors. For example, the sibling has to be added, and data gathered from their point of view. Then researchers repeat steps 1 through 5 until no new information becomes apparent to them.

   - We are now able to populate the conceptual interaction actors within Gus' and Siri's network. If we had more access to this case, we might want to gather data from the perspective of all other actors than the mother. As a final result we can see how the interaction between Gus and Siri is differently meaningful for different actors and that the experiences he makes with Siri have multiple effects on the network.

To show that this is a feasible evaluation strategy that creates valuable, novel and informative knowledge reflecting the complexity of HCI research projects, I applied it to the four first-year case studies within OutsideTheBox. The second-iteration case studies are analysed in Chapter 7, to show how the knowledge from the first year influenced the development of PEACE and how the implementation of that method re-configured the knowledge gained by applying Critical Experience on that set of studies.

5.3 Critical Experience in Practice

The data sources for each case study included contextual interviews with parents and teachers, research diaries from the researchers, protocols of meetings within OutsideThe-Box, 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 and photos of the design and evaluation sessions.

To provide the necessary depth and breadth, I show only selected steps of the process for each first-year case study[1]. I limit myself to the final state of the resulting networks and statements as they were available to me at the last iteration. This means, I do not illustrate the Rinse & Repeat step explicitly, but instead artificially narrate each step separately from each other, even though the actual timeline is more intertwined (which will be more explicit, for example, in Quentin's case from the second year case studies in Section 7.1.1 and Mia's case in Section 7.1.2).

Andy's case illustrates the construction of actor-networks, Blaine's case shows how log data can be converted into 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 steps I performed, I use the icons assigned to each step above. Repetitions of steps are not explicitly detailed, but instead, 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. I argue that my systematic approach uncovered a more vibrant and more detailed picture about these experiences than an evaluation solely relying on designers' empathetic assessment.

5.3.1   Andy

Define Context and Discourse
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 curious about and interested in 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. Figure 5.4 shows the actor-network as established by the final iteration of my methodological approach.

The interaction paradigm for ProDraw (see Section 4.2) 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 challenging 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. I reflect on this by showing how access to specific tools and particular skills of the team members shaped ProDraw aesthetically and determined which hard- and software components were used.

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[1]The second-year case studies are analysed in Chapter 7 and an overview over the actor-networks of all case studies combined is given in Appendix 10.3
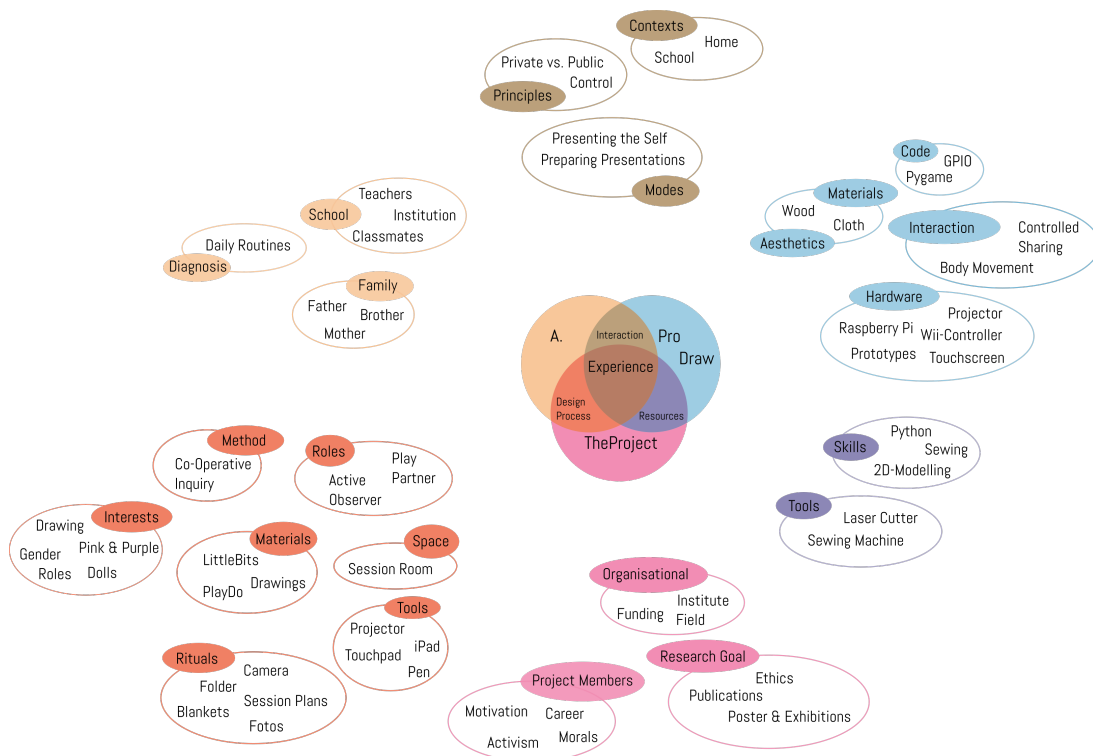
Figure 5.4: Evaluation Actor-Network for Andy

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 prompted 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.

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 5.1: Selection of statements identified in Andy's Actor-Network

Analyse Data and Identify Statements

Table 5.1 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 sentence (as it 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 5.1; this insight is established by *content* analysis of statements). Andy was proud about building the object together with us, especially because envy and admiration were 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 was deeply entangled with different contexts of use 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 him and made fun of the drawings. ProDraw, hence, mediated communicative experiences for Andy. It was only enjoyable as much as the communication was enjoyable.

5.3.2 Blaine

Gather Data

With Blaine's case study I 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 retrospective 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 the evaluation, the pictures were only moved and not deleted to be available for later analysis.

While Blaine had high verbal skills, he preferred talking about concrete things that were related to his core interest and remained mostly silent when prompted about abstract opinions. 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 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), it can be observed 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 image 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 repeated 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, I have to reject the statement "It's exciting to use me, but the excitement doesn't seem to last long.", because I 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. Hence, in the end, only one statement for ThinkM remains: "I'm barely used." It 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, I can report 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. Hence, Blaine might have considered ThinkM more as a tangible token of our cooperation than an object that can be used.

Ultimately, then, 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. By providing the context of that failure, it also allows designers and researchers to be informed when speculating about causes and potential modifications to mitigate failures.

5.3.3   Claude

Define Context and Discourse

Figure 5.5 shows Claude's actor-network, which I analyse in contrast to Andy's actor-network (see Figure 5.4). 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.

While OutsideTheBox and its sub-actors remained stable, the interaction in the design process was volatile. We used different materials and rituals played a less critical role. Different tools addressed the diverse interests and needs of Claude. Through using the Critical Experience Framework, I can explore which actors remain stable and which are flexible by comparing two or more actor networks directly.
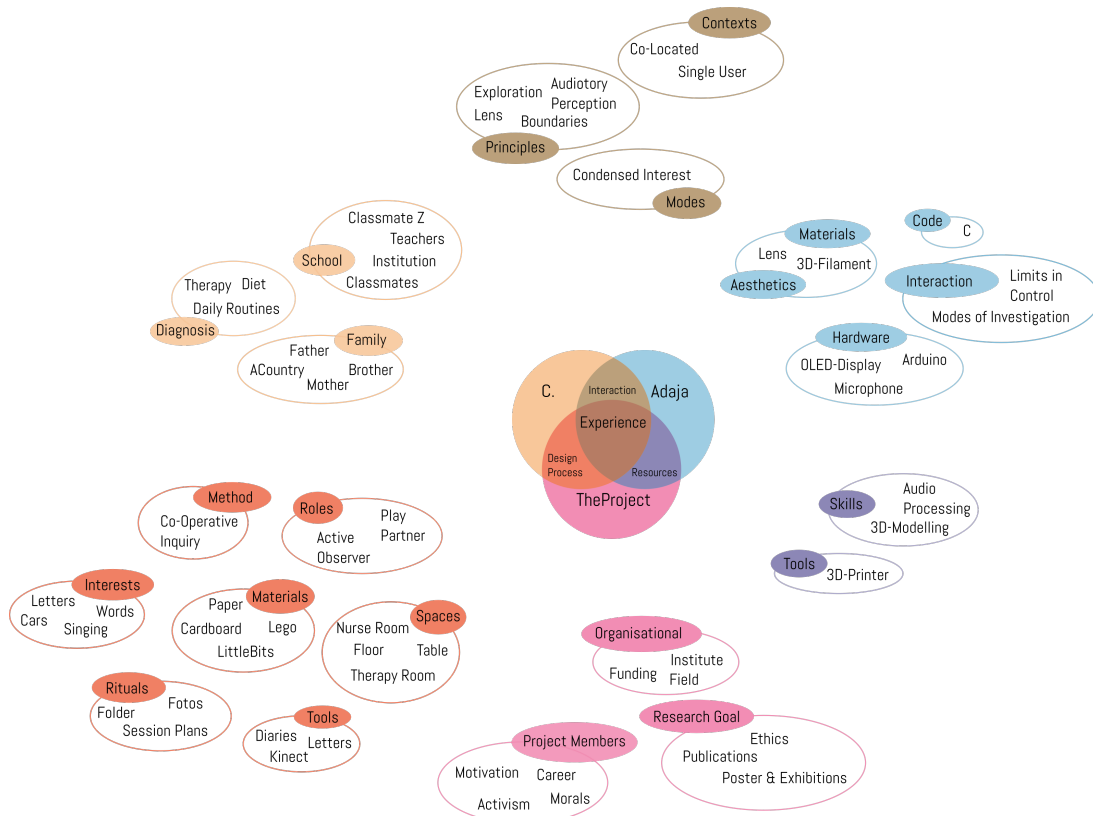
Figure 5.5: Evaluation Actor-Network for Claude

Gather Data

To account for Claude's perspective on the interaction, we developed a small game inspired by Theater Workshop methods [Sato and Salvador, 1999]. Three large pieces of paper signified answers of 'yes', 'no' and 'don't know' at different spots on the floor in the room. The Active Observer asked closed contextual questions while I as the Play Partner 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, I determine 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 our meetings. We were a little frustrated that Adaja was not as much created out of the co-design

procedure as much as made for Claude out of time pressure and the need to create an object. However, we gained valuable insights into the design process, which helped restructure future design co-operation. For Claude, the object in its actualisation was less important than the experiences made while designing it.

5.3.4 Dean

Gather Data

At the time we conducted evaluations, Dean was quite friendly with us. Even though, he was still shy about expressing his own opinion unfiltered. Because of that, we conducted a dedicated evaluation session with him that was based on a mix of Fictional Inquiry and Theater Methods. In a social outing Dean and I watched the movie *Inside Out* [Docter and Carmen, 2015] 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.

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 5.2: Selection of statements identified in Dean's Actor-Network

Analyse Data and Identify Statements

In Table 5.2 I show selected statements for actors in Dean's actor-network and the data sources I analysed to extract these statements. It shows how the silver carpet, a piece of cloth we introduced in one of the sessions that spatially marked the area of future in the form of 'the Year 3000', was relevant to the experience of designing DSmart, but not anymore for the final physical realisation. Dean expressed much frustration in cases where DSmart did not function properly or as quickly as expected. This scenario 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 [Odom
et al., 2016] instead of research prototypes when designing for the lived experiences of
autistic children.

5.4 Lessons Learnt

Through the application of my approach on evaluating the experiences of autistic children
with technology [Spiel et al., 2017a] on the OutsideTheBox first-year case studies, I was
able to gain methodological insights, especially into possible research settings in which the
approach could be used. Additionally, I could extract implications for experience-centred
design with autistic children. I did so by combining the children's first-hand perspective
on their experience with the perspective of other relevant 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.

5.4.1 Methodological Insights

Define Context and Discourse
Several insights help understand the methodological approach better. I found a set
of stable actors that played a role for all of the case studies (see Figure 5.6) within
OutsideTheBox. They are not the only actors or actor groups that are relevant to
a single case study, but that, 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
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 (such as daily
routines or teachers) are even more volatile. The further an actor is away from their core
actor, the more flexible it appears to be. For future case studies, I can draw on this to
set up initial actor networks faster, and others can quickly achieve an understanding of
their respective core-actors.
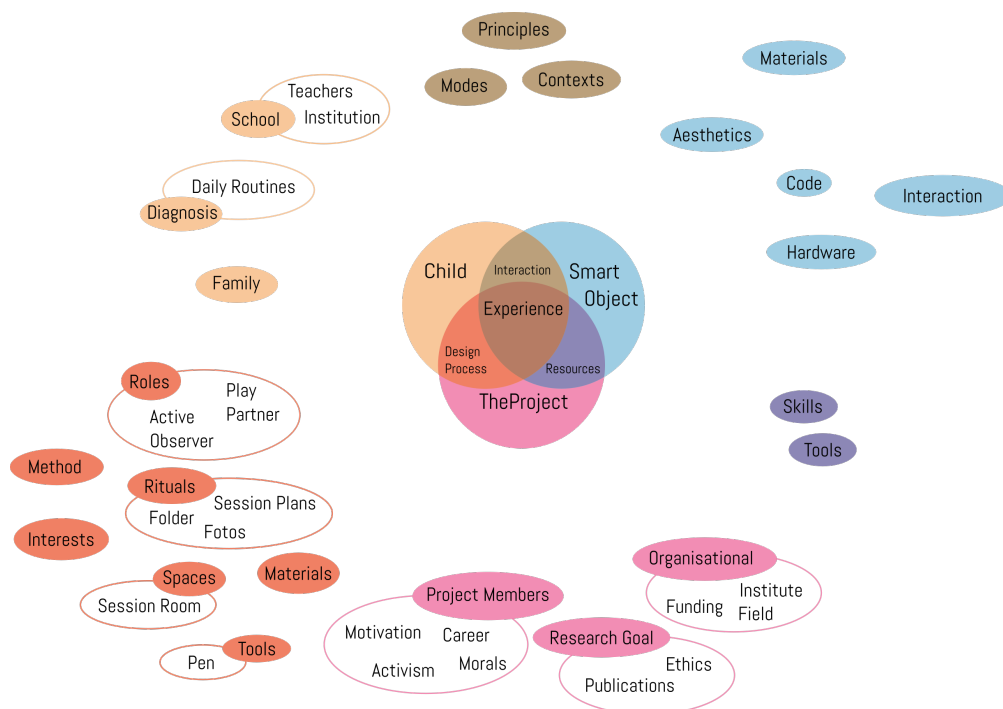
Figure 5.6: Stable actors in an Actor Networks within the context of OutsideTheBox

The actor networks show us what kinds of information I can get from the child's environment and teach us about the involvement of the child. By adapting, for example, materials, methods and tools, I can show that the 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 children can express their agency.

Contextualise Statements

Across all case studies acceptance of the technology 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 space that limited our possibilities in designing holistically for more aspects in the children's lives as we were set out to do.

Gather Data

Regarding data acquisition, I 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 I initially tried to tax the parents less regarding 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 Frauenberger et al. [2012a]). We also made good experiences with playing out different contexts of use with the children.

5.4.2 Implications for Experience-Centred Co-Design with Autistic Children

I see one implication in the non-use (similar to what Fuchsberger et al. [2014] described) I 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 [Mayall, 1994]. 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 the 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, which 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. I speculate that parents, who do not necessarily understand the technology and how it might be relevant 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.

Especially with Blaine and Claude, I could also identify how the process of designing might be more important to some children than the actual artefact. Blaine used his Thinking Machine as a token to illustrate the achievement he accomplished whereas Claude somewhat disregarded Adaja as a personal object. Similarly to Parsons and Cobb [2014] "it could be that in trying to value and include the user, whilst simultaneously aiming to produce a 'finished product' we were working on two competing or even opposing objectives". Following Druin [2002], the focus on creating actual artefacts limited the agency the children had in the process and in eventually contributing to the final object. Removing this limitation on the design might result in the children becoming

more equal partners in the design process; however, in an academic landscape where outcomes are a measure of success and need to be promised in exchange for funding [Stengers, 2018], this tension is difficult, if not often impossible, to reconcile.

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

5.5 Summary

I presented a novel approach to assessing experience in the context of how autistic children experience their interaction with technologies. For four case studies from the first year of OutsideTheBox, I provided a detailed account of how the experiences of the children come together using Actor-Network Theory combined with Critical Discourse Analysis. I have demonstrated how my approach leads to valuable insights, grounded in diverse data sources, most importantly including the perspective of children themselves. 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 particular context, I argue that our approach can initiate a broader discussion about the conception of experience in HCI. While the pragmatic perspective advocated by McCarthy and Wright [2007] has meant a step forward regarding a situated and nuanced understanding of experience, I argue that my approach can make a significant contribution towards a conceptualisation that is increasingly multi-faceted, multi-sourced and both extrinsic as well as intrinsic.

Participatory Evaluation

I have published large parts of this chapter in Spiel et al. [2017c], which I have also mainly conceptualised and written. My co-author, Laura Malinverni contributed in the initial planning phase of this article through questioning specific approaches and pointing out the Participatory Inquiry paradigm [Heron and Reason, 1997] and how it relates to my work. Judith Good assisted in structuring and fine-tuning the presentation in paper form, and Christopher Frauenberger gave general advice and polished the paper as well.

The chapter introduces Participatory Evaluation for Autistic ChildrEn (PEACE) as a methodological underpinning for inquiring into the children's perspectives explicitly. It conceptually centres around the children's agency about the technologies they co-created and aims at reducing the dominance of researchers' meaning-making about co-designed technologies. As such, it provides the methodological underpinning for the children's perspective on Critical Experiences.

6.1 Participatory Evaluation

The first conceptualisations of Participatory Evaluation (PE) date from the 1960s and 1970s [Brisolara, 1998], with initial applications in economic development [Garaway, 1995] and patient-centred health-care [Cousins and Whitmore, 1998]. Three primary characteristics of PE play a role in the process but can be configured differently: control of the evaluation (e.g., participants – researchers), stakeholder selection (e.g., individuals – group representatives) and depth of participation (e.g., determining goals and methods – gathering data) [Cousins and Whitmore, 1998].

PE can be used pragmatically or with a transformative agenda. In the first form, PE is implemented because it yields more productive knowledge, and results in higher acceptance by participants; in the second form, participants are invited to use PE as a platform for emancipation and empowerment [Cousins and Whitmore, 1998]. Separating these

two agendas makes sense in explicitly political environments such as the implementation of policies in economic development contexts, but in technical settings, both agendas converge – especially with marginalised people who are notoriously disempowered by technologies (see Chapter 2).

There are several issues commonly discussed in PE contexts, among them ethical questions about data ownership and the definition of technical quality [Cousins and Whitmore, 1998]. Relatedly, power differences between researchers and participants and protocols for interaction that aim to overcome these differences are considered in the literature [Bratteteig and Wagner, 2012]. Particularly marginalised user groups, such as autistic children, often face multiple power differences. In this specific case, allistic researchers have higher social status, are better equipped to function in a world with neurotypical demands and are not least physically taller, manifesting the power inequality through appearance. It is thus vital to the success of PE to reflect on existing power differences and ways in which they can be countered before conducting any participatory research, be it design or evaluation.

6.1.1   Participatory Evaluation in HCI

Participatory evaluation is not very prominent within HCI. The few cases in which it has been formalised include a cooperative work context [Ross et al., 1995] and a trauma resuscitation context [Kusunoki and Sarcevic, 2013].

The first context led to the development of the PETRA (participatory evaluation through redesign and analysis) framework, which states that one of the benefits of participatory evaluation within technological work settings is that viewpoints of theory-driven evaluators and design-based participants can be combined. In this way, evaluators gain access to the participants' perspective, and vice versa Ross et al. [1995]. However, the framework focuses on the *evaluators'* goals and methods, and reduces the participatory aspect to the execution of the methodological approach, through which evaluators and participants co-construct meaning about the technology. In the end, researchers perform the final analysis by themselves.

In the second context, trauma resuscitation, initial research by Kusunoki and Sarcevic [2012] suggests using participatory design methods for participatory evaluation, effectively merging phases of inquiry into the context of use, design and evaluation [Kusunoki and Sarcevic, 2013]. They describe applications of their framework to projects where participatory evaluation could function as a way to include users who cannot or do not want to commit to a fully fledged participatory design process. To date, however, they have not published a final version of their framework.

Bossen et al. [2016] propose seven questions for researchers evaluating participatory design processes: What is the purpose of the evaluation? Who is conducting it? Who is participating in it? Who has the power to define evaluation criteria? Which methods are used? Who is the intended audience? What is expected of the evaluation? In

participatory evaluation, these questions are not only asked of researchers but collectively decided upon by research participants and formal researchers.

What is currently lacking, however, is a methodology that ties together both the participatory design and participatory evaluation aspects of a project in such a way that the same participants can co-construct the evaluation of a technology in a way that is meaningful to them.

6.1.2 Participatory Evaluation with Children

Involving children in PE poses several challenges: it is important that a child can be met at the level of their abilities so that they can contribute in a way which is meaningful to them. Participating children must be able to express themselves, while researchers must attempt to ensure that they understand what has been expressed contextually; much in the tradition of listening as 'an active process of communication involving hearing, interpreting and constructing meanings, not limited to the spoken word' [Clark, 2005]. This can be achieved through observation, interviews, questionnaires, structured activities (such as role-play with dolls/puppets or game activities), multi-sensory explorations [Clark, 2005], analysing children's photographs [Einarsdottir, 2005], interviews guided by these photographs [Jorgenson and Sullivan, 2009], drawings/paintings [Frauenberger et al., 2010], photo/video tours or journals [Dockett et al., 2011].

Children already have different roles in technology research. Druin describes these roles as 'user', 'tester', 'informant' and 'design partner', implicitly indicating that this order also follows an order of participation and agency [Druin, 2002]. Participation along this categorisation seems to be limited to design phases only, however. As soon as a technology is developed, children are relegated to the role of testers without any agency in defining what makes a technology successful and desirable or, conversely, a failure.

Initial approaches to participatory evaluation with neurotypically developing children fall back on a combination of heuristics tied into participatory design methods with predefined goals and methods [Tan et al., 2013]. Similarly, Best et al. [2017] elicit themes in a participatory matter with young people. While they allow new themes to emerge, they also test the suitability of their themes with the population. Hence, meaning is again constructed primarily by researchers through the input the children deliver, without the children being able to intervene or put their interests forward actively.

Overall, a range of methods exist for accessing children's opinions, but none for structurally inviting them to participate directly in decisions about the goals and methods of an evaluation. They do not decide where, or how, to collect data, and their interests around the evaluation of a technology are not taken into consideration. Through more participatory approaches, children could be encouraged to reflect on the data acquired (be it quantitative or qualitative, from others or themselves). Furthermore, given that they are also part of the user group, such an approach would ultimately yield additional knowledge about what they deem essential.

6.2 Evaluating together with Autistic Children

As a consequence of most technologies for autistic children inhabiting an interventionist perspective, their evaluation has been framed around the researchers' goals of functionally understanding their effectiveness concerning behavioural outcomes. In both the development of such technologies and their evaluation, the perspective of autistic children becomes secondary. Often argued with the difficulty of accessing autistic children's opinions in researcher-driven settings, I (together with Lundy et al. [2011]) argue that researchers need to attune themselves to listening to the contributions in the ways they are made instead of presuming only specific modes of communication (such as well-formed language) as valid.

Starting with the definition of the goals of the evaluation, autistic children may already challenge researchers' pre-conceived expectations regarding the purpose and evaluation criteria as well as the intended audience and the required methods. In classical researcher-driven evaluation, the selection of methods is derived from a combination of the research questions and the epistemological stance of the researchers. However, when working in participatory evaluation, it becomes crucial to decide on methods based on the abilities of the participants and ensuring that the resulting data are meaningful to all involved [Nind, 2011]. By separating the definition of goals of participatory evaluation from the methods, researchers and participants can divide the questions of *what* is evaluated from *how* it is evaluated. Both parts inherit different aspects of meaning-making, agency and participation – as I will detail below.

When conducting participatory evaluation with autistic children, co-defining *what* to evaluate can be challenging due to the abstract nature of the task. To make it possible for the children to participate in the evaluation procedure meaningfully, some of these questions have to be asked via concrete illustrations. For example, when discussing how to find out more about the broader desirability of a technology, it can be helpful to provide details of who those 'others' might be, and relating them to populations familiar to the child, such as classmates or 'children your age'.

Specific goals implicitly or explicitly include or exclude particular methods. If we want to know whether other people like a technology or how useful it might be beyond its intended use case, observations of use are not sufficient. Similarly, if the goal is to understand the reliability of a technology better, it is less useful to interview others about the look and feel. However, each evaluation goal comes with a set of choices regarding data acquisition methods. If a method fails to address the way in which an autistic child makes sense of their environment, the participatory evaluation will be less successful.

6.2.1 Insights from Participatory Design

Given that participatory evaluation has rarely been explored within HCI, the field lacks proven methods, particularly in the context of marginalised user groups such as autistic children. Fortunately, in the past few years, several projects have explored the participatory design space opened up by the collaboration with autistic children. The expertise

which has developed around how to plan interactive sessions with autistic children and make their contributions count is invaluable when conceptualising participatory evaluation with them.

The IDEAS framework [Benton et al., 2012] emphasises the structural features of participatory design sessions to involve autistic children. It is – to my knowledge – the most detailed and prominent approach for PD with autistic children and rooted within the Diversity for Design framework [Benton et al., 2014], which argues that participatory research with neurodivergent populations requires researchers to understand the culture and the individual to structure environments and provide task-specific additional supports. It is, however, impossible to generalise the method reliably to a larger population of autistic children. The guidelines were derived through the engagement with mainstreamed children meaning that they might not apply as much to, for example, a non-verbal group. That means that similar limitations apply to my work. However, as a guiding framework for participatory evaluation, IDEAS provides a strong basis from which to draw that is conceptually rooted in the children's interests and abilities.

IDEAS consists of a set of seven guidelines which I have adapted for participatory evaluation with autistic children. I have retained the headlines, but re-situated their meaning to an evaluation context:

1. *Concept of Meaning*: ensure that children have a meaningful understanding of the goals and methods of an evaluation;

2. *Distractibility*: adapt to the child's hobbies and interests; include them when framing questions or offering methods;

3. *Concrete vs Abstract Thinking*: present options clearly and unambiguously; favour closed contextual questions over abstract ones [Frauenberger et al., 2013];

4. *Organising and Sequencing/Visual vs. Auditory Learning*: provide visual identifiers for available options, e.g., goals or methods;

5. *Excessive Anxiety/Prompt Dependence*: always have a set of alternatives when planning to engage with the child;

6. *Strong Impulses*: build on the abilities of the child and refrain from demanding modes of interaction they dislike;

7. Involve several individuals when conducting sessions to flexibly assist.

It is essential to provide a delicate balance between freedom and structure when working with autistic children [Makhaeva et al., 2016]. One way to achieve this is through a narrative frame in a freely explorable space [Malinverni et al., 2014], such that children are guided in their interaction by a background story which they can adhere to in their interaction or not. Malinverni et al. [2016b] structured the evaluation activities

of children but left space for individually guided exploration of the technology. Even methods designed to reflect on activities such as design exposés [Frauenberger et al., 2016a] can be useful in mapping out the potential evaluation space for and with autistic children. All of these concepts were influential in the development of my approach to Participatory Evaluation with Autistic ChildrEn – PEACE.

Stage	Child	Researcher
Setting Goals and Methods	Articulating goals	Offering different ways to express these
	Determining final goals and methods	
Gathering Data	Taking the lead	Prompting and supporting the child
	Coordinating data gathering	
Interpreting Results	Interpreting data	Pre-processing raw data
	Discussing interpretations	

Table 6.1: Stages in PEACE together with children's and researchers' contributions.

6.3 PEACE – Participatory Evaluation with Autistic ChildrEn

The PEACE framework comprises three stages, which roughly follow the PE phases identified in the principles of community engagement as defined by the CDC Agency for Toxic Substances and Disease Registry – Committee on Community Engagement [2011/Accessed July 14, 2016]. In my version the 'planning' stage became *setting goals and methods*, the 'implementation' stage became *gathering data*, while the 'completion' and 'dissemination' stages have been combined in *interpreting the results*. Throughout the description I reference the individual guidelines from the IDEAS framework [Benton et al., 2012], describing how they are relevant to a particular stage. Table 6.1 details these stages and the individual contributions of children and researchers alike.

6.3.1 Setting Goals and Methods

Since participatory evaluation is a process of collaborative meaning-making, researchers also bring their evaluation goals to the table and can negotiate them with the child. Contributions from researchers and children are addressed in the following way:

- Researchers' perspectives are part of the evaluation only if they *make sense to the child* as well;

- Children's perspectives are only disregarded if there is no way to answer them. No goal gets dropped, rather, researchers work to determine the intent behind the goal and then re-frame the question.

Following these principles, the child's perspective is privileged to counteract the traditional power dynamics of research projects. Researchers have the task of interpreting the child's communicative acts mindfully through actively taking back their own perspective as 'genuine participation cannot happen without some power sharing' [Kellett, 2005]. Sometimes, goals might be hidden in a drawing or in the particular way that the child interacts with prototypes or classmates. Previously conducted participatory design sessions can also indicate evaluation goals. These goals should be ranked by researchers and children together to establish which questions need an answer. This ranking of goals in order of mutual priority also allows the child to withdraw from the evaluation at the point where they feel satisfied that their goals have been met.

Given that many autistic children find it difficult to think in the abstract, questions about the goals of an evaluation should be grounded in the concrete. Goals can be identified through questions such as: "What does my family think about the technology?", "Is it still fun to interact with the technology after two months?" or "Could this technology be a commercial success?"[1]. Alternatively or in addition to such questions, tapping into existing routines of the children which are commonly used to elicit stories or feedback (for example, 'circle time') [Lundy et al., 2011].

If possible, methods should be adapted and re-framed so that the child feels competent in conducting part of the data gathering. Often, it helps to take a look at the hobbies or interests a child has and go from there. This might include coming up with creative methods for data acquisition such as drawings, narrative framings or dramatic encounters [Veale, 2005]. Not being able to adjust methods in a way that allows the child to participate in data gathering runs the risk that the child will feel and be less involved in the evaluation as a whole. However, it is also possible or even encouraged to engage in methodological training with the child [Kellett, 2005].

6.3.2 Gathering Data

The child can gather data on their own (e.g., recording the number of times they interacted with the object) or together with the researcher (e.g., interviewing other people). Researchers should ensure that there are several options within a method available to the child. For example, if it is essential to know what others think, they could suggest interviews or questionnaires. Within that, there are different questions to specify and also different ways to conduct them (e.g., on the street with strangers or at home with family or anything between).

Researchers can assist the child in carrying out the chosen method(s) by giving prompts and encouraging the child to go to the next step, e.g., the next question in an interview. If researchers are not present, they can give support and feedback on data gathering in evaluation meetings.

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[1]While the latter is technically an extremely abstract question, in our experience the concept has been used as a stand-in for the desirability of a technology. For younger children, it can be rephrased as "Do you think others would like the object for themselves?"

6.3.3 Interpreting Results

While some children might enjoy processing and interpreting the raw data, data should in most cases be pre-processed by researchers, and in a way which acknowledges individual children's preferences regarding, for example, visual or auditory modalities. Even though every processing step adds a level of interpretation to the data, it also helps create opportunities for discussion with the child. With pre-processed data and options for alternative interpretations, a child can make qualified judgements and challenge the presented research perspective on the data. For example, visualising which questions in interviews attracted the most attention (e.g., by length of answer) or at which times a technology was used and then debating the importance of that information gives the child the opportunity to acknowledge different angles from which to see their technology, but also gives the researchers insight into what the child deems vital to know about a (co-designed) technology, and why. This step might, again, necessitate a non-verbal mode of communication, such as a Picture Exchange System, sign language, or spatial positioning and interpreted behaviour/reactions towards the pre-processed data.

6.4 Participatory Evaluation in Practice

I present here four case studies from the second year in which we conducted participatory evaluation. Three of them occur in Spiel et al. [2017c]; the last one has not been published as of yet. During the first year, the method was not available yet, as it originated in our identified lack of opportunities for children's direct contributions to the evaluation of their co-created technologies.

6.4.1 Quentin

Setting Goals and Methods

Throughout our collaboration, Quentin was continually making sure that he performed well. He asked about the quality of his work and – because he was quite aware of the research project and its context, and knew of other children we worked with – asked how his work related to that of others. Whenever he asked for feedback from his classmates, he presented what he had constructed in that session, but did not let them interact with the objects. These utterances and observations made it clear to us that it was necessary for Quentin that the cubes be *desirable to others* as well as *functional and reliable*. The latter point coincided with our interest, as we also wanted to know *who would use the cubes, and how.*

Since Quentin was also an enthusiastic member of the 'Science Club' at his school, we decided on a data gathering method that could generate numerical data. That way, we could create visuals and data that was expected of a positivist approach, which is the dominant language through which *science* is represented in popular media. We hoped that such data would be most meaningful to Quentin. Additionally, he had a tablet device, which he liked interacting with. We developed a set of relevant questions together

with him (see Table 6.2), which had the added benefit of giving us the opportunity to discuss with Quentin the different types of questions that can be used in questionnaires.

Question 7 was particularly important to him: "Others should want the device, but I will be the only one who has it!". Our questionnaire platform was QuickTapSurvey, which allowed Quentin to gather data on his device while also giving the research team access to the questionnaire responses.

#	Question Type	Question
1	Binary	Did you use the Cubes yourself?
2	Number	How often did you use them so far?
3	Ranking	What attribute of the Cubes is most important to you?
4	Scale	How well do the Cubes function?
5	Text	What would you change about them?
6	Mult. Choice	What do you least like about them?
7	Binary	Do you want to have a Cube for yourself?
8	Text	Do you have an idea for a different name?

Table 6.2: Quentin's questionnaire, showing specific questions and question type

Gathering Data & Interpreting Results

We planned that Quentin would gather data independently at home using the tablet version of the questionnaire and, if possible, gather more responses together with us at school. Unfortunately, there were strict rules imposed on using private tablets on school grounds, which rendered the second endeavour impossible. Additionally, Quentin did not collect any responses himself.

From this, we understood that there were two problems with our approach. While Quentin wanted to do science-related activities, they focused on *constructing* physical objects rather than the general ideas behind scientific methods. The purpose of gathering answers to the questionnaires was not tangible enough to find it interesting.

Quentin's case study illustrated the need to be more concrete and more situated in activities the children already enjoy when conducting participatory evaluation to make it fruitful and meaningful for everyone involved. Additionally, it encouraged us to reflect on the "tyranny of participation" [Cooke and Kothari, 2001] and how not every participant will be equally interested in every part of the design and evaluation process. However, by creating a space in which Quentin could have more power over outcomes if he chose to do so, we learnt more about the interaction between Quentin and the Sound Cubes. The joint formulation of questions helped us, in particular, to understand which aspects of the Sound Cubes were essential to him.

6.4.2   Mia

Setting Goals and Methods

After each session, Mia could show what she had accomplished that day to her teacher and afterwards to selected friends. During one of those after-sessions in class, one of her friends told us that Mia occasionally distributes a self-edited newspaper with news for the class (albeit with not much text written in them). It was deemed desirable to belong to the group of people who were allowed to read the newspaper.

Figure 6.1: Announcement of the Rattle Cushion Alarm System

To co-establish goals for the evaluation, we asked Mia to create an advert of her technology that focuses on desired effects and how mornings are shaped with the Rattle Alarm System. Figure 6.1 shows the core part of her finished advert. All components of the system are depicted with their functionality: the clock plays Super Mario music, the cushion rattles and the mat gives a horoscope. The text below reads (translated): "The way to get up happy!". In addition to giving us an idea about her mental model of the functionality (e.g., placing the melody-as-horoscope functionality on the mat instead of

the clock), the advert also tells us that one of her goals in the evaluations is to find out whether the system has *a positive impact on her morning routine.* The research team was interested in *how the technology could be truly integrated into Mia's life.*

Methodologically, we (Mia together with the researchers from OutsideTheBox) created a pool of methods with which we could answer these questions – all of them related to article types found in newspapers.

- A *report* about how the Rattle Alarm System and who uses it. It would inform us about the elements and contexts of use that are important to Mia.

- A *review* of the Rattle Alarm System with an accompanying rating. It would give us an insight into what works well already and what we need to improve to make the technology robust enough to be part of Mia's life. The review and report also potentially tell us about how the interaction shapes the morning routine.

- *Interviews* in which Mia asks others about their opinion of the system. The questions can tell us more about Mia's interests; the answers provide an understanding of others' interpretation of the system and the choice of interviewees also show us whose opinion is important to Mia.

- An *illustration* of the system in actual use, which we could then use and compare to the advert to see how the two drawings relate to each other.

We also agreed that we would bundle all contributions together to create an issue of her newspaper that focuses solely on the Rattle Alarm System.

Gathering Data

Mia could either gather data on her own at home or during the sessions with support from a researcher – and she chose both, resulting in a report on the design process and two interviews.

The report about the design process was integrated into one of her usual newspaper issues, in which she picked up on daily news with her take on the European Soccer Championships and the performance of the Austrian team on the front page as well as comics and jokes on the last page. On the pages in between, she detailed the design process within its context of a research project with autistic children. She also made clear that she saw herself as an inventor of something that might be useful to others as well. "In an interview (!), [Mia] said: (...) I can understand that others have similar problems with getting up in the morning."

Several weeks after receiving the prototype to test out at home, we conducted an evaluation-oriented meeting. In that meeting, Mia role played the situation in the mornings and gave critical feedback on the sensitivity of the top button, the structure of the cable connecting the mat and the alarm clock as well as the intensity of the vibration

of the cushion. She then decided to interview her mother and a co-located researcher. She asked about the quality of the system and about what the interviewees felt should be changed. She also asked how many 'stars' on a scale of one to five the system would get and inquired what they would invent if they were part of a similar project. Parts of the questions were defined before the first interview, whereas she established the rating scheme ad hoc while conducting the first interview. During both interviews, she had a professional demeanour. One of the researchers prompted her to ask further questions when she appeared to be stuck. This additional structure enabled her to get through all questions without being required to read handwriting – a task she finds exhausting.

Interpreting Results

From the interview with her mother, Mia could establish that others indicated a positive influence of the design process and the technology on her life. During the session, she noted that she agreed with that assessment, even though she had so far only used the system occasionally.

We were also able to identify necessary improvements that would make the system more robust: a better protected and tighter connection between the alarm clock and the mat, more vibration power in the cushion as well as a better distribution of the vibration next to an adjustment of the sensitivity of the top button on the alarm clock. We decided on further meetings to improve those open points. An actionable plan also shows all participants, formal researchers and child alike, what the effects of an evaluation can be and how to act on its results.

When asking for the star rating during the interviews, Mia's mother awarded five stars for the aesthetics and two for functionality (motivated by the lack of robustness). The other interviewee awarded four stars. Afterwards, Mia announced that she now had collected eleven stars and that she wanted to see how many stars she could earn in total. That way, she re-appropriated the interpretation of the rating and gamified the evaluation process on her own. Additionally, Mia's report indicated that the process and resulting prototype were having a positive and affirmative effect on her life.

From working with Mia, we learnt that data gathering methods could be interesting to a child, if framed correctly and if the child can assign a potential utility to the activity. Even if researchers and the child differ in their interpretation of a method – as seen with the stars – the child's interpretation is more important and more indicative of their perspective on the technology to evaluate, but also the evaluation process as such.

6.4.3   Yvan

Setting Goals and Methods

Next to the evaluation goal – established through our collaboration –, that *the Time Machine should be enjoyable for his brother Hank as well*, we asked Yvan directly, what would define success for his technology, since he was using the concept himself previously.

He stated that *others should deem the Time Machine as cool* and also, that *it should be really fast.* Since the speed of the time machine is virtually constructed by the given story context, we re-interpreted that goal and wanted to find out *whether the Time Machine suitably supports immersive narratives for Yvan.* Assessing the speed of the Time Machine remained part of the evaluation as a goal by itself.

Methodologically, we established a TV show called *Research with Yvan*, in which he presented the Time Machine and reported on trips undertaken with it. This was requested by Yvan himself, who was continuously fascinated by the video camera which recorded all of our sessions together. We also set up a showcase of the Time Machine in Yvan's classroom and – somewhat impromptu in an evaluation session together with Hank – let both brothers create a drawing of the context of use of the Time Machine.

Gathering Data

All data gathering was done jointly with the researchers. The TV show was filmed during a late design session to evaluate how well the blanket idea and initial prototypes matched Yvan's expectations. He animatedly reported about a trip to Saturn and Jupiter that he had just undertaken with one of the researchers, detailing especially how fast the Time Machine was and what kinds of things they found on these planets during their trip.

When Yvan received the first fully functional prototype, we also showcased it in class. He presented photos from the design process and led some children under the blanket to take a trip to different planets. Unfortunately, a soldering seam became loose, and the lights did not work correctly. Many children were confused about what exactly was happening, although some were open to the frame of pretend play and talked about their perspective on the time travel.

After several weeks in which they used the Time Machine in a home setting, Yvan and Hank created the drawing depicted in Figure 6.2. It shows both of them (drawn in each of their favourite colours with size following age) under a fully illuminated blanket with two different navigation boards, even though only one exists. On the upper left, there is an alien they encounter on the planets they visit (depicted at the top).

Interpreting Results

Yvan took the opportunity to reflect on the perceived speed of the Time Machine himself during the recording of *Research with Yvan.* He enthusiastically established that the machine was, indeed, really fast. Since he is the only person who can judge this, his opinion is the most important to consider when trying to answer this question. The research team also inferred from this that immersion was successfully supported.

Due to the malfunction of the blanket in the showcase, only a couple of classmates were enthusiastic about the invention. Yvan (and the formal researchers) had hoped for more success. While he was initially very excited about presenting his technology, he did not want to do another showcase once the short circuit was fully functional again. The

Figure 6.2: Drawing by both users of the Time Machine on how they interact with it – real name initials have been smudged

research team would have liked to investigate this question further. However, it was answered for Yvan. Therefore, no further inquiries were undertaken.

Hank expressed being very happy with the Time Machine. While Yvan and Hank were drawing Figure 6.2, Hank said that he would like to play even more with it, but Yvan did not want to play as often. Yvan also reported that whenever they went on time travel, they did so together (which has also been confirmed by their parents). From this, we inferred that Hank enjoyed the Time Machine as much or even more than Yvan.

6.4.4   Oliver

Defining Goals and Methods

Oliver was very young throughout our collaboration, which meant, we had to be particularly careful when we talked about highly abstract concepts such as evaluation and introduced them with caution. During several sessions, we inquired about potential use cases he was interested in and where he saw the object in the future. Through careful probing, we could establish, that he wanted to have the appreciation of his family (with a

particular focus on his brother), classmates and teachers. Hence, he was mostly interested in *social validation* of his co-creation. He focused primarily on using Öxe within the school environment to share learning endeavours with his friends. We did not devise any specific methods to know about the success of the technology along these axes, as the goals were also implicitly established.

Gathering Data & Interpreting Results

Since Oliver reacted positively to introducing new activities and concepts during the design sessions as well as new tasks with Öxe, his final object, we used storytelling on Öxe as our data gathering method. We devised a story template about our shared history in the development of Öxe. While there was a core structure given, he had to fill in qualifiers and draw elements of the story on paper or illustrate parts through the technology. When he was encouraged to draw Öxe itself, he focused on an emotional attachment and the control part with its buttons(see Figure 6.3). The focus on only one part of the technology indicates that this is where Oliver considers the core point of the development of his technology.
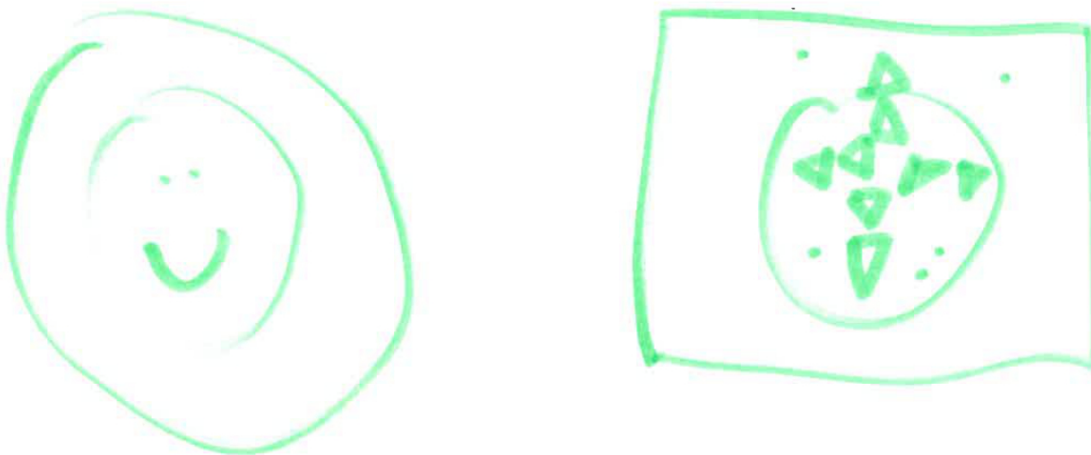
Figure 6.3: Oliver's visual interpretation of Öxe, focusing on mood and control piece.

Later in the same session, his special needs teacher joined us and was very excited about the invention. She sat down where I was previously and let Oliver explain to her the functioning of and the interaction with Öxe. He made sure, she understood what it was meant for and saw the potential for school purposes, especially with Maths exercises. This focus on embedding Öxe in a school environment then also lead him to leave it in the classroom so other children could use it as well. Even after the summer holidays, he was excited about it and told his teacher that he wanted to use it for learning.

Unfortunately, we could not conduct a dedicated session where we discussed the meaning of these activities together, due to the time constraints on the side of the participants.

Even though we met Oliver later again, it was within different circumstances where it would have been confusing to him to inquire about the object.

While this case shows a somewhat impure example of Participatory Evaluation, it is still important to note that being willing to use the method, we had tools at our hands that enabled us to listen to him and to offer him a space to reflect about the object he co-created and the design process leading to it.

6.5 Discussion

PEACE achieved what the original concept of PE set out to do: involve the primary stakeholders of an intervention or design directly in assessing its effect. Through this, we created a space in which researchers acknowledge the children's agency and meaningful interpretations of technologies and how they can be evaluated. Pragmatically, this provides us with insights that were previously unattainable. Autistic children had control of the evaluation, and were individually involved and deeply engaged in conducting the evaluation. As such, all three characteristics [Cousins and Whitmore, 1998] of PE are present. PEACE could allow for a range of contexts of use and is adaptable for other user groups as well.

From Quentin, we learnt that methods must be chosen in tune with *activities* that the child likes. Mia showed us the necessity of carefully managing structures and freedoms to create a space in which she could perform the evaluation. Yvan challenged our pre-conceived notion of the team always being able to reach an agreement by interpreting a one-time failure as absolute whereas the researchers still saw it as an open question. This case also shows that researchers have to actively put themselves and their agenda in the background to avoid accidentally overriding a child's perspective. Even though we did not perform pure Participatory Evaluation with Oliver, by being guided by its principles, we were attuned to listen to what he thought of the technology and were better able to create a space in which he could express his opinions.

In addition to these individual insights, we also learnt what is essential to autistic children across these case studies. I discuss this as well as the roles and responsibilities of everyone involved in PEACE.

6.5.1 Insights from Case Studies

Across the case studies, the success of a PE endeavour—as with any participatory project—relies on the interest that participants have in undertaking the action. Some participants are more interested in creating the outcomes of a participatory design project and do not feel the need to inquire more formally about the process or outcomes.

Furthermore, these cases showed that participants' goals do not necessarily have to be attractive to formal researchers or make sense to them. However, for participatory evaluation to earn its name, it is vital that we take these goals seriously, assign proper

methods to evaluate them and create results that are meaningful to all. Those results should be reflected together with the participant to ensure that they see their questions answered, especially if researchers interpret a goal differently.

When data is created, the same data can be interpreted differently. We saw this with the stars assigned to the Rattle Alarm System, where they became part of something that had to be earned in sum, or when the research team attributed others' lack of enthusiasm to a system failure, whereas the child was acknowledging a more generic failure and was no longer interested in further enquiring into that evaluation goal. Both interpretations must be seen as equally valid, with action being taken based on the child's agreement and interest, not solely motivated by researchers' agendas.

It was interesting to me to see that all children included some form of external validation within the evaluation procedure. They wanted their objects to be desirable to others as well, be it out of envy (Quentin), a desire to be meaningful for more people (Mia), to make sure that a specific person benefits from the design as well (Yvan) or to incorporate it in daily activities with teachers and classmates (Oliver).

6.5.2 Roles & Responsibilities

When I started conceptualising PEACE, I thought carefully about the roles that researchers might take in Participatory Evaluation processes. After all, one could argue that the reason why researchers take over the evaluation of PD processes is because they possess the necessary skills to do so.

In PEACE, researchers facilitate the evaluation process and encourage autistic children to explore angles of their work they might not have explored otherwise. Through appropriate framing and structuring, they provide space for the children to answer the questions that interest them. To suitably support the child, researchers must not only know the child's interests and preferred activities well, but they must also have an extensive pool of evaluation methods from which they can draw. They choose a set of potentially useful methods, introduce them to the child and agree on the final ones together. They must also have additional methods at the ready that they can flexibly switch to if a child shows decreased interest in the established one. Researchers' skills, competency and experience, together with the child's interests, focus and questions, are the ingredients of successful participatory evaluation.

In some cases, researchers may have additional research questions which they are trying to answer that might be unimportant or meaningless to the child. While these questions cannot be addressed within the PEACE framework, I encourage researchers to augment the process with established modes of evaluation that can yield different types of knowledge. What PEACE offers, however, is a previously unexplored perspective on the experiences of autistic children with technologies: their own.

6.6 Summary

In this section, I presented participatory evaluation with autistic children. After detailing the parameters and particularities involved in participatory evaluation with autistic children, I introduced the PEACE framework, which comprises three essential steps: defining goals and methods, gathering data and interpreting the results – all done in a participatory and evolving fashion. Four case studies provided insights into potential pitfalls, as well as insights that can be gained from unexpected outcomes, even if particular steps within the evaluation are not carried out according to plan. Finally, I discussed the implications for participatory evaluation across these case studies and considered the role of researchers in such a process.

This is a proof of concept that it is possible to include autistic children actively in the evaluation of the technologies they co-design. PEACE is the first framework that allows researchers to conduct participatory evaluation with autistic children in a way that appropriately acknowledges their agency, needs and abilities.
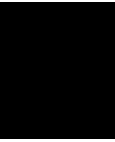
Reflecting Back on Critical Experience

This chapter contains original work that has not been published yet. It takes a look back at the Critical Experience concept along the second year case studies. Such a reflection allows for an examination of the concept outside of the immediate context of its development. While the circumstances remain mostly similar, this chapter offers a first step towards a broader and more general validation of the concept. I detail the analysis of the 2nd year case studies within OutsideTheBox before I present a brief analysis of an ongoing project through which I can show how far the concept stretches, but also illustrate further steps it has to take from there.

7.1 Analysis of 2nd Year Case Studies

The second-year case studies had longer collaboration cycles (up to 24 months) and overall more meetings (up to 20). These enabled us to engage the children more in the design process, fabrication and extensive testing of prototypes. Further, through these case studies, I developed the notion of Participatory Evaluation with Autistic Children, which I expected to result in more insights into the children's experiences.

This chapter contributes to the thesis by contesting the strengths and limitations of Critical Experience independent from the case studies it has been developed in. Through these challenges, I was able to reflect on potential improvements and future paths of the concept to strengthen it beyond the focus of design with individual autistic children. Further, analysing these case studies using the framework adds to the corpus of different experiences made within OutsideTheBox.

7.1.1 Quentin

Define Context and Discourse

The design process with Quentin was the shortest within the second-year case studies since his family had to stop the collaboration after the summer holidays. Hence, his actor-network similarly covers the most relevant aspects of our interaction. It indicates that the school environment was much more present than in the other second-year case studies. On the one hand, we conducted our sessions in an empty classroom, on the other hand, topics of other classes were continually present. Quentin disliked spending time in the theatre classes and often regarded our project as a treat if it led to him 'getting out' of theatre class. However, Science Club was one of his favourite activities, and often much more exciting than our collaboration, as it was not a longer-term engagement for one object, but defined projects which resulted in a single object that he could take home every time.
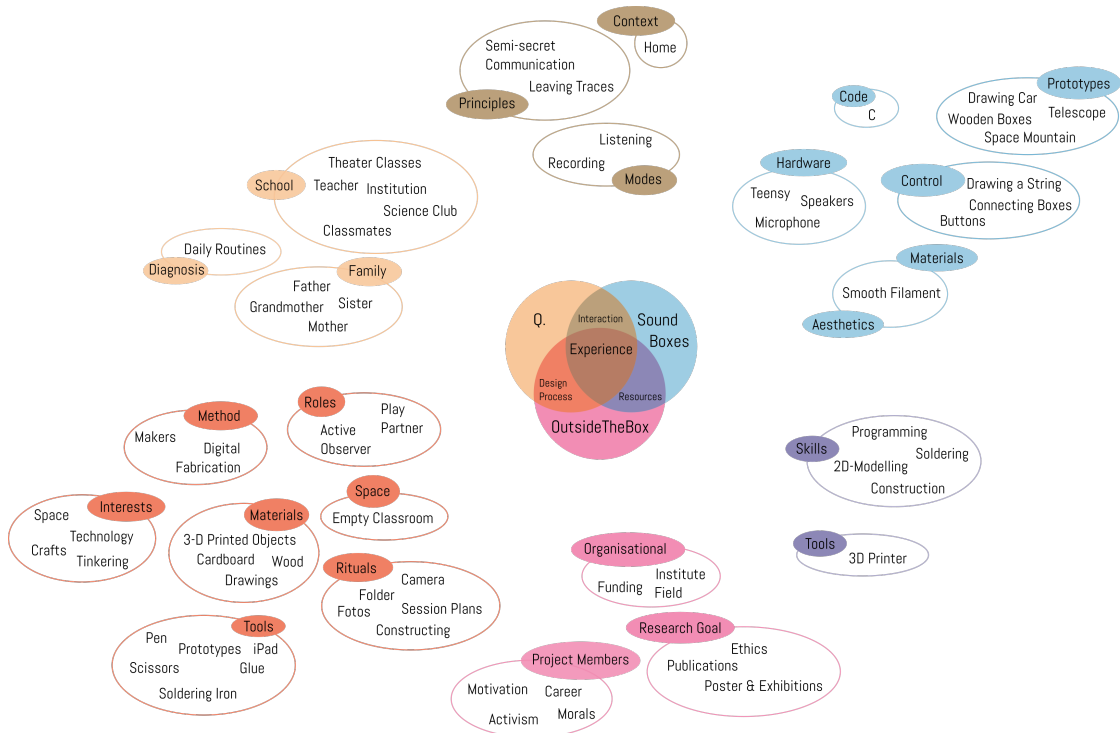
Figure 7.1: Actor-Network for Quentin's context

This competition with the Science Club led to our process (which was Maker inspired and following Digital Fabrication [Frauenberger and Posch, 2014]) being guided by a series of prototypes, each one either exploring concepts or building on an aspect of the final object. Quentin kept all prototypes and showed them to his family at home. Considering how crafts, tinkering and technology are some of his core interests, the network indicates that the method and the execution of the method through prototypes seemed to have

been appropriate for that child. It additionally shows how different aspects are differently relevant to different children and how a child-led design process within the same project can be actualised differently.

Gather Data

What is not apparent from the network, though, is the method for evaluation. While the design process and its methods are explicitly mentioned, evaluation procedures are hidden in this visualisation. The participatory approach does not make itself transparent within the Actor-Network as is. The overlap of child and project should then maybe be called 'Collaboration' and, if necessary, be separated in phases. An alternative approach could be to reflect evaluation methods in the intersection between child and technology; however, this would also mean that the researchers who as observers shape the assessed experience [Obrenović, 2014] are hidden again. Ultimately, this might be best tied to the 'Experience' intersection, which is currently not populated with its sub-actors.

As described in Quentin's case for the participatory evaluation above, we did not obtain much data from his perspective on the final object, also because the angle of evaluation remained relatively meaningless to him. What we have, though, is observation data from the design sessions and diaries from unrecorded interactions with prototypes and the Sound Boxes with his classmates. Since our last session was the one where we also handed over the Sound Boxes, I was unable to gather additional data from close actors or perform the object speculation on the boxes themselves.

Actor	Statements	Source
Quentin	In Science Club I can always take something home with me. Look, what I've made! I like to try and make new things. My sister annoys me. Let me take this right home. What if we try it this way? How are the other children in this project performing?	Video Recordings Observations Diaries
Researchers	The relationship between Play Partner and Quentin is not very harmonic.	Diaries
Science Club	Even though Quentin was always present he didn't come when he finished the boxes.	Diaries
Teacher	Quentin showed me the boxes long afterwards and reconfigured them constantly until they were broken.	Interview

Table 7.1: Selection of statements identified in Quentin's Actor-Network

Analyse Data and Identify Statements
Despite being limited in the actors we could collect data for and the participatory evaluation not being very fruitful, it turns out that we know a lot about Quentin's perspective on the design process (see also Table 7.1). However, we know little about the experience relating to the interaction between him and the Sound Boxes. The relating subactors are mostly informed by the aspects we had considered about the interaction during the *design* process, but they have – compared to other cases – not been subject to *evaluation*. Interestingly, this shows (again, as so many other contexts before) how essential it was, in this case, to not finish at a design and prototype phase if technology stemming from participatory design processes is supposed to fill a significant place in participants' lives.

Contextualise Statements
As mentioned above, we know little about the interaction experience between Quentin and the Sound Boxes. However, we do know about the experiences that emerged during the design process. As his Play Partner, I found it difficult to work with Quentin, because he was much less appreciative of us as design partners. While that can also be considered a behaviour stemming from Autism, it was still difficult – and sometimes even hurtful – for me to handle the situation. I actively sought out advise from Julia as the Active Observer as well as in my social environment when it came to interacting with Quentin. However, this also resulted in me taking longer than with any other child to establish a productive and fruitful relationship.

Similarly, Quentin found the project often to be lacking activities important to him. While we said we would take his interests seriously, we never followed through on making a money-printing machine. Also, in Science Club, there was always a tangible reward at the end of the session, whereas in our case, the outcome was often intangible as an idea and only later, when we started more prototyping activities, similar. He asserted himself in the process, which resulted in his case leading to one of the technologies, where the child was most involved in the final creation process. We saw that in the design process letting a child participate in the steps of creating the final prototype makes it much more *their* object to them (compared to the first year case studies). We also observed him, how he proudly presented the object to classmates. However, for a long time, it was unclear whether he interacted with the object in a self-driven manner at all, also because the contact with the family was lost. However, a year later, I had the opportunity to revisit the project with his teacher, who indicated that he re-appropriated the boxes long after the project ended. He constantly shifted the meaning and use of them until they were entirely non-functional. Hence, in his case, the final object was more relevant than the design process – contrary to other children, especially those in the first year.

7.1.2   Mia

Define Context and Discourse
With Mia we had one of the longest collaborations, spanning over two years with more than 20 meetings. With her, we also had one of the closest relationships we
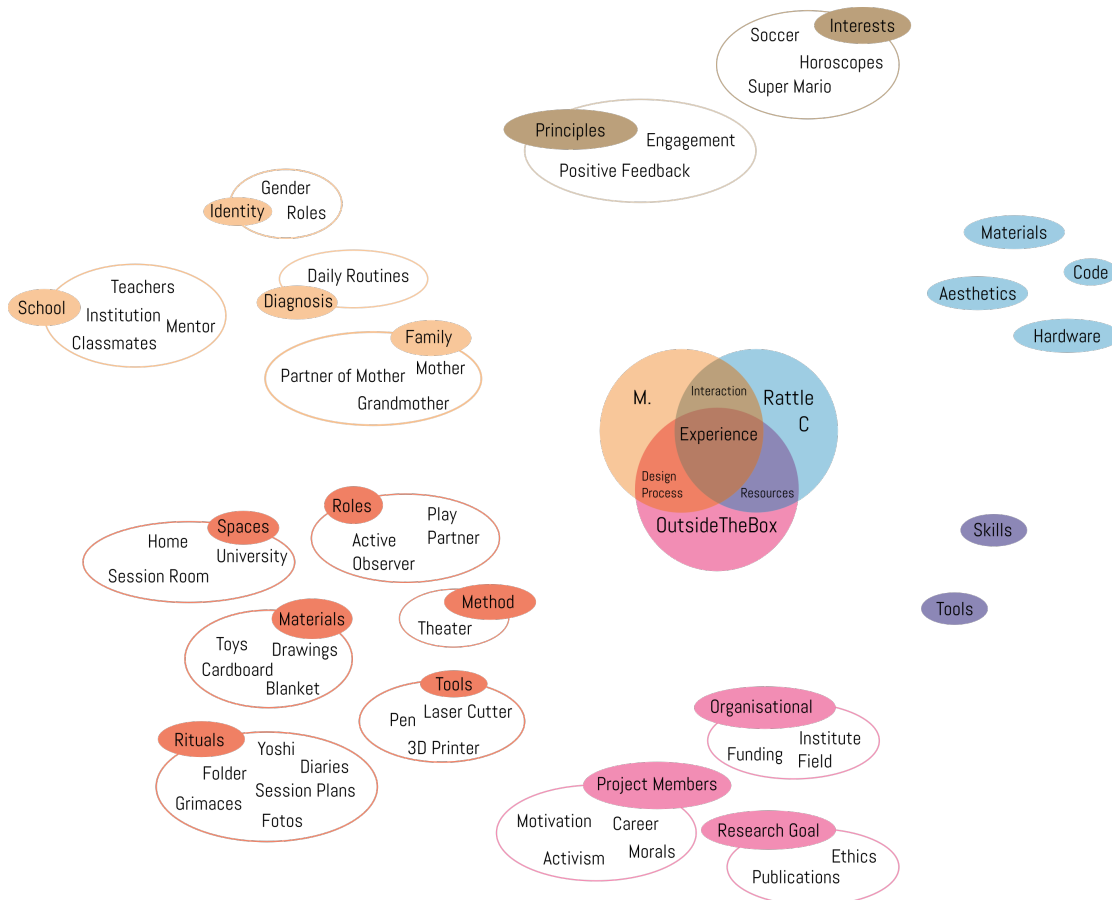
Figure 7.2: Early Actor-Network for Mia's context

built with a child. As already mentioned when introducing the concept, what an actor-network on itself cannot do is indicate the quality of relationships, which is why these graphs are not an endpoint of analysis.

Rinse & Repeat

To illustrate the Rinse & Repeat stage of the process, I added an earlier version of Mia's actor-network in Figure 7.2. This one is taken at a point where the concept of the technology was clear to the point that certain interaction principles were already clear, and so were core parameters of the design process as well as the contexts of her and the research team. However, the technology itself is not concretely visible yet. While some parameters are foreseeable due to the design brief (such as, that the core components of the technology), the technology and researchers resources leading to its actualisation remain unspecified at this point. At this stage, an actor-network may serve as a visualisation of the current state of tentative decisions made around the design of an object.

Define Context and Discourse

With Mia's actor-network (Figure 7.3), I ran into another problem. I had so far conceptualised the meeting point between child and project as the design process. This approach, however, neglects the evaluation process, which caused the problem for me that I had no place to put Mia's magazines conceptually.

It might be debatable whether the evaluation process should be at the intersection between the child and research team. As the technology is a core part of the evaluation as well, it might need representation in the process. However, the intersection between all three of them constitutes experience whereas evaluation is the form in which we can understand aspects of said experience. Should they show up with Mia as she re-appropriated them? However, does that not neglect the shift from the idea coming from the research project and then becoming hers? How can we refer to them as a core outcome of our collaboration and a crucial conceptual actor, both as an evaluation method and appropriated as an identity machine? For now, these have to remain open questions, but they show a burning limitation of the concept of Critical Experience.

Gather Data

Next to the PEACE process described above, we gathered data mostly through object speculation, interviews and researchers' diaries. As Mia's position in this project was so essential, her perspective is most prominent in our analysis.

Actor	Statements	Source
Mia	This is how I feel. I am a real inventor now. We will make this available to you, but for the specifics you have to ask my co-designers. I use it in the mornings. The best part is the horoscope. Let's invent a nose warmer!	PEACE Observations
Link	Mia lets me speak when things are critical. I'm always with Mia.	Observations Object Speculation
Mother	Mia learned to get up in the mornings. I'm so happy to see her feeling confident about this.	Interviews
Rattle C	I'm an integral part of Mia's room. I am under heavy use. I might be too fragile for everyday use.	Object Speculation

Table 7.2: Selection of statements identified in Mia's Actor-Network
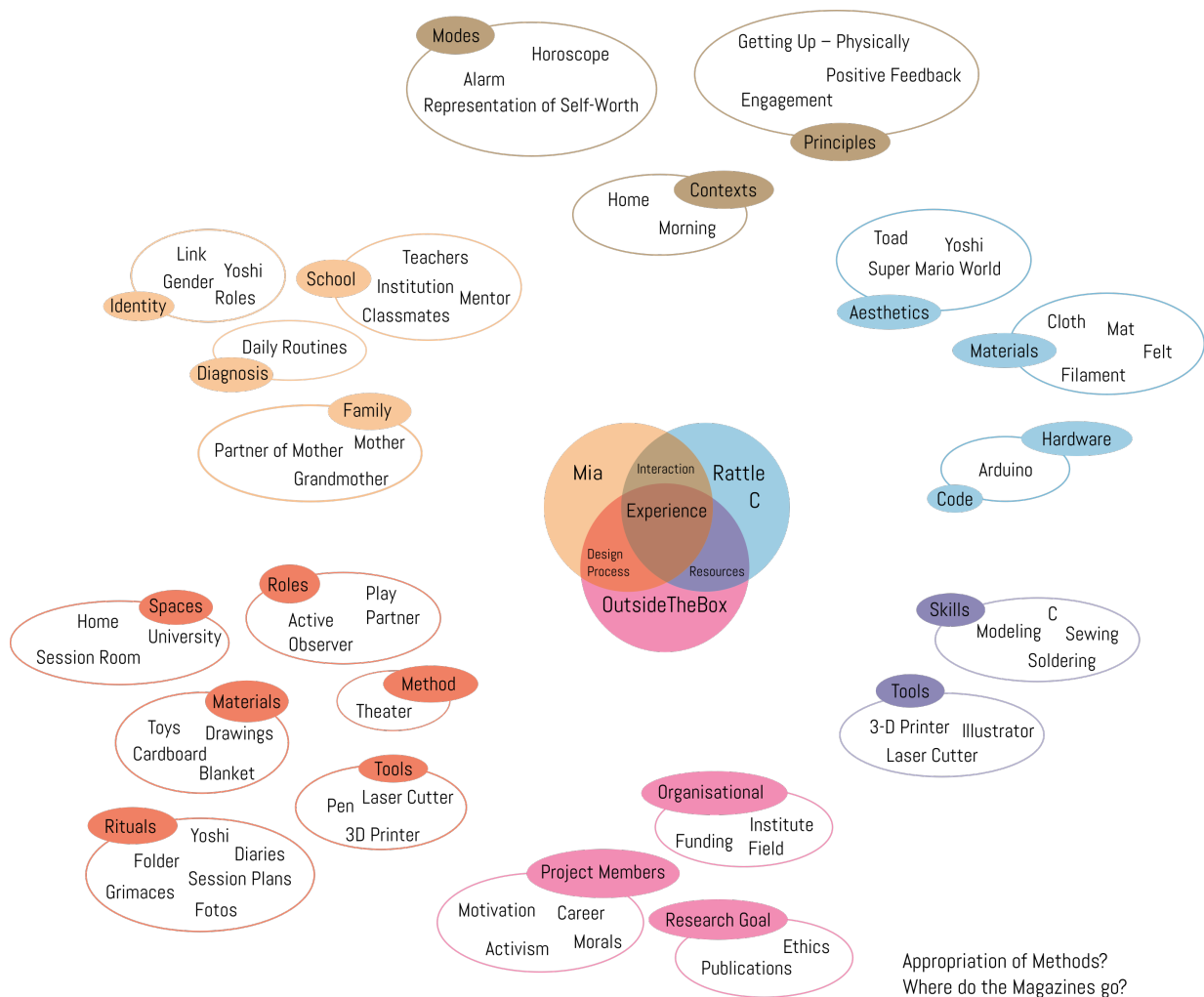
Figure 7.3: Actor-Network for Mia's context

Analyse Data and Identify Statements

Table 7.2 shows a subset of actors I focused on closer during my analysis. Next to Mia herself, I chose to take a closer look on Link, a puppet she used to talk about things that might have been important socially (such as addressing dislikes or critique), her mother, who is a core part in her social environment, and the technology itself as the object of design and evaluation.

Contextualise Statements

The Rattle Cushion is one of the objects, which has been used in the daily life of a child the most. In its appearance, the object itself communicated to us that it had been heavily used, e.g., by wear and tear (to the point that it was brought back to us for repair). Together with the mother's report, that the object guided Mia in

finding a morning routine that would help her get up easily, indicates that the object plays a positive part in her life. However, Mia was less interested in repairing or further developing the cushion but instead focused on new ideas like a nose warmer. Hence, the process of inventing is interesting to her, but the process of repair and refinement probably less so. Her experience with the object cannot be entirely removed from the experience of the design process, but the object played a role in Mia's life (at least temporarily) *as well as* as a representation of our design processes.

7.1.3   Yvan

Define Context and Discourse

In Yvan's actor-network (Figure 7.4), we can see in the School environment as well as in the Rituals section that some subactors are denoted with an asterisk*.

In Yvan's case, some of the actors are temporally constrained. We had different rooms (though they shared similar characteristics) and different contexts to work with. The ritual of performing regular time travels only emerged later in the process. The actor-network in its static form has difficulty capturing these temporally relevant actors.
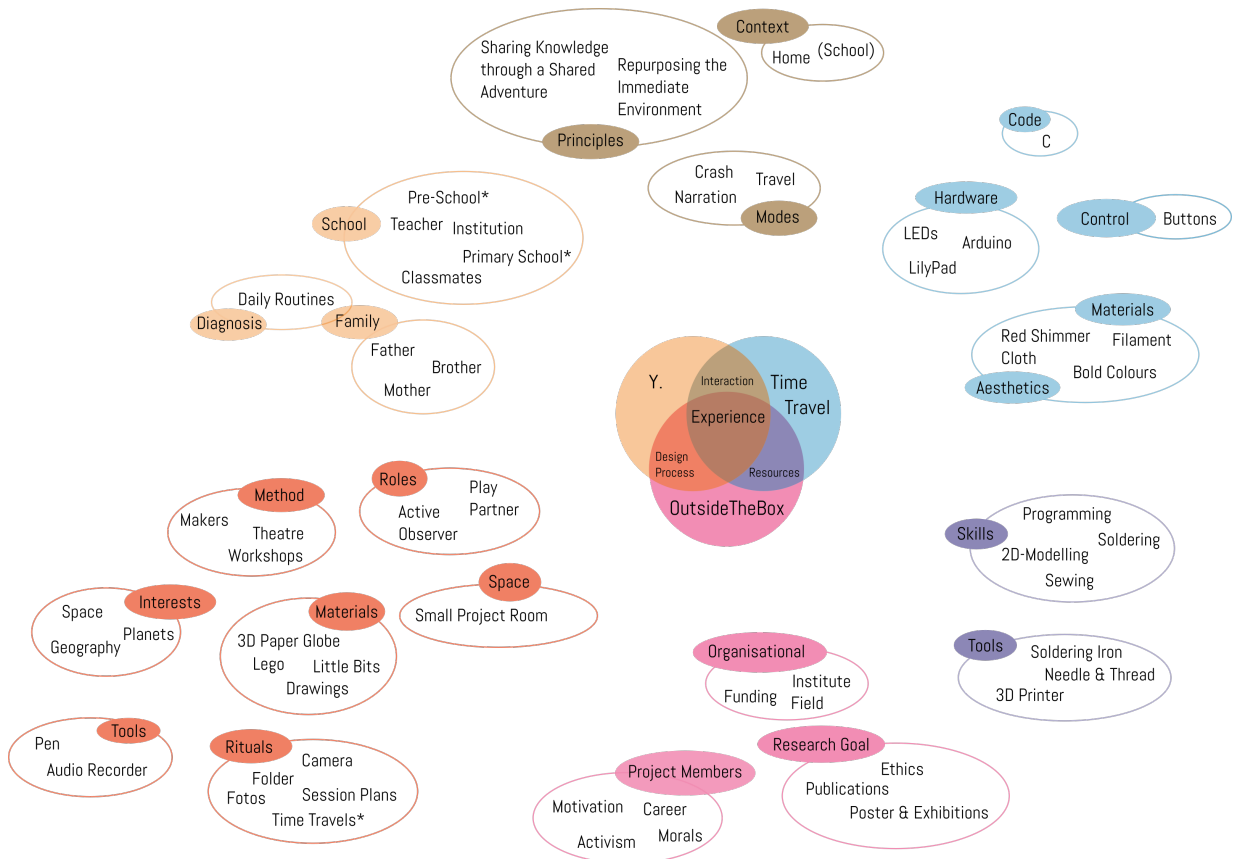
Figure 7.4: Actor-Network for Yvan's context

Gather Data

The data we analysed for this case includes the drawings and videos from the PEACE process with Yvan (and his brother Hank), researchers' videos from most of the design sessions, diaries, interviews with parents and object speculation. Not all of those, however, yielded insightful interpretations. Actors we had no chance to inquire into included the classmates and teachers, who were relevant in the acceptance of the technology within school settings. Hence, the evaluation method necessarily yields painfully incomplete data.

Actor	Statements	Source
Yvan	It has to be faster! Look, what we have here! Oh no, we're going to crash! I don't want to show the machine to my classmates. My brother is my best friend.	PEACE Observations
Time Machine	I am too fragile for this child.	Object Speculation
Hank	I want to have my own control that reflects my favourite colours. I usually have the control anyway and Yvan says where we travel to. I like the Time Machine	PEACE Observations

Table 7.3: Selection of statements identified in Yvan's Actor-Network

Analyse Data and Identify Statements

Due to the nature of the PEACE process, I was able to focus on Yvan's statements, and during the analysis, I found out, how important a role Hank plays not only in interacting with the object but also in making meaning about it. This aspect of the experience is already somewhat visible in the statements (Table 7.3) as Hank becomes an equally important role not only in designing the Time Machine but also in using it and making the interaction possible.

Contextualise Statements

Next to Hank playing an important role in the conceptual interaction with the object, the setup for the lights and buttons on the control were too fragile to resist the children. However, the children still reported, using the Time Machine extensively. Hence, the blanket alone became the Time Machine. While they might have been supportive in conveying the idea of a story *to others*, it was not necessary for Yvan and subsequently not for Hank after he understood how it worked. Hence, the technological aspect of the Time Machine is more transitional than actualised, which constitutes a novel form of interaction, which has not been addressed properly so far but might spark further research in decidedly non-sustainable technology.

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Yvan & Hank

Define Context and Discourse
Since Hank was already quite relevant in meaning making and – in absentia – the design process, it is difficult to discern when exactly he joined the project. Hence, in the actor-network, he moves from being Yvan's sub-actor to a core partner. As is depicted in Figure 7.5, this changes aspects of the analysis Critical Experience uses. Instead of three core actors, there are now four with different overlaps indicating different relationships. The grey areas (overlaps between Hank and the Technology, as well as Hank, Technology and Resources) are not active as there was no unique relationship established between these (and only these) actors.

Gather Data
Since the sessions with both children were most often conducted in the open space within the family business, most of the recordings are not covering all of one session. Hence, researcher diaries and photos the children made were my core data sources from different perspectives for the process. Additionally, we conducted interviews with parents and – tangentially – with the children themselves. Since I had not seen the technology since handing it over to the children, object speculation was no option here, and the technology perspective is missing from the evaluation.

Actor	Statements	Source
Yvan	Make a photo of the fidget spinner!	Observations
	I want the light to be red!	Interviews
	I like that I can explore with it.	
Parents	This is quite the impressive object the children created.	Interview
Hank	Red indicates danger.	
	I want the light to be blue.	Observations
	I want my needs to be acknowledged.	
	Let's go and find treasures!	
Researchers	We need to ensure that the object is robust.	Diaries

Table 7.4: Selection of statements identified in the Actor-Network of Yvan & Hank

Analyse Data and Identify Statements
When analysing the data, I noticed that especially the interviews with the parents seemed not to lend themselves to well-formed statements. Hence, there might be an indication of a lack of rapport, which existed, not with the children, but with the parents. Seen in a broader light, though, this also means that even though we might try to populate actors with data and have the data, there might not be many highly informative statements to extract. Further, no explicit evaluation session has been conducted with the children yet, so I rely mostly on statements extracted from data that was gathered during the design process.
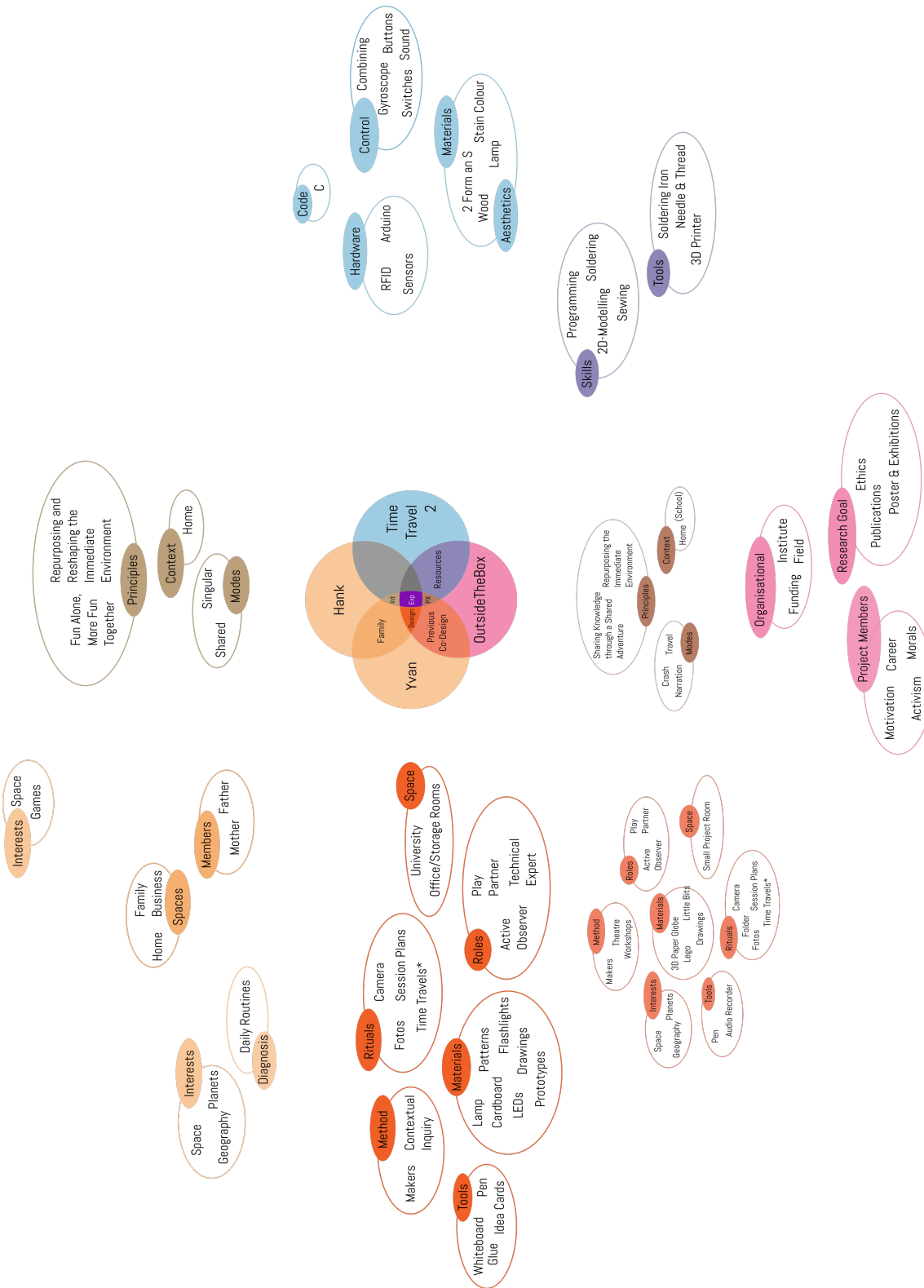
Figure 7.5: Actor-Network for the context of Yvan & Hank

Contextualise Statements

In the statements, we find that the created objects needed to reflect both children's interests and needs. Moreso, Hank often felt he was not taken as seriously as his brother because he was younger and knew us (and the things we did) for a shorter time frame than him. Hence, it was paramount to the design of the object and eventually as an evaluation lens to ensure equal access, participation and opportunities to engage for both children. From the statements (and also within the original data), we see a conflict between the children which is mostly fueled by Hank feeling that his needs are less important than those of Yvan. For example, Hank associates Yvan's favourite colour with 'danger'. It was then important to us to ensure that the object would not play destructively into the conflict. Lastly, both children were also quite active, spurring ideas, exploring their environments, spinning stories but also experimenting with objects roughly and testing their limits. Hence, we had to ensure the final prototypes would be robust enough to be a match for the children. It is yet to see whether this is the case.
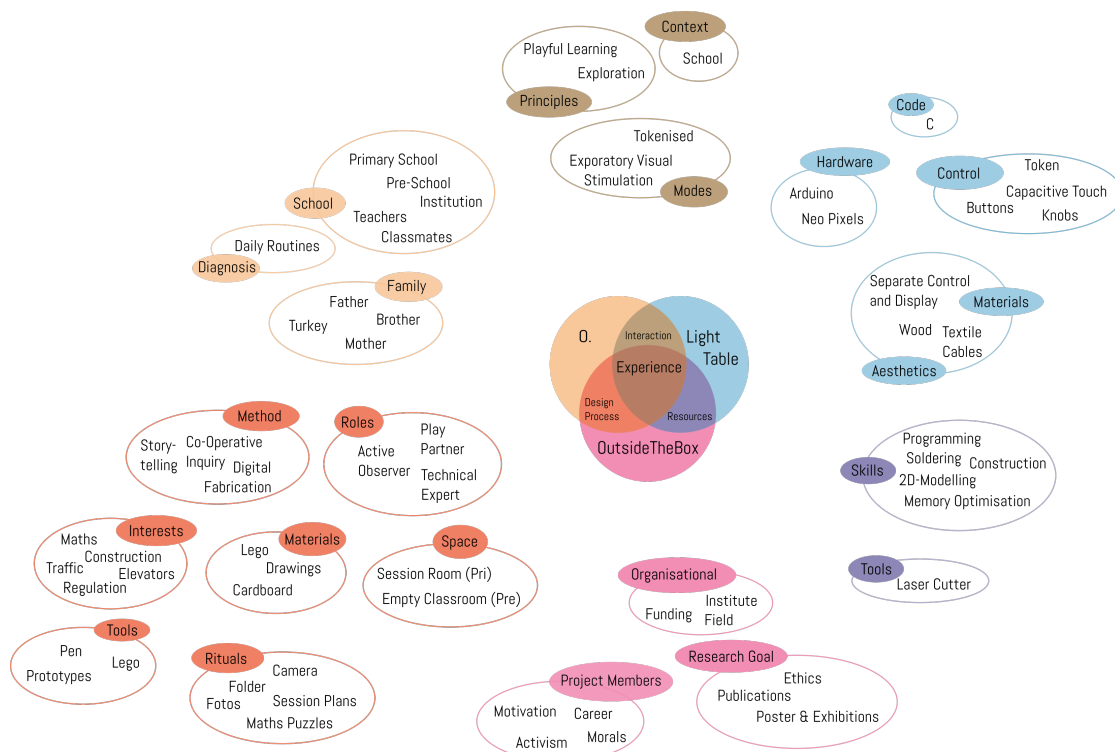
Figure 7.6: Actor-Network for Oliver's context

7.1.4   Oliver

Define Context and Discourse

We collaborated with Oliver for more than a year, and during that time, he transitioned from a specialised pre-school to an integrative primary school. Here as

well, we can see how it is difficult to capture temporally dependent data within the static 2D Actor Network (see Figure 7.6). The attempt taken on representing the different contexts here, was taken, for example, in the design Spaces bubble, where there are small indicators in brackets to refer to which room was relevant in which context. However, this is not suitable for a proper analysis allowing us to contrast the differences across these settings (other than by presenting several different Actor-Networks).

Further, while the Technical Expert role is reflected, there is little indication that the project members changed. During my time in parental leave, a colleague took over my post, but due to gender and personality differences as well as the fact, that I would be returning as Play Partner, has been taken on a different, newly constructed role. However, the descriptive part in the Actor-Network does not capture this at the moment. What this actor-network still gives us is an overview of the complex involvement of stakeholders at an abstract level. It provides a suitable *starting point* for the analysis of Oliver's experience, where subactors need to be reflected with these limitations in mind.

Gather Data

Next to the participatory evaluation endeavours, we conducted with Oliver himself (see above), we interviewed teachers, chatted with parents, speculated around the object and observed Oliver in his interaction with the object alone and with a teacher. Next to Oliver, a highly relevant source was the special education teacher from his primary school as the context of use for the Light Table is also within the school.

Actor	Statements	Source
Teacher	Oliver urges us to use the Light Table in class. The Light Table motivates our students to engage with numbers and letters.	interviews
Oliver	I made this. I can show you how it works. :)	PEACE observations
Light Table	My energy cable is missing. The children have access to me, but it's hidden.	object speculation

Table 7.5: Selection of statements identified in Oliver's Actor-Network

Analyse Data and Identify Statements

In Table 7.5 I present a selection of statements over the three actors we consulted the most about the experience. Along the three actors, we received very different statements which are differently contextualised and also speak of what is most important about the experience to a single actor. Hence, this shows again, how using Critical Experience can guide a process aiming at capturing multiple perspectives to establish a more holistic view on the experiences an autistic child might have with an object.

Contextualise Statements

While the teacher focused on how the Light Table related to the educational
context and how it can ultimately be useful to her, Oliver expressed pride and
joy (:)) when talking about or interacting with the Light Table. Interestingly
enough, communicating via smileys (sad or happy) has been so important for him to give
feedback that I decided, it was its statement in the end. The location of the table (in a
box within the classroom) allows the children to reach it, but usage traces indicate that
this is rarely the case. It might be that the teacher feels responsible for facilitating the
interaction with the Light Table as its use within educational contexts is most obvious.
Hence, Oliver might ultimately face limitations on access and experience. However, this
is now a point where I would go back to the teacher and ask them further questions about
this after I analysed the contextual meaning of the Light Table's perspective on this. In
summary, it seems that Oliver's experience with the Light Table is associated with pride
and the exhibition of knowledge, but also very much rooted in a school context with the
associated experiences that frame his education.

7.2   Insights

The insights of this endeavour are two-fold: for one I extracted knowledge on the
children's experiences as I did before, but this time in connection with the PEACE
process. Additionally, applying the framework to case studies that were not paramount
to its development offers new methodological insights for developing it further.

7.2.1   Children's Experience

Each case showed that the individual lifeworlds and the subsequent individual technologies
addressing them also resulted in situated individual experiences that unfolded between
children and technology in use. Even though, these experiences are distinctly different
from the first year case studies.

Quentin showed continued engagement with the objects themselves, even though he was
less attached to the design process. He shows a keen interest in the final product, but
finds the process of creating them and solving problems less rewarding – at least as a
group exercise. During the process, he was always inspired by the objects around him,
but also quickly bored, mainly when a session did not result in a finished artefact. When
he had full control over the Sound Cubes, he made them his through constant engagement
and improvement.

What can happen with an object being integrated into a child's life was visible with Mia's
morning routine. Her Rattle Cushion alarm system was vital for self-confidence in that
she showed it to her environment as an achievement and explained her contribution to it,
but it also was useful to develop a working routine for getting up in the mornings. While
the technology essentially made itself obsolete, it was tailored to her needs at the time of
development and helped her grow her skills.

The Time Machine facilitated a collaborative experience which gave Yvan an environment in which his specialised knowledge would be appreciated. His brother Hank was an essential part in this experience, but – as it turned out later in the design process with both brothers – also struggled with Yvan's demands. However, they had defined their roles in interacting with the Time Machine (and its later version, the Time Machine 2) clearly, giving Hank the steering wheel and the commando to decide where they would go and allowing Yvan to tailor the story around that decision. Hence, it also allowed them to subvert the tendencies of other interactions they had. Hank gained a sense of control and Yvan's need for discussing his interests were met as well.

Oliver exhibited pride and a sense of achievement in his co-creation when showing it to others. When he suggests interacting with it, he feels a sense of control and engages with rewards at his own pace. The Light Table allows the self-guided exploration of learning goals and educational games.

Overall, the children expressed a sense of pride when conceptualising themselves as co-designers of technologies. However, all these technologies bridged the memento status, that was so prominent in the first year case studies. While the process was still a core part framing the children's experiences, the technology itself provided enjoyable experiences on its own.

7.2.2 Methodological Insights

Several methodological insights come from analysing the second year case studies. Across them, we can see the children's first-person perspective reflected in more depth as can be seen by them taking up more space in the statements table than was the case for the first year studies in Chapter 5. In that regard, the concept of Critical Experience can illustrate which actors shape the discourse dominantly and allows for adjustments if undesired actors take over discoursive power or desired actors are less heard. Next to this general insight, each case study also provided a different angle for methodological insights for the concept.

Quentin's case constitutes the one with the most limited data set. Seeing how we can still learn about aspects of his experience shows, that the conceptual approach of Critical Experience might be a useful endeavour even if not all steps can be thoroughly performed. Ultimately, this provides researchers with a harsh limitation, but also an exciting opportunity of using the procedure: On the one hand, it is difficult to judge scientific rigour in the actor-network as the data sources themselves are not part of it. On the other hand, we can also see that we still learn about influencing actors even if we are not able to inquire about them directly. We can still capture the complexity of the experiences autistic children have with technology and the uniqueness and situatedness for each case.

In Mia's actor-network I found that the concept lacked an explicit representation of the evaluation process and was at a loss as to where I could situate the actors that were relevant as that part of the process. An option could be to remodel the intersection

between researchers and participants as design *and* evaluation. In processes without a design aspect this would be necessary either way, but even in projects where both are occurring, I could colour code the two processes differently and try and illustrate overarching ones with gradients. However, in some cases, there is a temporal shift between actors taking a different role in design or evaluation.

Such a shift became especially apparent in the collaboration with Yvan and Hank, where Hank was first conceptualised as part of Yvan's subnetwork but became a core actor during the process. While I have shown this shift by artificially describing the process as two different processes, a more dynamic representation (similar to how Bokhove [2018] did this for social actors) could probably aid in illustrating how actors shift in their meaning. Within the scope of this thesis, this is an endeavour I like to explore in different projects at a later point.

Finally, in Oliver's case, it became apparent just how crucial it is to gain an understanding of statements beyond words. The smiley was an expressive statement for him that he used to give positive and negative feedback. While the academic process often requires researchers to illustrate their findings through words, it is paramount in working with participants who might have different modes of communication to find creative ways to illustrate their perspective appropriately (see also, Frauenberger et al. [2012b]).

7.2.3 Indications of Group Settings

To find out how the concept of Critical Experience would expand, I created an initial actor-network for one of the groups we work with in OutsideTheBox's follow-up project Social Play Technologies. That project works with groups of autistic and allistic children of four to six children and co-creates technologies which facilitate social play within the group. Figure 7.7 shows the initial actor-network of the group at an early stage in the design process, where the technology is only tacitly present as an abstract concept.

Creating this figure forced me to reconsider the core actors and to come up with a strategy that shows the individuality and interconnectedness between the children while at the same time indicating their shared circumstances. I solved this by following the format of the core actors where overlapping areas stand for shared concepts and interactions. For example, the friendship between Fabienne and Ethan is essential for how they interact with each other and how they relate to the group. It is seen simultaneously as positive that they are both part of the project (by them as gathered from their exclamations of how they enjoy each others' presence) and problematic (by the teacher who set out guidelines of what signs of affection are allowed).

The network also indicates that the design process is underway already and that the personal history of project members became much more present in this process. Two of three project members have autistic family members, which shapes the way in which we interact with the children. This brief exercise shows how the concept can be expanded to account for group settings in shared design processes. Whether it will be useful for the analysis of the children's experience in groups and individually, is yet to be seen.
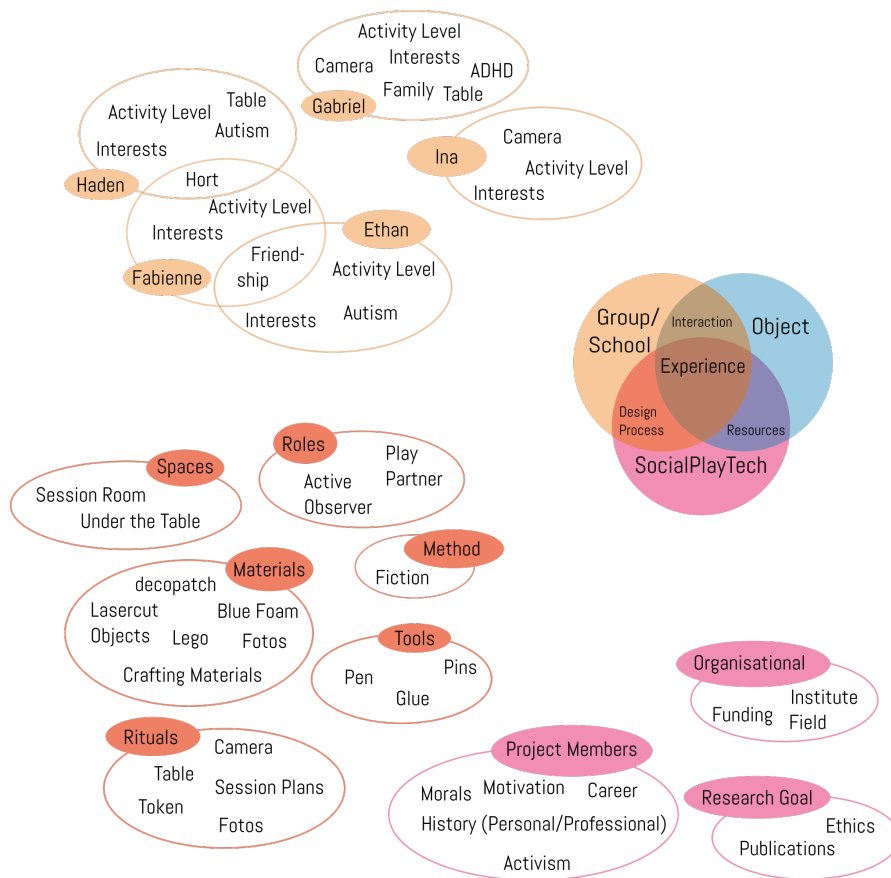
Figure 7.7: Actor-Network for a group context

7.3 Summary

In this chapter, I have revisited the concept fo Critical Experience as outlined in Chapter 5 and applied it to case studies from the second year of the OutsideTheBox project. By doing so, I showed how the concept could constitute relevant knowledge for the experiences of autistic children outside of the case studies the concept has been developed in. I could illllustrate how PEACE (see Chapter 6) has had an influence on the depth of data I could acquire from the children's perspective. However, applying the concept on second-year case studies pointed to edge cases that call for further development of Critical Experience, e.g., in group settings. Hence, analysing the experiences of autistic children with technologies is only the first step towards understanding experiences more generally from multiple perspectives.
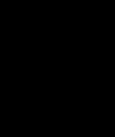
Micro-Ethics in Participatory Research with Autistic Children

The work in this chapter has been published previously [Spiel et al., 2018a]. This paper was jointly driven by Emeline Brulé and me, with the further co-authors providing academic guidance and help in revisions. What I write about here originates from parts that have been mainly written and conceptualised by me. The chapter reflects on ethical conduct in participatory research with autistic children. Working in a space with marginalised perspectives means that clear-cut guidelines are not always the only appropriate tool to define what ethical conduct means in working with vulnerable populations, but instead requires researchers and required me to form *judgements* based on their experience and the situated context in which these judgements become necessary.

8.1 Revisiting Selected Cases

As this section takes on a different perspective, some information from the case studies might seem repetitive, but are contextualised as an *ethical case* instead of a design or evaluation case.

8.1.1 Enabling Experiences

Sometimes children communicate on several levels, which makes putting their interests at the centre challenging to do, as we noted in Andy's case, where we had to go against what he explicitly said to enable implicit desires. Andy's use of language was somewhat idiosyncratic and required much knowledge of context and interpretation which meant that I had to tread carefully not to override his goals and agency. During the first meeting, a special education teacher was present to provide him with social safety. Andy was initially a little reluctant to work with us, but warmed up when we explained that

our activities would revolve around drawing and playing. Since the teacher had other children to take care of, she occasionally left the room in which we worked in to check into the adjacent classroom and ensure that her other pupils were doing fine. Whenever this happened, Andy indicated that he was unsure about the meaning of this and waited for her to come back to continue what we were doing. All in all, though, he seemed to enjoy our activities and indicated looking forward to our next meeting.

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

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

While he was reasonably cooperative during the next session, from the fourth session on, his teacher was absent from our meetings as she was more and more on the sidelines in the previous two sessions. From now on at the start of every meeting, he played hiding games and initially refused to work with us. It became part of a ritual where we had to rebuild the trust to work with us anew at every single meeting. It bothered us to some extent, but since he enthusiastically reported to his teacher how fantastic it was to conduct the design sessions with us after every one of them, we continued our collaboration despite the continued initial refusals.

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

8.1.2 Child Context

While in all other cases, the collaboration between researchers and children was initiated by schools or mentors, in Dean's case, his parents contacted us. During the first meeting with his parent, they informed us about the likes and dislikes of their son and also had mentioned that they were not only seeing themselves as a parent but also as an Applied Behavioural Analysis (ABA) therapist for their child. They implied that they expected us to follow the structural approach of ABA. However, after close inspection of the principles, we felt uncomfortable adhering to it. Seeing that ABA requires a child, to be under a near-constant therapeutic setting ('intense' treatments expect 36 hours per week [Eldevik et al., 2010]), we wondered when the children were allowed to follow their interests and be self-guided. I do not intend to go into the details of the controversies surrounding the approach [Raeburn, 2016] but want to illustrate our critical stance towards it. Still, we continued collaborating with Dean as we figured that it might be relevant to create spaces for self-guided interests through participatory design.

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

When we inquired about the frequency of use of the final object, the parent informed us that they used it during ABA and that Dean was not playing with the artefact in a self-driven fashion. By connecting the technology to therapeutic activities within the home environment, he refrained from using it in the playful modes of interaction we had established between us. However, when he was with us, he happily shared his experiences and initiated play with DSmart. Unfortunately, our collaboration was of limited time, which meant that the object use eventually solely remained in a therapeutic context.

Through our rejection of the dominant therapeutic model, we ended up ignoring a core part of the child's context and what it meant for the further use of an object once the participatory design cooperation ended. We were not well prepared for a shift in use that would be initiated by his parent and failed to negotiate our values with those coming from the child's context in a productive way. Hence, in line with our values, we might have missed an opportunity for empowerment. However, our judgement entailed that we created an alternative space for the child through our participatory design research, which might have ultimately been beneficial. Due to the limited-term nature of participatory design research projects and research projects more generally, it is highly unlikely that we can ever know about the long-term effects of our judgement call.

8.1.3 Bodies in Research

In several of our collaborations, the physicality of my body mattered. Children sat on my lap or climbed on me during design workshops, disregarding whether I would feel comfortable with this interaction or not. However, as long as my body was used playfully,

I was able to establish and negotiate boundaries through play. In one case, though, my physical body mattered as signifiers of hierarchy and dominance.

When working with Hank and Yvan, we did not meet them in an established school environment, but rather in a section of their parents' workplace. Hence, the physical environment was much more known to the two of them than to us. Subsequently, the children challenged existing power structures with the researchers much more than when we had worked with Yvan alone in a school setting.. While we encourage these subversive strategies in most occasions, the exploration of social boundaries led to situations in which we could not fully foresee potential consequences and occasionally even had to fear for the children's physical safety. For example, when they started throwing objects in a room with cardboard boxes full of glasses. However, intervening meant here – due to the architecture of the space –, using my larger, stronger body to pick up one of the children and physically move them out of the zone of potential danger.

Ultimately, both children seemed to appreciate us as design partners and liked engaging with us even though I had to assert a more hierarchical position as Active Observer than in other cases and sometimes manifest it through bodily interactions to keep all participants safe.

Using my body to assert dominance in situations where children could be harmed or cause damage to their surroundings was uncomfortable and unusual. My general ethical framing had the value that the children should not be put in harm, but using one's body as a tool for setting the children out of potentially dangerous situations also meant counteracting against a child-led process and making power dynamics we tried to tear down in our interactions all the more visible. Considering all this, I still my judgement in the situation as appropriate, but it led to broader ethical implications about the nature of our collaboration than apparent in the moment of execution.

8.1.4   Leaving the Field

Mia had just recently been diagnosed. She and her parent were still figuring out what the diagnosis meant to them and others. Since I have an autistic family member as well, the parent bonded quickly with me and asked for support and strategies she could try out with her daughter. This seeking of advice continued when the family experienced hardships that were unrelated to our collaboration with the child.

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

We understood the process of ending our relationships as 'transitional', in which the needs of multiple stakeholders (parents, children, researchers) are negotiated [Coad et al.,

2015]. We had been such an essential part of their lives that we felt an abrupt ending would be uncalled for. Our strategy was then to phase out the contact slowly by having longer intervals between meetings after our primary design and evaluation processes had ended. In those meetings, we discussed aspects of the child's life, designed little tokens or reviewed our work – with longer and longer time spans in between.

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

8.1.5 Intersections

Within OutsideTheBox, we focused on marginalisation on the account that the children were autistic, but they were often marginalised in more than one aspect of their lives. For example, several children were not raised by parents of the same nationality of the country they resided in, and two children expressed an elaborate alternative understanding of their gender identities as different to the ones they were assigned at birth. For one of the children, the family had stringent boundaries and expectations when it came to gender preferences and behaviour. In this context of complicated family dynamics, we had to mindfully weigh between acknowledging a child's desires and wishes and the consequences they might face in their immediate environment for expressing them.

In the other case, the child's parents actively sought my advice on how to identify and handle trans identities. Since I am non-binary myself, I had to pay close attention not to bring my agenda into the research effectively over-interpreting what the children might have wanted to express. Hence, I explicitly did not address any related topics myself and only reacted to the children if they brought something up (such as the fixation on pink and purple colours in the case of one child which had been assigned male at birth). Even though these marginalisations were not in the focus of our research, it was essential to be aware of them and acknowledge them as relevant for successful design partnerships.

Being aware of further aspects of marginalisation in a child's life allows co-designers to develop more relevant technology for the children [Schlesinger et al., 2017], but also comes with the associated risk of researchers sharing marginalisations dominating with their agenda. To counter such a risk, we actively shied away from discussing overlapping marginalisations with the children without their explicit input. However, without positive (or in some cases even just any) role models, children cannot find ways to express themselves productively in their identity. In choosing to refrain from not bringing up specific topics, we reduced the children again to the marginalisation the research context had focused on (in this case the disabilities) even though we aimed at designing for their holistic life worlds.

8.2   Discussion

Across the individual case studies, I identified several higher-level challenges, but the ethical judgements differed according to context and needs. I now highlight the consequences of these different judgements which builds the starting point for an understanding of micro-ethics in participatory design with marginalised populations on my example of working with autistic children.

8.2.1   Negotiating Multiple Agendas

The first re-occurring theme is about the multiple agendas that need to be negotiated. While carers play a role in any work with children, in research with marginalised children the carers' presence is even more prominent. They set the framing of the children's life and structure, in the roles of social workers, medical personnel, specialised teachers, therapists or family members. In our case studies, carers framed the research in often unexpected ways.

Our strategies in negotiating with carers were manifold, all of them with unforeseeable consequences at the point where they had to be enacted.

- We retreated when a co-researcher or other adult acted contrary to our judgement and only discussed our concerns afterwards. While this meant that children were potentially exposed to a negative experience, we also learnt that it was more effective, if we brought up potential issues we felt were part of the adult intervention in a setting where we would not threaten their authority over the children as a by-product. There were cases where a direct response might have been the better approach and reduced tensions between the carer's procedure and the design process. However, as the carers were paramount to being able to conduct the participatory research at all, we had to partly adhere to their desires as well. This aspect of participatory research with marginalised children inherently complicates virtue ethics proclaiming child-led processes.

- We established alternative approaches to working with the children. In part, this meant excluding or ignoring parts of their context during the design process for the benefit of opening up new spaces in which empowerment and design activities were possible. Together with the retreating strategy, however, this potential space becomes fleeting and insecure as it can only happen through precariously balancing the values of carers and researchers alike.

- We carefully navigated the influence of different carers and mediated on topics where there were already existing tensions between carers and children. This strategy had several sub-strategies where we would either not bring up a controversial issue (or change the topic with reference to external sources) or talk about it in a normalising way to everyone involved. Which one of these sub-strategies was adequate changed

according to the context of the situation in which it occurred, as can be seen in how they were differently applied within and between the projects.

These strategies show, that even in participatory design research in which we attempt child-led process carers play a relevant role in not only enabling researchers with access to the children but also in shaping the context in which the research can happen at all. As such, their tangential role in participatory processes not explicitly including them might be under-conceptualised. In our cases, their presence made us carefully prioritise topics and aspects over others, which meant they had a tremendous circumstantial influence on the participatory design work and its outcomes. The analysis of Carer-Children-Researcher relationships through an ethical lens can increase an understanding of how processes are shaped and which strategies exist in including carers more explicitly since they already implicitly influence the research. That way, caring strategies in research can be negotiated explicitly – appropriate to the level of involvement in the research activities – as well, which might resolve potential tensions beforehand.

8.2.2 Being at Risk

Appropriately assessing risk factors was another common theme. When working with marginalised children, risks become at the same time more explicit *and* more implicit. We have to take care of the marginalised children and ensure that we are not exposing them to harm, but we are also vulnerable ourselves. Our comfort zones are challenged continuously. When children are invited to long-term research collaborations needed to design in a participatory with disabled children, they are also enabled to build complicated personal relationships with researchers (including, for instance, demonstrations of affection). On the one hand, this might allow them to make new experiences and widen their horizons, on the other, the more personal relationships get, the more vulnerable the children and the researchers themselves become.

How to appropriately balance professional conduct and personal relationships is a matter that can only be practically engaged with at the time the research activities are conducted; anticipatory deliberations remain theoretical and speculative. In the case where a participant displayed inappropriate conduct during a research activity, we had to weigh several risks: the risk of the child being impacted disproportionately in the future, the risk of the researcher who was unsure how to appropriately handle the situation and who was in a position of liability, and the adherence to the nature of privacy of the meeting which has been ensured to participants before they engaged in the research.

Hence, participatory design projects not only pose potential risks to the children but similarly to the researchers themselves as well. These risks are not always physical, but might also affect mental health, the career of people involved or the development of the children. While researchers might not ever be able to eliminate or foresee all risks, it helps to be aware of them and consider which choices might lead to which potential outcomes and the attached risks for researchers and children or other stakeholders in the participatory processes alike. As a core point of care ethics all participants in the

research, researchers as well as marginalised children are vulnerable and 'at-risk' when they cooperate [Tronto, 2001]. It is ultimately down to our judgement to limit the risks for people, in a context where the most appropriate procedure is not necessarily clear-cut.

8.2.3 On being Care-ful

Within OutsideTheBox, we were of the opinion that the processes should be conducted in a child-led fashion. We understood the children as design partners with equal rights who were not only allowed to shape but to lead the design while being equally able to end all collaborations. In practice, however, we had to carefully negotiate with the children about their level of participation. In the most extreme case (see Section 8.1.1), we were initially timid and unsure about how to proceed but over time became more confident in our judgement. We convinced the child to engage with us since they continuously raved about the activities after the sessions. In our opinion, we were also negotiating between needs here: the desire of the child for sameness (which is not fulfilled in progressive participatory design sessions) and the opportunity to make new experiences, expand their knowledge and find new ways to express themselves. This complicates the notion of seeking assent in a child-centred approach [Dockett and Perry, 2011]. One could also argue, that it might also not be too beneficial to focus research on only children who readily participate as this might neglect quieter children. Still, participation should not be forced upon them against their explicit, continued dissent; however, challenging some notions of initial refusal can be appropriate in some contexts.

Another aspect of caring for the children required us to be mindful of the responsibility put onto us as adult researchers not only by the adult environment of marginalised children but ultimately also by the children themselves. They trust us to keep them safe. Such trust is fundamental for a productive participatory research relationship. At the same time, we are creating a space in which they should also feel free to express themselves in creative ways and explore the boundaries of what they know – which includes rules. As researchers, we tried to engage with the children at eye-level in a relationship of equal partners. However, situations can occur (like the one where children were about to smash a whole lot of glasses) where researchers need to assert authority to keep everyone safe. In negotiating the different needs of marginalised children, the design process and the researchers themselves, we need to find a balance between rejecting and embracing responsibility, between equal partnership and care.

8.2.4 Acknowledging Personal Context

Our work with autistic children gave us additional insights into the importance of positioning ourselves transparently as researchers within the research project towards the children and their social environment. Professional and personal aspects of ourselves played into the participatory design research [Hopkins, 2007]. For example, I identify as a queer-feminist researcher, which led me to be wary of over-interpreting any related issues regarding gender identity or expression – even though there is tentative evidence for this

being more prevalent at least with autistic people [Janssen et al., 2016, Rudolph et al., 2017]. However, researchers' gender expressions shape participatory research in often unforeseen ways [Ward, 2016]. We judged that it was best to shy away from discussing these issues pro-actively with the children despite the fact they inquired in different ways about it, given the risks we would face if we were identified as activists. Through that, we implicitly adopted a (hetero-)normative discourse, despite personally experiencing it as repressive. This normative discourse builds upon a strictly binary concept of gender and does not enable alternative gender expressions (especially not in German).

I realised across all case studies how it matters who embodies the research. Different bodies invite different interactions. Children engaged with my uncommon bod (other-gendered, fat and with an unconventional hairstyle) in curious, playful and exploratory ways. Through the comparatively long collaborations, the engagement with the children built closer relationships, also physically. However, I was also forced to use my body to exert dominance in situations of potential harm. Hence, researchers' bodies can become ambivalent in how they act in participatory research with marginalised children: friendly and engaging, but yet with the potential to set firm boundaries.

8.3 Micro-Ethics

While checklists [Read et al., 2013] and rolling ethics approaches [Frauenberger et al., 2016b] have discussed the ethical framing of research more generally, within HCI, little attention has been paid to the concrete situations in which ethical choices arise and in which researchers have to make in-the-moment decisions. However, in other fields, the necessary judgements and ethical complications that arise in doing research with participants have been extensively discussed. [Christensen and Prout] [2002] were among the first who presented their experiences and difficulties when working with children who they conceptualised as 'social actors' in their research (instead of object, subjects or research subjects). Within education, [White and Fitzgerald] [2010] illustrate how emerging responsibilities need to be negotiated and how the agenda of ethics committees might be contrary to that of participants' needs and desires. [DePalma] [2010] had similar experiences in a participatory action research project in which they found the institutional review at the same time not strict enough on some issues (e.g., consent) and not flexible enough on others (e.g., participants' anonymity).

Our circumstances make it necessary to reflect on the ethically charged situations that require judgements, or how I like to call them, *micro-ethics*. Their interaction with other ethical constraints of research (e.g., pre-established research conditions or ethical guidelines) complicate the matter, as [Renold et al.] [2008] illustrate for on-going procedures regarding consent with young participants. These micro-ethical judgements cannot be presumed or pre-defined. Hence, it becomes all the more important to be reflective practitioners during research engagements. The themes above provide starting points for reflecting on similar situations through a lens of micro-ethics.

8.3.1 Micro-Ethics as a Lens

While virtue and care ethics provided an overall frame to our research that helped orient our actions, actualising them in research requires different strategies. Micro-ethics, as developed Komesaroff [1995], provide a lens to look into the mundane everyday activities that contribute to ethical conduct on a larger scale. When interacting with marginalised children in participatory design research, the necessary in-situ judgements might appear contradictory to the broader ethical goals and create tensions with these in their actualisation.

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

Table 8.1: Tensions between ethical principles stemming from virtue ethics and strategies used in micro-ethics

In Table 8.1 I list the ethical principles guiding the discussion above and which micro-ethical strategies we employed among them. It illustrates the negotiations necessary between different stakeholders in the research be it the children, the context of their marginalisations, their social environment or the researchers themselves. To account for a broader context of the children's lives, their existing carers require careful navigation and certain aspects will be prioritised. The avoidance of harm has to be weighed against the opportunities specific activities can offer and, hence, risks become much more complicated to assess. Even in child-led PD, researchers have to be aware of their responsibilities as adults and, finally, professional conduct has to be negotiated with being personal and committed to embodied research.

While these tensions are ever-present in participatory design, I argue that looking at them precisely on a micro-ethical level and making them transparent in reporting about the research not only aids researchers in reflecting about their work but also provides an opportunity to discuss ethical conduct in participatory design with marginalised children more generally. Instead of ignoring the tensions, I suggest critically engaging with them to understand better how ethical principles are enacted micro-ethically and in-situ.

8.3.2 Practical suggestions

Towards this, I suggest actively identifying these situations after each encounter with participants, determining the choices and the judgements made and then reflecting on them with others. I also recommend that it might be additionally useful to discuss them with people who are not directly involved in the research since shared assumptions within a group might hinder the identification and explicit discussion of some of these choices.

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

8.4   Summary

This chapter reflected on ethical dimensions and situated judgements that are relevant to participatory research with autistic children. I argue that as a research community, we should be aware that such decisions are omnipresent. Though research with autistic children comes with particular challenges, I expect that researchers can draw parallels to their own work where they see fit. The reflection comes with a uniquely situated account of myself as one of the researchers within OutsideTheBox. Alternatively, one could also think about joint reflections between researchers, child participants and their social environment.

At this point, the chapter makes two main contributions: the first is pragmatic and resides in the empirical grounding of complex judgements during interactions with autistic children in participatory research as provided by my examples. The second is the articulation of an approach to ethics which combines normative ethics frameworks and situated moral judgements made over the course of the research through the analytic lens of micro-ethics.

Discussion

In this chapter, I revisit my contributions in the light of existing literature before I go into more detail about the research questions I asked in the introduction. Then, I reflect on agency as a lens for academic research with autistic children, discuss power dynamics in participatory research as well as epistemological consequences of my work.

9.1 Major Contributions

In Section 1.3 I detailed my aims and subsequent research questions. In revisiting them, I give a more structured presentation of my contributions.

9.1.1 Aims

Aim 1: Provide a concept to holistically and qualitatively understand the experiences of autistic children with co-designed technologies.

Critical Experience offers a qualitative understanding of experiences with technologies developed in co-design work with autistic children. In that, it is an early work looking at these specific experiences systematically through predominantly qualitative methods. While my approach explicitly includes different perspectives of single and multiple actors, In using my approach we can gain a more well-rounded impression of these experiences and refrain now from attributing the word 'holistic' to my analysis as it describes an effectively unattainable goal.

Aim 2: Methodologically and conceptually account for the agency of autistic children and their perspectives within the research about them.

As we will see in more detail in Section 9.3, the notions of power and agency greatly influenced the conceptual work on Critical Experience and the methodological grounding in Participatory Evaluation. Whether this aim was sufficiently addressed in my work

cannot be part of this work as it requires stakeholders from the autistic communities and the children themselves to acknowledge whether this is the case. I am aware, that this might in part be of quite limited validity in an academic context, especially as the form of expressing such acknowledgements, concretely when coming from children, rarely constitutes a position from which they can speak with the discursive power to influence meaning-making of such processes. As such, this aim remains a constant aim about which I and the research community will never be able to know whether it has been met or not.

Aim 3: Let autistic children co-define the interaction and co-construct the meaning of technologies.

This aim has been most distinctly followed in the development of Participatory Evaluation (with Autistic Children). In this process, researchers actively make space for meaning-making and knowledge contributions from their participants. The resulting space has been filled by different perspectives on what the technologies we co-designed could mean to different participants. As such, I deem this aim has been addressed in my work.

9.1.2 Research Questions

RQ 1: How can the experiences of autistic children be captured conceptually?

Critical Experience offers a way of engaging with these experiences in a way, which invariably stays open for interpretation [Sengers and Gaver, 2006]. An explicit step focuses on resolving contradicting perspectives to uncover the shared meaning behind them. Hence, this research question is addressed in Chapter 5. I show how looking at the experiences of autistic children with technologies from multiple perspectives allows for a range of insights. The concept is embedded in Actor-Network Theory and Critical Discourse Analysis to allow for a structured approach in finding relevant viewpoints and assessing them with an eye towards power relationships.

RQ 2: How can autistic children be actively involved in the meaning-making about technologies they co-created?

With Participatory Evaluation, I provide examples of how autistic children can be involved in the meaning-making of their co-designed objects even when their preferred modes of communication are not shared in a society catering to neurotypical needs (described in Chapter 6). Through my work, I actively extend the notion of participation in participatory processes more generally. In a three-step process, the children are invited to make meaning about their technologies, by setting goals and choosing appropriate methods to reach them. By creating space for the children's perspective more explicitly than previously, I gained insights into which aspects of a technology mattered to them.

RQ 3: What are the qualitative aspects of the experiences of autistic children?

The experiences of autistic children are manifold and tied to their contexts. Still, I could extract aspects that are different between the first year case studies described in Section 5.3 and the second year case studies described in Chapter 7. However, the question

is only partly answered as the experiences are limited to the participatory design work we conducted in OutsideTheBox. Further work would start analysing the experiences of autistic children with more conventionally available technologies in their environment to capture a more well-rounded picture of how they experience these technologies. For now, however, we learned about a set of different roles the objects can take on in the children's lives, among them: 'memento'-object (ThinkM), everyday support tool (Rattle Cushion) or exploratory toy (SoundBoxes). While Critical Experience allows for a detailed view of the children's experiences already, in using PEACE, I created richer and more nuanced knowledge than before.

9.2 Experiences with Objects in OutsideTheBox

This work presents one of the few accounts in the field of HCI that explicitly contextualises its work within a neurodiverse understanding of autism. It acknowledges the expert knowledge of autistic children explicitly and challenges societal (and subsequently research related) notions of power dynamics between them and the researchers. Whereas previously autistic children were limited in their agency to make meaning about a technology and decide actively on purpose and context, within OutsideTheBox, we not only designed technologies that were meaningful to the children, my work on understanding their experiences shows pro-actively ways to include them in the assessment of the experience as partners.

Previous technologies (see Section 2.3) were limited in their purposes and driven by the desires and concepts of autism as developed by a predominantly neurotypical, adult environment. Through Critical Experience, I provide a way to look at the context for experiences of a child more holistically, and with Participatory Evaluation I offer a methodological grounding in understanding the children's experiences through making space for their interests and perspectives in assessing technologies. I argue, that, as we move to design that acknowledges the experiential qualities of interactive technologies [McCarthy and Wright, 2007] and the need for making these experiences accessible to more than just the dominant user group, we need to consider participatory design with autistic children as an issue of social justice [Dombrowski et al., 2016].

OutsideTheBox still had extrinsic criteria for evaluating the technologies we designed with the children: they were supposed to support sharing positive experiences made with the technologies. However, through conducting our evaluation using Critical Experience and PEACE, we expanded our understanding of what sharing experiences with a social environment can entail. All of the eight technologies offer opportunities for sharing in different ways but always put the children *in control* of whether sharing occurs or not.

ProDraw allows sharing explicitly through projecting drawings (also in the making) or animations on a wall. However, the touch display allows for private interaction with the device as well, and Andy can choose which aspects he shares if he wants to. As the sharing is tied directly to the object and has to be activated, it is done *explicitly*.

ThinkM   has no explicit mode of sharing. However, it can be argued, that through the reflection it affords, even if Blaine does not share his experiences directly with the environment, through his actions he might share his experiences. As he did not interact much with the object as is, I can only speculate about this kind of sharing. In the use pattern he showed with it – employing it as ticket-to-talk about the design process itself –, he shares his experiences with the design of the object *implicitly* through the object.

Adaja   affords *explicit and implicit* sharing simultaneously. Claude can choose to engage with others in investigating the environment or tell others about the findings he made by himself.

DSmart   enters a mode of *explicit* sharing if Dean invites others to look at movies together or tells stories to them. However, it also allows for private interaction in that Dean can decide which surface and area he projects the images and videos on.

Sound Boxes   are a device for *explicit* sharing (of voice messages) as a core part of the design idea. As Quentin can decide who he sends which message by giving them the second cube (or not), he is in full control of what he shares with whom as well.

Rattle Cushion   as an alarm system is the system which affords sharing in the most *implicit* way. In waking Mia up in the morning and providing her with a melody suggesting horoscope information for the day, others are never directly included in the interaction with the object itself. However, by telling others about the technology, Mia shares the positive experiences it makes with it, more directly. Additionally, she still creates magazines describing her experiences as an autistic person, which means she found a medium that more generally allowed her to share her individual and situated experiences with others.

Time Machine   expects the people interacting with it to share the story that unfolds *explicitly*. The technology (in both forms) can also be engaged with on an individual basis if Yvan (or Hank) desire to do so. In its second version, though, special effects only occur if they use both controls together. We could observe that with the first version Yvan gave the control to Hank and reacted through storytelling on what happened. Hence, sharing control can be a means of controlling the sharing in return.

Öxe   has *implicit* and *explicit* features for sharing. The technology itself is fairly agnostic towards being shared, but the infrastructure around it (through the games and tasks) includes others dynamically in the process. However, here Oliver has the main control over the device and the sharing through his expert knowledge he gained as partner in the design process.

The agency and perspective of the children are then inscribed in the objects and enacted (from the researchers) through Critical Experience as an experiential framework and

PEACE as a methodological basis. Both in combination allow researchers to put the children into the centre of the evaluation, directly acknowledging their expertise and commit to understanding them directly instead of going the supposedly easier route of relying on proxies.

My work focuses on experience, not efficiency and provides an account of understanding technological experiences of autistic individuals. The concept of Critical Experience considers empathy as a limited resource and productively works around that to offer further actionable concepts on experiences to the HCI community. With the specific population of autistic children, it comes with a profound neurodiverse understanding of difference. Additionally, it questions and expands what the HCI community might mean when they talk about experience and how it can be assessed while simultaneously respecting the situatedness of these experiences. PEACE provides further detailed information on how one might go about methods to expand the notion of participation beyond design towards meaning-making and evaluation of a technology. It requires researchers and designers to be humble about their contributions to the process and open about having their presumptions challenged.

I dare to speculate that my work might provide a useful approach beyond the population of autistic children. Experience researchers and designers rarely share the life world of the people they design with or for. When working with older adults, for example, there is also a gap in life experience, knowledge and overall embodiment. For instance, Nunes et al. [2012] state for older adults that "the age difference makes it more difficult for the designer to put himself 'in the shoes' of the user". The systematic differences in lifeworlds as embodied might be the case for any interaction between two humans. Empathy can help understanding one another and relating oneself to the experiences of someone else, but it ultimately remains an issue, that the privileged perspectives of researchers remain precisely that: privileged. By giving up some of that privilege and allowing participants to take up more space in the meaning-making about technologies, though, we can potentially gain richer insights and more diverse understandings of what technologies might mean to all kinds of people, how they engage with them and how they experience them.

9.3   Agency as a Lens

By choosing agency as a lens, my research has to be judged along the criteria of how it allows autistic children to express their agency and act on it accordingly as well. Especially as an allistic researcher, it becomes necessary to have an eye on representation and give space to the self-expression autistic children use [Mankoff et al., 2010]. That way, I aim at providing an example on how allistic researchers can engage with the 'double empathy problem', which postulates that empathy towards autistic people is at least as much lacking as it is assumed to be lacking from them towards allistic people [Milton, 2012]. I further aim at finding solutions for overcoming it from their side and acknowledge the agency and identity of autistic children in their research better.

Within the work I conducted along 'Critical Experience', children are first conceptually put on the same level as every other (core) actor in the network. As previous research projects were rarely interested in inquiring into the experience of autistic children, they have been systematically excluded from participating from most of the previous research projects (as evidenced by only 9.4% of papers in the analysis in Section 2.3 following a participatory design approach). Hence, putting the children on the same level as technology and researchers while at the same time understanding the child's social environment as consisting of subactors relevant to the child's context, is a radical move that actively makes space for a child's agency. Through critical engagement with the extracted statements, the existing power dynamics between actors are additionally reflected and considered as part of the analysis. However, while the concept assigns a theoretical space for the children's participation, a methodological space for how to communicate with the children in participatory sense-making research is not offered by this framework.

My work on Participatory Evaluation addresses this gap. In using the method, researchers are invited to explicitly create the space in which autistic children can make meaning directly and jointly with the researchers. By acknowledging different ways for expression and communication and also conceptually providing the children with the choice to participate at all, as this form of structured inquiry might not be relevant to all of them.

In conceptually focusing on the children, I provide a way to include their agency more directly. To fully understand how it expresses itself, however, I need to also pay attention to the lived experience of their everyday life, which is often defined by the adults around them. Hence, autistic children's agency is difficult to assess as there are often multiple individuals who speak for a child, which might lead to contradictions between different stakeholders. When conducting participatory research with autistic children, their social environment becomes more relevant to the processes. For example, caretakers, parents and teachers tend to be much more present when children are disabled. Researchers need to carefully immerse themselves into autistic culture and reflect status and the consequences of specific actions more carefully. Hence, we need to be more attuned to children's perspectives and might even need to carefully weigh contradicting messages we are receiving from adults in the children's environment not to accidentally override the children's agency [Thomas and O'Kane, 1998].

It is further essential to negotiate between what the children can do and the desires they have. With autistic children, researchers have to pay close attention to the children's abilities and preferences about the high cognitive and sometimes even physical demands participatory design can require from them. For example, to avoid overwhelming some children, it might be appropriate to partly include others. Ruland et al. conducted participatory design with children with cancer and used groups of children without cancer at some points in the design process to not demand too much from the first group [Ruland et al., 2008]. While this might leave marginalised children out of parts of the design process, which consequently leads to them not having direct influence over those parts, such a procedure might be desirable in the grander scheme of things.

Agency, participation and what is possible to ask for without 'tyrannising' [Cooke and Kothari, 2001] the children has to be continually conceptualised anew for each research collaboration with autistic children. While this is true for all participatory design collaborations, I argue that researchers have to be especially careful when aiming for child-led processes with autistic children as, for example, they might not use the same vocabulary to express their thoughts as the researchers. Hence, researchers have to be attuned to explicitly making space for the participation of the children on their terms.

While I am not able to make a definite statement on whether the children themselves felt more empowered through my methods, I aimed at creating spaces in which there is an opportunity for this. Guldberg [2010] has analysed conditions that lead to best practices for inclusive education. These include:

- considering the strengths, interests and abilities of each child as unique,

- targeting learning and, in my case, design and research practices towards the needs of that child,

- adapting communication and structures to the child to create an enabling environment, and

- fostering positive relationships with the child, their carers and other social actors that are relevant to their context.

PEACE acts on the first two conditions surrounding the strengths and needs of the individual child, Critical Experience then concerns the last two by targeting the environment of the collaboration and acknowledging the broader techno-social context of the child. Hence, taking my work as guidance, researchers have the opportunity of creating spaces in which they can more readily acknowledge the agency of autistic children.

9.4 Understanding Power in Participatory Design

Even when researchers are trying to establish a relationship with the children that aims to minimise existing power differences between them, multiple aspects play into any participatory research which inherently leads to ethical complications. Researchers are older than the children, have better social status, and their statements are given more validity within society. As researchers, we need to be aware of these power differences and how they actively shape our collaboration. Further, we need to monitor who is making which decisions carefully [Bratteteig and Wagner, 2012].

The physical presence of all participants – researchers and children alike – additionally affects the power distribution in research contexts. Researchers tend to be taller and broader than the children who are participating. They take up more space, even when they lower themselves to the eye-level of the children. Further, researchers have acquired more practical skills and experiences in design processes than the children by merely

having had more time to improve them. Especially in longer-term collaborations, the children build up trust towards the researchers. It may result in researchers becoming aware of private and confidential information, which is less expected in the other direction. Hence, careful management of hierarchies and how they might be subverted in the interest of the children becomes paramount to participatory research with marginalised children (see also Abebe [2009]).

However, along with Foucault, I understand power relations as actions upon actions, which leads to a conceptualisation of power as a productive *and* a repressive force [Foucault, 1982b]. Hence, through subversion strategies formally oppressive power can be redirected [Holland et al., 2010]. For example, children can refuse to engage with researchers leading to new strategies for mutual engagement.

In this understanding of power as a multi-directional force, I want to emphasise that "children may exploit, appropriate, redirect, contest or refuse participatory techniques" [Gallagher, 2008]. Such subversive strategies of the children should be identified and then encouraged – primarily with autistic children as they are often limited in the resistance they can exercise in their daily life. Researchers can then follow the child on their subversive path and engage with it productively, for example, in participatory design processes through acknowledging the creativity such strategies afford and incorporating it into the design activities. Through fundamentally taking back their own agency and deliberately letting go of the power they hold over the process, researchers using PEACE to evaluate technologies can actively counteract traditional power structures and allow space for the children's actions to become meaningful and relevant to the process. This is not a simple political rally cry, and it has limits when a child endangers themselves or others in doing so. Instead, if researchers are open to, encourage and expect resistance, they allow the children to express themselves through the research process and can become equal partners of the children [Yip et al., 2017a].

OutsideTheBox focused on autistic children in a way to counterbalance their under-representation in research and had a strong focus on empowering them. Some scholars have argued that focusing on marginalisation may backfire and essentialise inequalities and that marginalised group may oppose such categorisation [Morris, 2016, Nygreen, 2006, Watson, 2002]. The potential consequences of this can have different effects: enable resistance or reinforce biases against minorities.

Conceptualising autistic children as marginalised required me to be explicitly attentive to ethical questions posed by the research. Had I tried to neglect and equalise their disability, I would lack the tools to address the resulting tensions within power differences. I put the focus on marginalisation to point out how autistic children are systematically absent from society and research projects as people with their agency [Watson, 2012]. Ultimately, though, neither the focus on nor the levelling down of marginalisations is merely productive, but rather the political and ethical background from which one or the other approach is judged to be appropriate.

9.5 Epistemology in Participatory Research

As discussed previously in Section 3.2, my research can be situated within a co-constructivist, participatory paradigm. Hence, my research fits into a third-wave HCI context [Harrison et al., 2011], where situated knowledges [Haraway, 1988] are valued as their own research contribution. Explicitly drawing on feminist practices and feminist disability studies [Garland-Thomson, 2005, Morris, 1991], my work seeks not only to expand the knowledge within the research community on experiences of autistic children with technologies but also has a transformative agenda aiming at the expansion of methods available to let autistic children participate in research as well as a more neurodiverse understanding of cognitive conditions. As (quantitative or qualitative) research is never a neutral endeavour [Stengers, 2018], this agenda is not a problem per se, but preferably one that needs to be made transparent and should be available to readers to understand the position from which the work has been conducted and written.

Specifically in Section 3.2.2, I have listed several sets of criteria that can be used to reflect on the quality of my research. I will now briefly revisit each one of those to understand how my research could be judged along them. However, as I am doing this analysis, I am very likely biased towards aiming at the most suitable defence of my work. Hence, I encourage readers to engage critically with this section.

9.5.1 Integrity

The criterion brought up by Seale [1999] is probably the most difficult to assess by myself. They indicated that researchers' integrity as professionals, but also through personal experiences, is core to the quality of qualitative research. My academic background is in Cultural Studies, Computer Science and Human-Computer Interaction. I identify as disabled and am involved in queer-feminist activist networks. Both of these contexts have informed my approach and, in particular, the transformative agenda associated with it.

9.5.2 Rigour

Epistemology, Values, Stakeholders and Outcomes are the four lenses aimed to assess rigour in participatory design projects as proposed by Frauenberger et al. [2015]. While my work does not directly contribute to design, I deem these lenses appropriate for its assessment.

Regarding *epistemology*, my work provides mostly *social*, *methodological* and *theoretical* knowledge. The social component is provided by enquiring into the experiences of autistic children and reporting on them. Methodologically, I offer PEACE as an approach to include autistic children in sense-making about the technologies they co-create and allow researchers to evaluate together with marginalised participants. Finally, the analysis of my work along ethical notions provides further theoretical insights into the specifics of micro-ethics in participatory research. In trying to make my processes transparent to readers, I aim at increasing the credibility of my work. While the resulting knowledge is

situated in nature, I argue that similar contexts of participatory research more generally and, in particular, with marginalised participants can inform their processes through my work. The created knowledge itself is shared in academic venues (as evident by the list of paper associated with this thesis), public engagements (exhibitions and talks) and, more implicitly, between colleagues.

My work comes with explicit and implicit *values*, though implicit values are difficult to capture. Explicitly, I strive for participation and empowerment, a child-centred approach and more generally, fairness in technological design and access. I tried to meet my participants with respect and kindness. The conflicts and dilemmas arising from these values are, to some extent, reflected in Chapter 8. There, I also show how some of the values needed updating or refinement, for example, when it came to seeking assent from the children, but also trying to not take the potential for positive experiences away from them. The values guiding this research are inherent in the methodological and theoretical outcomes it provides.

There are several *stakeholders* relevant in my work. First, there are the individual autistic children and autistic children as a population. While there is no means to generalise from the findings of the individuals, the population is implicated methodologically: I argue that Critical Experience and PEACE are potentially applicable to any participatory project with autistic children. Additionally, their parents and social context has stakes in my work in some form or another. As can be seen in Chapter 5, I conceptualise researchers themselves as stakeholders in a given participatory project as well. Direct participation is mostly limited to the children and the researchers within the design sessions and, other than with PEACE, only indirectly given. As the children were encouraged to take home their prototypes, they benefited by having an object tailored to their individual needs as well as technical support by local OutsideTheBox researchers (even after the end of the project). Additionally, I expect that they were able to take some of the methods they encountered and appropriate them for their means. At least for one child (see Section 7.1.2), I could see that this was the case. Regarding exit strategies, I provide an example in Section 8.1.4.

Different stakeholders then interpret the physical *outcomes* of the project differently. I could show that the meaning some technologies within the project took on were, for example, more as tokens, others were meant to become obsolete, and others again were used as intended or re-appropriated. The ownership of the objects lies with the children. However, they are only of limited sustainability. While, especially in the second year, we were keen to develop durable research products [Odom et al., 2016], they did not necessarily withstand continued use over a long time.

Due to my position as a doctoral researcher, I have different needs and desires when it comes to the outcomes of the project. As this is my dissertation, I hope to attain a particular academic and societal status through my work. In publicising it, I want to contribute to a specific knowledge discourse that inspires future, similar projects. Choosing particular venues, though, is also meant to further my academic career and put me in an excellent position to do the work I want to do. These are non-trivial goals, and

it should be acknowledged that the children participating in our research, as well as their social context, tremendously contributed to that without necessarily gaining similarly high-level benefits. It is also worth noting that the demands of the research community regarding generalisability or, more appropriately in qualitative research, transferability stand in contrast to a situated design project that aims at empowering individual autistic children. Hence, the contribution of my work regarding theoretical and methodological knowledge might be more applicable to the goals of the research community whereas the social knowledge is much more situated and not necessarily transferable beyond the core argument that design with autistic children comprises a productive activity.

The four lenses indicate rigour within the OutsideTheBox project more generally, but also concretely, for the work in this thesis. As Frauenberger et al. [2015] state, it is ultimately the coherence between the lenses that qualifies the rigour. The situated knowledge I create reflects the values I hold, which in return influences which stakeholders I include to which extent and how that is reflected by their different meaning-making of the physical outcomes. Using that framework, I can claim rigour in my work to some extent.

9.5.3 Inclusion

Nind [2014] suggested another set of quality criteria for collaborative research projects. I could not feasibly answer questions about autistic children's experiences without their direct involvement (see also Section 2.4.1). Through PEACE, I offer a method that allows access to autistic children's modes of communication and ways of knowing in different, individually situated forms. Critical Experience is my attempt to understand the culture of an individual child by including their socio-technical environment, interests and preferences. Considering the long-term engagements, we could not help but have an impact on participants' lives, though the level impact differs individually.

In conversations with parents and the children, they indicated that they saw the resulting knowledge as valid. However, this should be taken with caution as in Austrian culture direct, explicit critique is not readily given. There are other indicators, though. For example, a few parents asked to read the academic contributions of the project and disseminated them in their private network. One parent explained to their child the specifics of a paper. Some children asked about coming back and also in evaluation sessions turned back to create new ideas and designs. Further, whenever we had a public engagement or an exhibition, the children could and did participate and presented their object to a general audience. This increased engagement with the subject matter around OutsideTheBox is indicative for approval from the children and their social environments.

9.6 Summary

In this chapter, I discussed the contributions of my work in light of the existing literature in the field of technologies for autistic children and the evaluation of these technologies. Mainly, I contributed to a conceptual understanding of experience that allows going

beyond empathetic notions of considering others' experiences through Critical Experience. Additionally, I put on a methodological foundation to this that actively includes autistic children in a participatory evaluation of technologies through PEACE.

In the discussion, I then further analysed how agency contributes to my work as a lens and how power relationships shape participatory research. Additionally, I reflected on epistemological consequences this type of work has within the research community.

CHAPTER 10

Conclusion

With my thesis, I have expanded the question about experiences with technologies to marginalised people, notably autistic children, who in their majority have so far been conceptualised as more passive *users* of technology. My work shows how we can look at those experiences from diverse perspectives and how we can actively include participants in making meaning about technologies. The work comes with some limitations and an outlook into future research activities, which I will briefly discuss here before taking a step back and revisiting the contributions I detailed in Section 1.4.

10.1 Limitations of this Work

The diversity of the children is limited due to the project location being in Austria, which is a reasonably wealthy country in the centre of Europe. All of the children we worked with were white. While some of them had a second native language due to the migration background in their families, the economic background of their families was about equal, and their family members all spoke German with us as well (excluding one). Hence, my account is limited to those perspectives.

Several aspects influenced how we could engage with the children within OutsideTheBox. For example, our recruiting strategy was profoundly affected by a pre-selection of the mentors from the Stadtschulrat, which regulated the access we had to the children. Further, we had to acknowledge the rules and regulations put in place by the children's social environment (e.g., parents, teachers), which required careful negotiations between our scientific curiosity and the time resources as well as privacy needs of all participants. Hence, with some children, I had more data available than with others, and in some regards, the conclusions stemming from a case are necessarily incomplete.

Only one female participant took part in OutsideTheBox. As technology is consistently associated with a male gender which reinforces adoption and overall use [Jackson et al.,

2008], the mentors might have been more inclined to connect us with male students. The present gender split is further aggravated by the gendered diagnostic procedures for autism, which improportionally target a more male presentation of the condition [Cridland et al., 2014]. Hence, more work is needed that includes more genders.

All of the children who participated in this research were further placed in mainstream schools. While some of them had different curricula, all of them were relatively closely aligned with the expectations of an allistic society on how to perform. For example, all of them were verbal – at least to a certain degree and all of them had reasonably unobtrusive forms of stimming such as light flapping or rocking (instead of, for example, loud singing). Especially with PEACE, it would be relevant to understand how it would look with non-verbal participants.

10.2 Future Work

The present work then has so far only been used with children and adolescents, predominantly autistic, even though, I argue, there might be more general ramifications for how we as HCI researchers define and understand technological experience – especially with marginalised people. However, I am not the only one using Critical Experience (or parts of it) to this date. Washington et al. [2017] took the concept to consolidate different data sources in the context of the development and evaluation of an at-home therapeutic device performing the automatic recognition of facial expressions on a Google Glass. Schaper et al. [2018] took my understanding of Critical Discourse Analysis to analyse oral, written and drawn data sources in a participatory project in a museum. To show the feasibility of the concept in a diversity of contexts, I will analyse players' experience of idle games as a vastly different setting than these and find out more about the limitations and possibilities Critical Experience has to offer. Such a project should further indicate the viability of the concept. Similarly, it will be necessary for PEACE to be applied by others and its basis re-examined for other populations.

Further, I position the work itself in opposition to more functional approaches and argue for making space for autistic agency. However, in that it misses a point that consolidates a potential third space of technology, one in which autistic and allistic people learn about and from each other and can make choices about how they want to frame their interaction aligned with each others' needs. Some of this work will happen in the Social Play Technologies[1] project from which the group analysis in Section 7.2.3 stems. Using my work in this setting, I might be able to expand the concept for multiple participants.

Finally, in constructing the networks, it became clear that they lose historicity in later forms; temporal aspects cannot be captured in this visualisation. It can also become reasonably complex making it difficult to understand the bigger picture with an increasing number of actors. Hence, a more dynamic representation with an appropriately easy to

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use interface for researchers to populate actors quickly might help in making this aspect of my work more accessible to other researchers.

10.3 Main Takeaways

I had initially indicated three principal potential contributions to our knowledge on the experiences of autistic children with technologies. Here, I briefly revisit them to assess whether the claims hold up.

In Chapter 5, I detailed how experiences with technologies can be understood beyond empathetic approaches. With Actor-Network Theory and Critical Discourse Analysis as a basis, the framework of 'Critical Experience' systematically offers insights into multiple perspectives which are then contrasted with each other to understand more about the experiences autistic children have with technologies without claiming a complete picture analysis. The chapter also details the case studies which guided the development of the framework. Additionally, Chapter 7 discusses four case studies of the same project, but not associated with the development of the framework and briefly presents potential future work for participatory research with groups. Hence, I contributed not only to understanding more about the experiences autistic children had with the technologies developed in OutsideTheBox but also *provided a framework that informs **how** we can conceptualise experience as a matter of multiple perspectives in a discoursively challenged space consisting of different human and non-human actors.*

As applying the concept of 'Critical Experience' uncovered a methodological lack of first-person accounts from the autistic children, Chapter 6 presents Participatory Evaluation with Autistic ChildrEn (PEACE) as an approach to *co-construct meaning about technological objects together with participants in participatory design projects.* Taking the individual skills, abilities and interests of a child as a starting point, using PEACE, researchers give up their privileged position in the creation of knowledge and definition of meaning of prototypes and technologies coming from participatory design processes. In doing so, however, I showed how we could not only learn more from the children's first-person perspective, but also in failing to find appropriate modes of interaction ended up with meaningful interpretations when the refusal to participate was contextualised in the overall evaluation using 'Critical Experience'.

While I attempted to *rigorously create the space for autistic children to have the freedom to express their voice and opinion throughout the evaluation within OutsideTheBox and would argue, that this attempt was successful,* ultimately, time will tell whether autistic people and the research community engage with my proposed method and analysis framework. The meta-contribution of dedicating space in research for the perspectives of marginalised people who have different experiences when interacting with technologies, can at this point only be theorised. Whether future research will pick up on the notion and whether autistic people endorse such approaches remains to be seen. However, I contributed to establishing the foundations to go in these directions in the future.

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Appendix A: OutsideTheBox Ethics Guidelines

Introduction

OutsideTheBox (OtB) aims to invite children with autism spectrum conditions (ASC) to co-design ubiquitous computing artefacts. The project will implement 6 different participatory design approaches over three years (2 in parallel each y ear) to demonstrate how this target group can be meaningfully included in the design of technology. By implementing these case studies we aim to substantiate a bigger argument about a necessary paradigm shift in the design of assistive technologies, away from designing for functional deficits towards a holistic design for experience, wellbeing and empowerment.

Thus, the design brief is deliberately kept open to enable the researchers and the children to explore new roles of technology that are meaningful in their lives rather than focusing on a specific intervention target or feature of the disability. The technologies we develop have to fulfil two basic requirements:

1. applications afford meaningful and positive experiences within the life-worlds of children with ASC and

2. they support children in sharing these experiences with their social environment.

Workplan

The work is organised in three, identical cycles, each lasting one year. Within each year, we will implement two different participatory design approaches, each with two to four children, i.e., we aim to involve four to eight children each year. Cycles start in July to allow for preparation work and initial recruitment to be done over the summer break. Actual recruitment of participants and contextual research will commence at the start of the school year in September with design work starting when appropriate relationships have been fostered. For contextual research we will arrange meetings with parents, carers, teachers and the children for informal interviews and conduct observations in schools and use alternative methods such as probes and diaries to augment the data we collect.

We aim to meet children in intervals of two weeks for design work over a period of five months (depending on holidays, roughly 10 - 20 sessions). Each session will take place in the school, in a separate room with one child or a small group of children, a professional carer (mentor or teacher) and the researchers present. Sessions will last between up to one hour depending on the routine and attention spans of children. We will prepare appropriate materials and activities for each session which interpret one of the chosen participatory design approaches. Since we develop these activities as part of this research, it is impossible to provide details at this point in time. However, we will implement a rolling ethics monitoring mechanism (see below) that ensures that each planned activity is considered from an ethics perspective and is compatible with the overall research ethics we outline in this document and poses no risks to the participants.

In some cases, we will try to arrange excursions with children, for example to visit a FabLab or the University. All excursions will be planned carefully in accordance with the children and the parents and at least one professional carer or one parent will accompany the group at all times.

In the evaluation phase, the interval of meetings will be increased to every two to four weeks. At these meetings we will conduct observational studies and interviews, and collect data from the artefacts. In between we will ask parents, carers, teachers and children to keep diaries or make notes of observations. We aim to minimise the work load by supporting each group with appropriate tools to collect such data.

By the end of the cycle, children and parents will be invited to participate in a small exhibition, however, taking part is voluntary. The goal of the exhibition is to showcase the resulting artefacts and tell the stories how they were created. We thereby hope to engage the general public and contribute to a wide social discourse about the relationships between technology, disabilities and society at large.

The exhibition will also mark the end of the formal working relationship with our participants. Since this will coincide with the end of term we anticipate that this will be perceived as a natural ending point for our participants. As a token of gratitude, all artefacts will remain with the children after our collaboration ends. Time permitting, the research team will maintain these artefacts, if necessary, while the project is running, but we cannot guarantee any support afterwards.

Participants

Our target group are children with ASD between six to eight years of age (i.e., primary school entry level). Two considerations have led to this decision:

1. Children should be able to participate in the likely workshop activities and thus have basic skills such as drawing, constructing with building blocks, imaginative play etc., depending on the PD approach.

2. Children should have an official diagnosis, but they should be as young as possible to be minimally primed by the existing technology landscape.

Autism is incredibly diverse and often additional disabilities or behavioural problems are present. The decision to involve a child in the project will be made on a case by case basis, carefully judging whether the child would be able to meaningfully participate in the planned activities. A decision will be made in collaboration with the parents, teachers and mentors who know the child well.

In the project, the social peers of the child are recognised as important stakeholders in the process and are therefore considered participants too. This includes parents, teachers, mentors or close friends and other carers. The scope of the relevant group around each child will be determined as part of the initial contextual inquiry.

Recruitment

Participants are recruited through three main paths:

- Through the "Integrationsberatungsstelle des Stadtschulrates für Wien" which is the central service provider in the regional education system for all children with special needs who attend school (special or mainstream). The service has agreed to facilitating access to schools, mentors and parents of suitable candidates who we can approach with information material and an invitation to participate.

- The "Institut Keil" is a special education unit with many children with more severe levels of ASC. It provides day care as well as primary and secondary schooling.

- We will use previously established contacts to recruit participants. This mean, if we made contacts with carers parents or other organisations such as the "Autistenhilfe", we will ask them about other children they might know would have fun with the project. This also helps us streamline processes.

The recruitment process in each project cycle will be as follows:

1. Definition of a minimum skill set that is required for children to be involved in the planned activities.

2. Based on this skill set, the Integrationsberatungsstelle and its mentors will compile a list of potential list of suitable participants.

3. The project team establishes contact with the schools, mentors and parents of this list, sending out an invitation letter and tailored information material for each group.

4. We arrange a meeting with parents, teachers and the child, individually or combined, to provide further information and to get to know each other in person.

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5. We ensure all information has been provided to enable parents to make an informed decision about participating in the project (informed consent, see below).

6. Start of contextual research.

Consent

Informed consent to take part is central to the ethical procedure we implement in the project and we will ask all participants, including children, parents, mentors, teachers and others, to formally agree to being involved. This will mostly happen in written form, but can if needed also be done orally. Sample consent forms share the following qualities:

- Forms are written in accessible, age-appropriate language and provide unambiguous ways for participants to agree or disagree with aspects of their involvement.

- Participants are fully informed about the purpose and the goals of the project as well as their intended role in it.

- The forms provide information about what participants can expect from taking part, both in terms of likely activities, required investment of time as well as potential outcomes and ownerships.

- Participants are free to terminate their involvement at any time and without providing any reason. In situations where the feedback towards activities is ambiguous, we will carefully determine whether it is in the interest of the child to continue the process.

- Participants are encouraged to ask any questions as they arise.

- Specific attention is paid to the legal implications of collecting data from the work such as personal information, pictures or video. Participants can choose between different levels of anonymity in the publication of their data (see below).

Collaboration will only commence if all participants have provided consent.

Risks and benefits to stakeholders

Children

The physical, psychological and emotional wellbeing and safety of the children involved is centrally important to us. If any of the researchers or participants observes any signs of the work having negative impacts on the children, or any other involved stakeholders the collaboration will be immediately paused and only continued once all participants have agreed that it is safe to do so (see conflict resolution below).

We are aware of the following **potential risks** to the children and will act to minimise the risk of their occurrence (potential counter strategies in parenthesis).

- Anxiety and stress during workshop sessions (flexibly adapting tasks during the workshop, taking breaks, aborting the session, seeking the help of professional carers).

- Behaviour meltdowns including actions intended to cause physical harm or self-harm (being vigilant for early signs and immediately seeking the help of the professional care team)

- Injuries during workshop activities (materials for activities have to be chosen to minimise the risk of any injury, the use of materials will be discussed with teachers and mentors considering each particular child. e.g., regarding DIY materials like glue, scissors etc., activities must be designed to ensure physical safety)

There are also various **potential benefits** to participants that the project aims to realise:

- Enjoyable and novel activities for children during the design process.

- Empowerment of children and other stakeholders by demonstrating how they can take charge of the design of technology they interact with in their lives.

- Scaffolding a novel interaction channel between the child and her social peers that potentially leads to positive behaviour change.

Parents

Potential risks to parents include:

- Parents might have unwarranted expectations about the benefits of the projects for their child (the information for parents will state expected benefits, but also be very clear that this project is not a intervention, and as such does not promise any cognitive or behavioural improvements or gains).

- Additional time effort might be required by parents due to the direct involvement in the research as well as by the involvement of their children (the project team aims to minimise these disruptions and will work with the parents to ensure they are not overcommitted).

The work has the following **potential benefits** for parents:

- Novel and shared activities with the child

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Teachers and mentors

Teachers and mentors play a key role in the collaboration we aim to establish. **Potential risks** to them include:

- Additional time effort (the project team seeks to minimise disruptions in schools and is sensitive to the work load of teachers and mentors)

- Mismatch between activities in the project and the curriculum in class (the team tries to design activities considering the current curriculum and thereby work in accordance to educational goals)

The work has the following **potential benefits** for teachers and mentors:

- Novel activities to engage the child and supporting mentors and teachers in their daily work.

Researchers

The project recognises the roles of researchers involved as stakeholders in the work and is committed to provide an equally safe and enjoyable working process for them. Below, we have identified potential risks and possible counter- strategies:

- Emotional and psychological stress. Working with children with disabilities can be strenuous and may effect researchers on an emotional and psychological level. (researchers are encouraged to seek advice from the academic peer group at the institute, particular from Prof Geraldine Fitzpatrick who acts as a mentor and advisor for the project. Psychological support structures are also in place at TU Wien which the researchers can contact).

- Pressures related to academic work (as with potential emotional stress r elated to working witch children with disabilities we encourage team members to make use of psychological support if needed. Additionally, we aim to find an external mentor for each team member who can advice regarding academic work, e.g., secondary PhD supervisor, career coach)

- Injuries during workshop activities (as for children, we aim to design activities with health and safety for all participants in mind)

It is the hope that researchers also benefit from their involvement on different levels, ranging from conducting enjoyable workshop activities to the academic achievements and rewards.

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Data Collection & Protection

During the work we will collect data in the form of personal information, photos, videos, drawings and/or artefacts. For example, we will describe habits, video tape workshops, photograph artefacts built during the workshops, audio record interviews, keep research diaries detailing our experiences or collect drawings made by children (or parents). Most raw data will be digitised and stored electronically on the project server. Access to the raw data is restricted to the members of the project and appropriate measures are taken to protect the data on the server and the backup (encryption, access control).

We will ask participants as part of seeking their consent whether they are comfortable with us collecting data in this form and under which circumstances they would prefer us to not collect any data. We will also stress that participants can always ask for us to stop recording or delete any previous recording without providing any reason.

In the project, the raw data will be analysed and processed as part of our research. We will provide participants with a range of options regarding the potential use of this processed data. The levels of use are:

1. Data can be used in scientific publications if fully anonymised (all personal data removed)

2. Video and pictures can be used in scientific publications if faces and other significant personal features are distorted.

3. Video and pictures can be used in scientific publications unaltered if no other personal information is provided.

4. Data can be used in clear and for any kind of publication (e.g., webpage, news papers) after seeking consent from the parents for each individual case.

The use of data that allows the identification of children is strictly an exception and will generally be minimised, even when consent has been given. Unintentional consequences like stigmatisation in peer groups can never be fully avoided and parents might not always be aware of such implications. The project team has a general responsibility to make judgements in the best interest of the child.

Rolling Ethics Monitoring

The nature of our work requires us to remain open for change and flexible with regards of developing our methods. Consequently, the way we interact with participants and involve them in our research might change. We therefore need a mechanism to continuously assess our research ethics. To this end, we introduce the following rolling ethics monitoring into our research process:

1. Before each coherent series of workshops with participants, the project team will hold a designated meeting to assess the ethical implications of the specific activities that are planned. The assessment will be guided by a check list developed from this document and the recommendations of the ESRC Research Ethics Framework.

2. After each cycle, there will be an annual, comprehensive research ethics review on the basis of the experiences made in the work. The project team will adapt its ethics procedures accordingly and will document any change in subsequent version of this document. If any substantial changes are planned, the project team will call on a panel of experts within the Institute to collect feedback.

Conflict Resolution

In case of any conflicts arising during the work, we have two mechanism to resolve them:

1. If any conflicts involve the work with children, we will pause the collaboration immediately and call a meeting with all participants around this child (parents, teachers, mentors, carers) or the group of children. If no resolution can be found that is supported by all, the collaboration will be ended. Naturally, the parents of the children always have the last word in determining the kind of collaboration they want them and their child to be involved in.

2. If conflicts arise within the research team, we seek the advice from our academic peer group at the institute, particularly from Prof. Geraldine Fitzpatrick who has agreed to act as an advisor and mentor for the project and its members. Any member of the team is encourage to contact her directly if they do not want to voice the issue within the group or if the issue is confidential.

Appendix B: All Actor-Networks

OutsideTheBox

Year 1

Andy
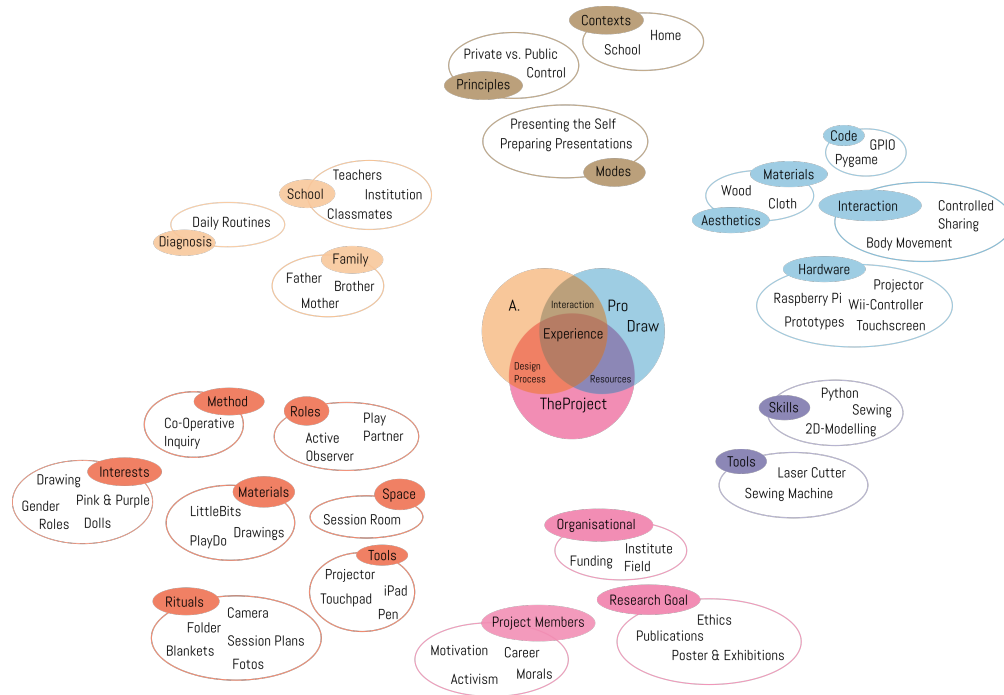
Figure 1: Actor-Network for Andy

Blaine
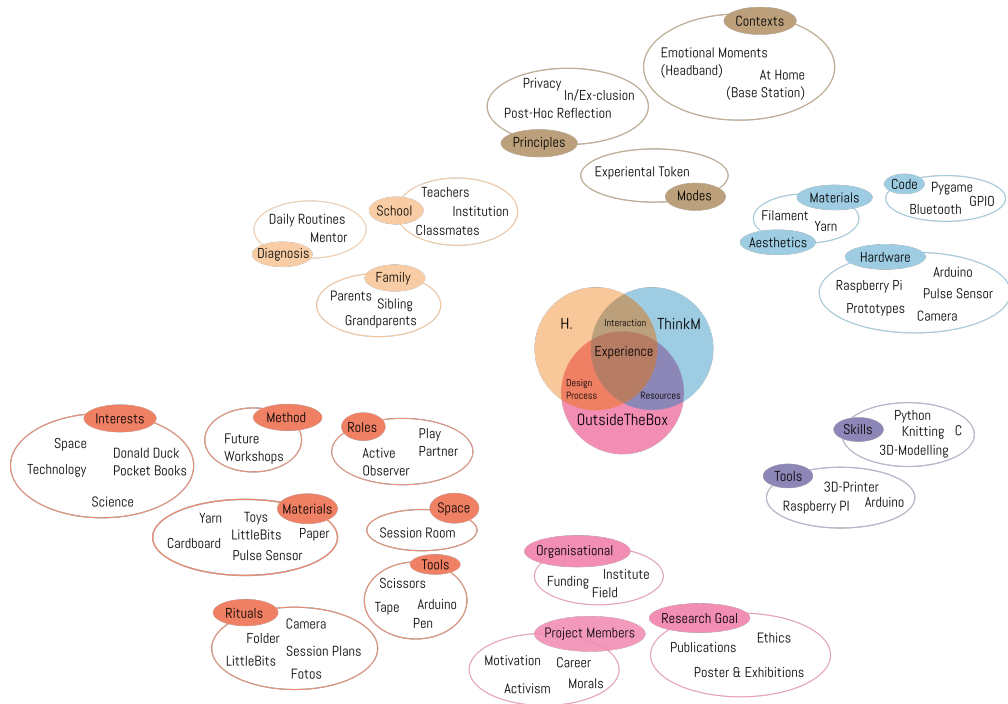
Figure 2: Actor-Network for Blaine

Claude
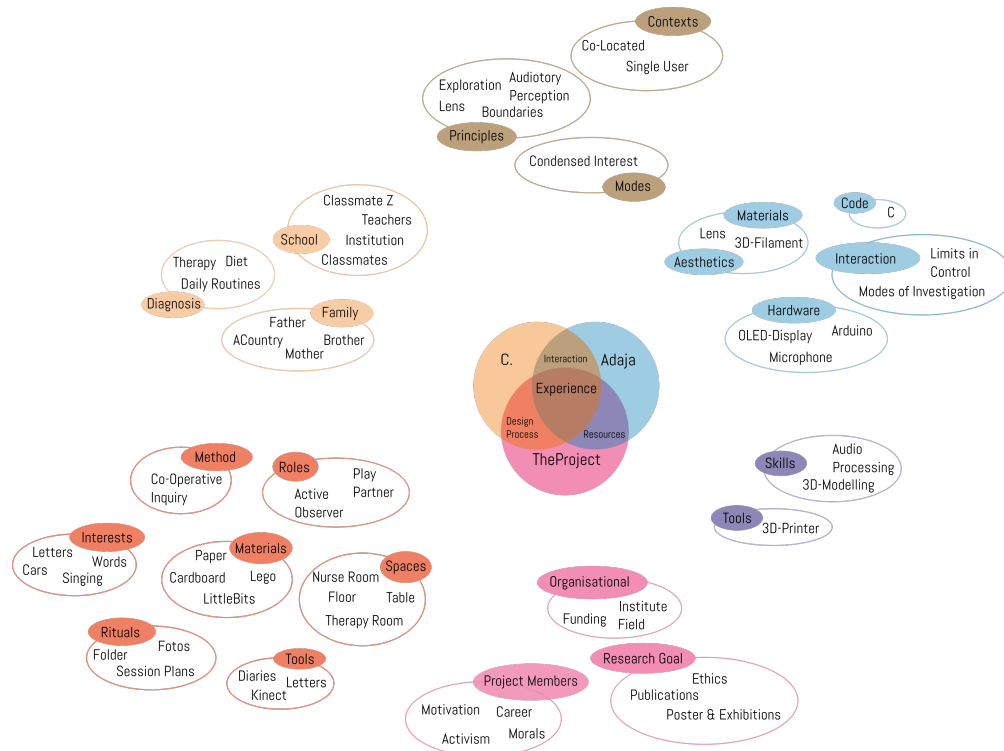
Figure 3: Actor-Network for Claude

Dean
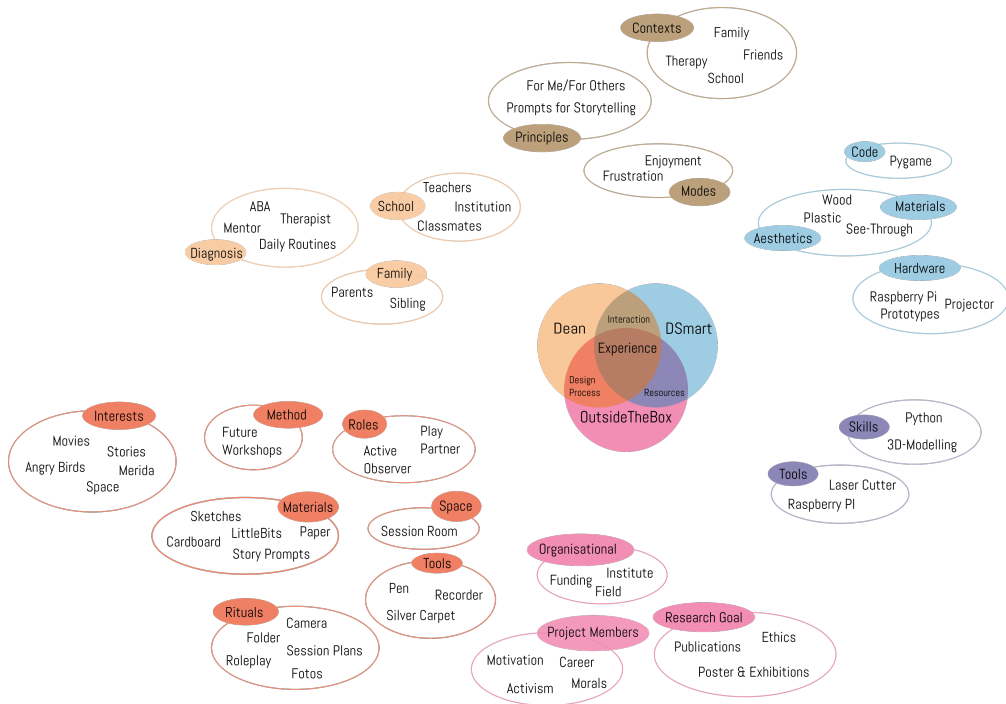
Figure 4: Actor-Network for Dean

Year 2

Quentin
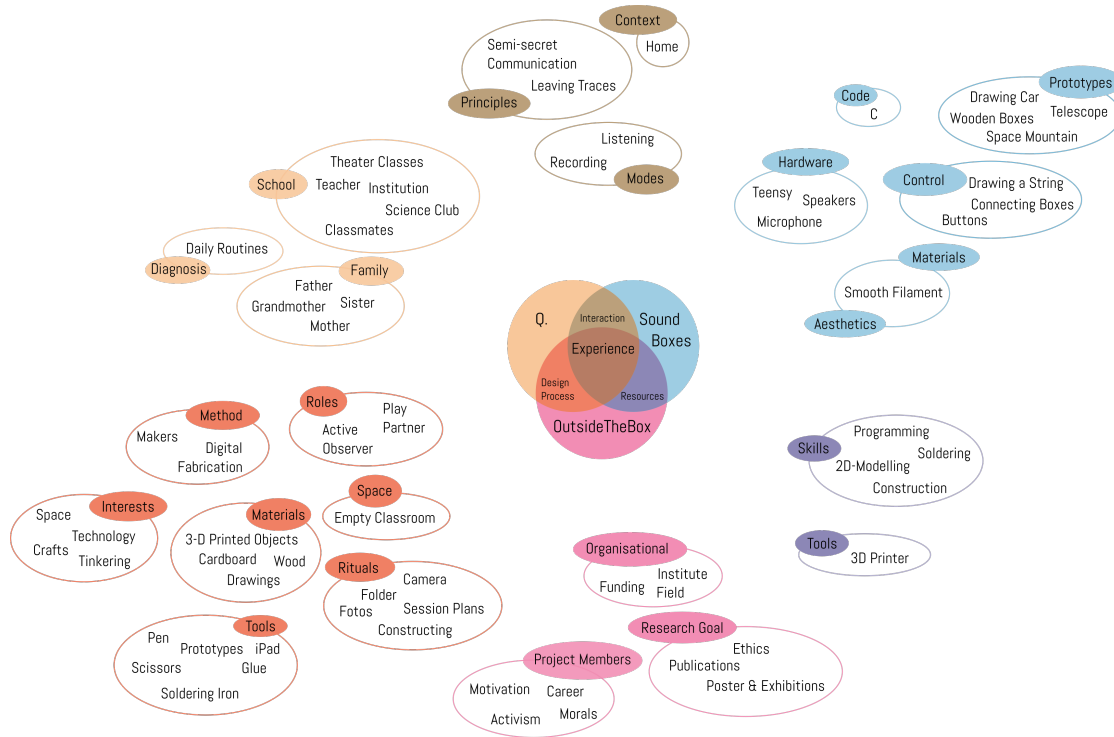
Figure 5: Actor-Network for Quentin's Context

Mia
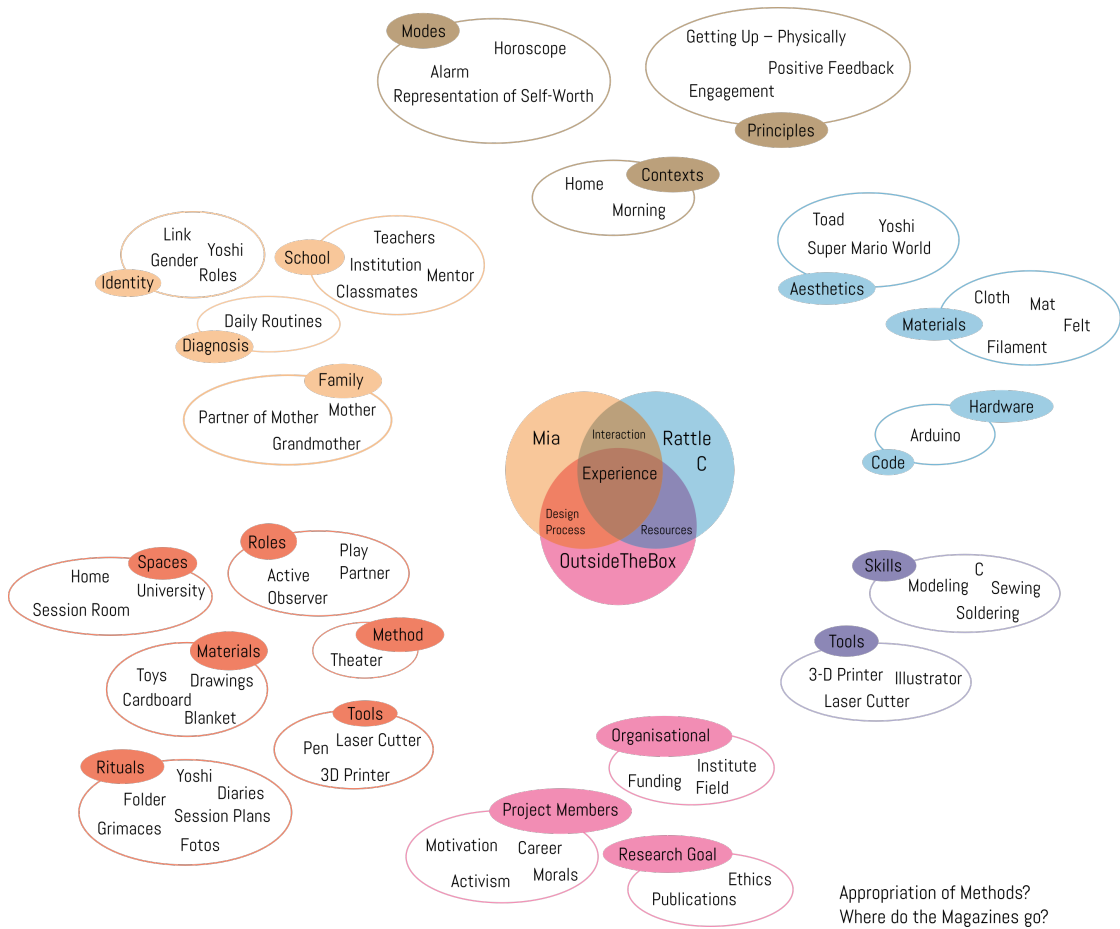
Figure 6: Actor-Network for Mia's Context

Yvan
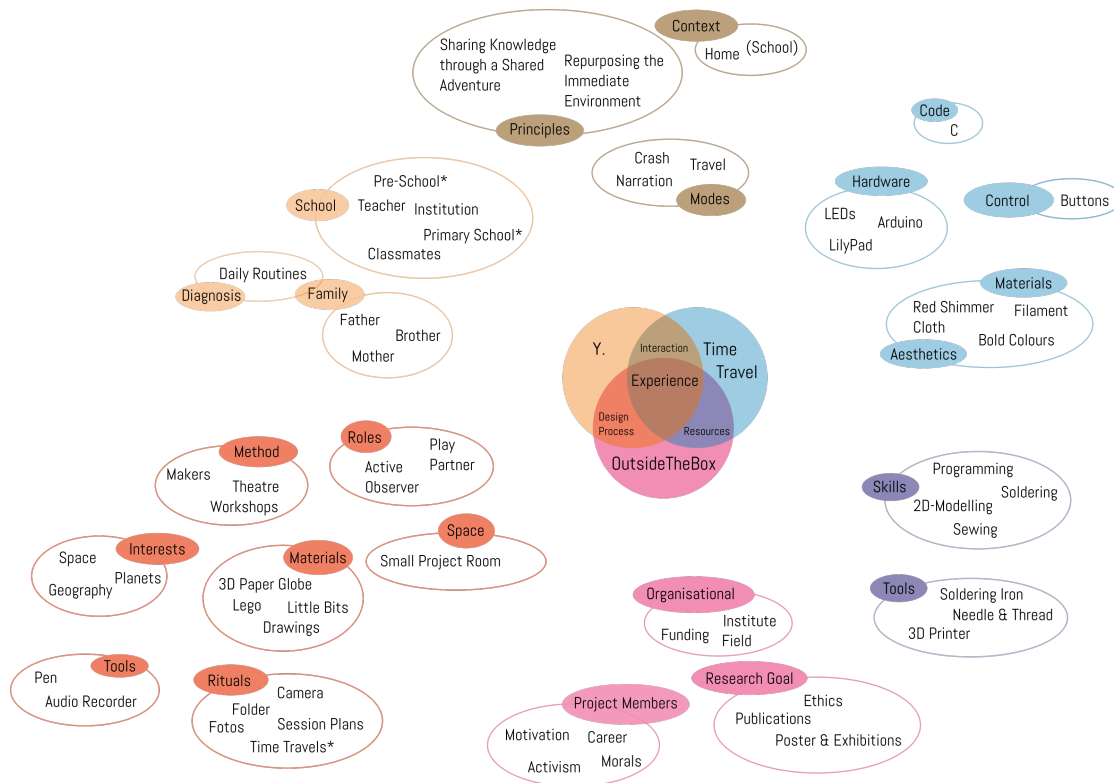
Figure 7: Actor-Network for Yvan's Context

Yvan & Hank
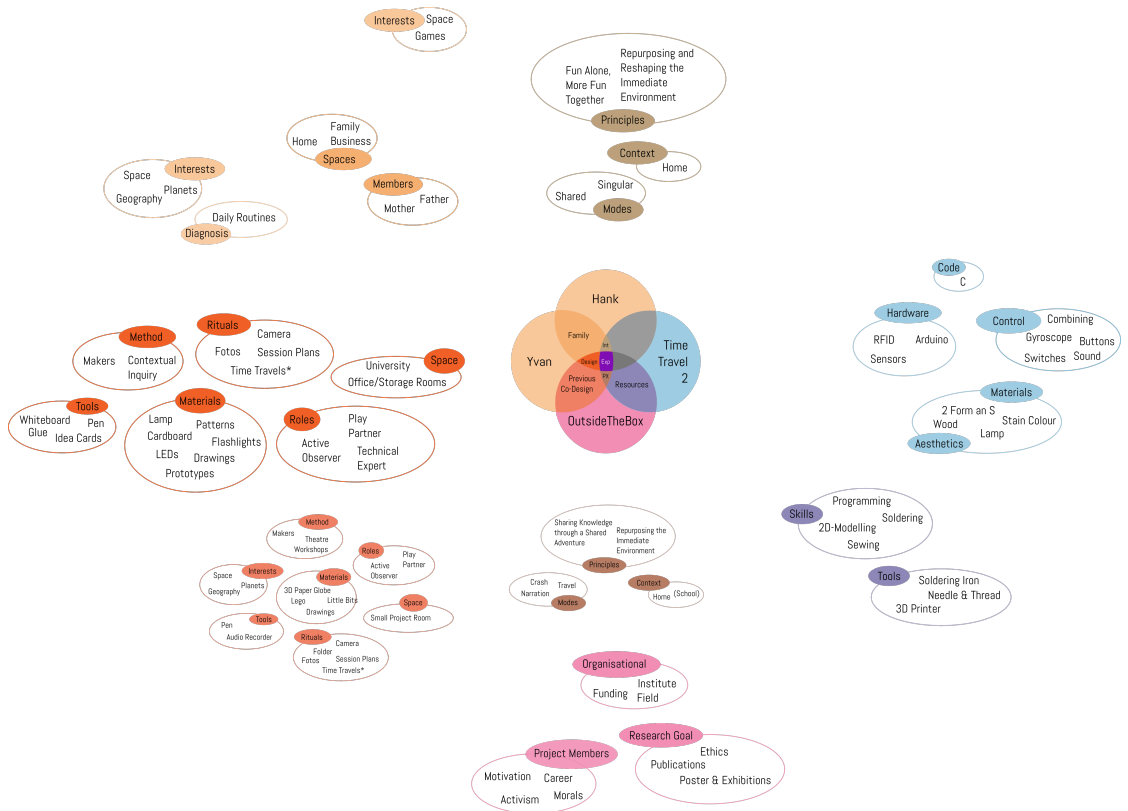
Figure 8: Actor-Network for the Context of Yvan & Hank

Oliver
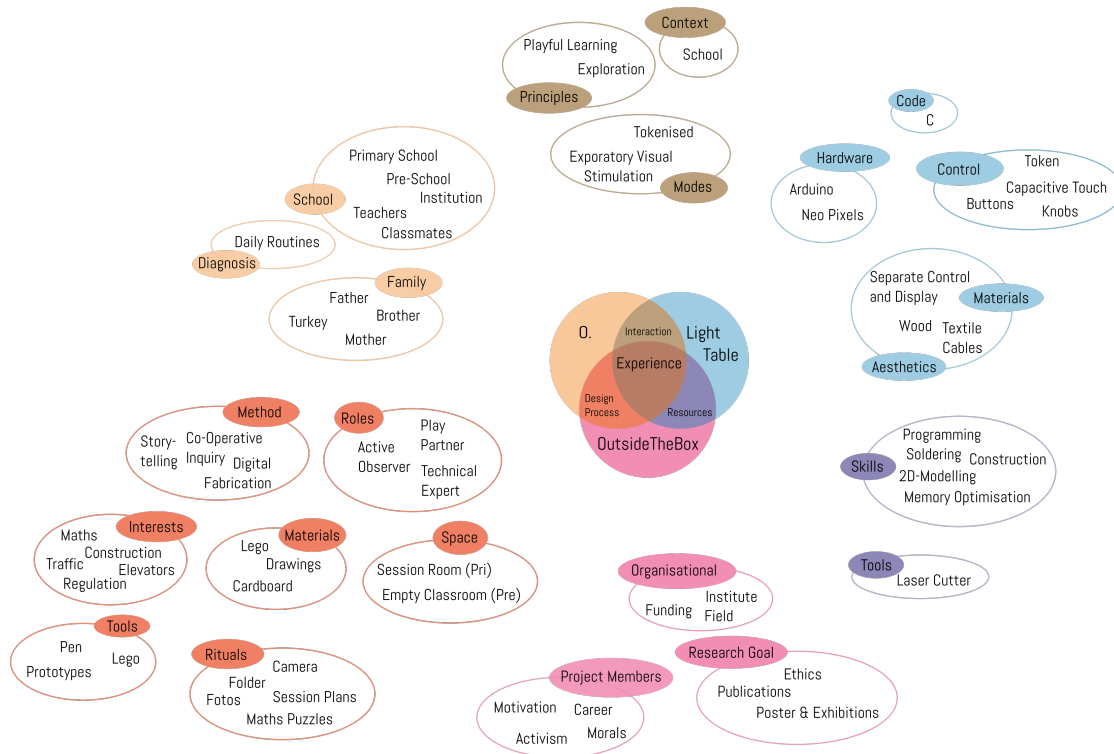
Figure 9: Actor-Network for Oliver's Context

Stable Actors
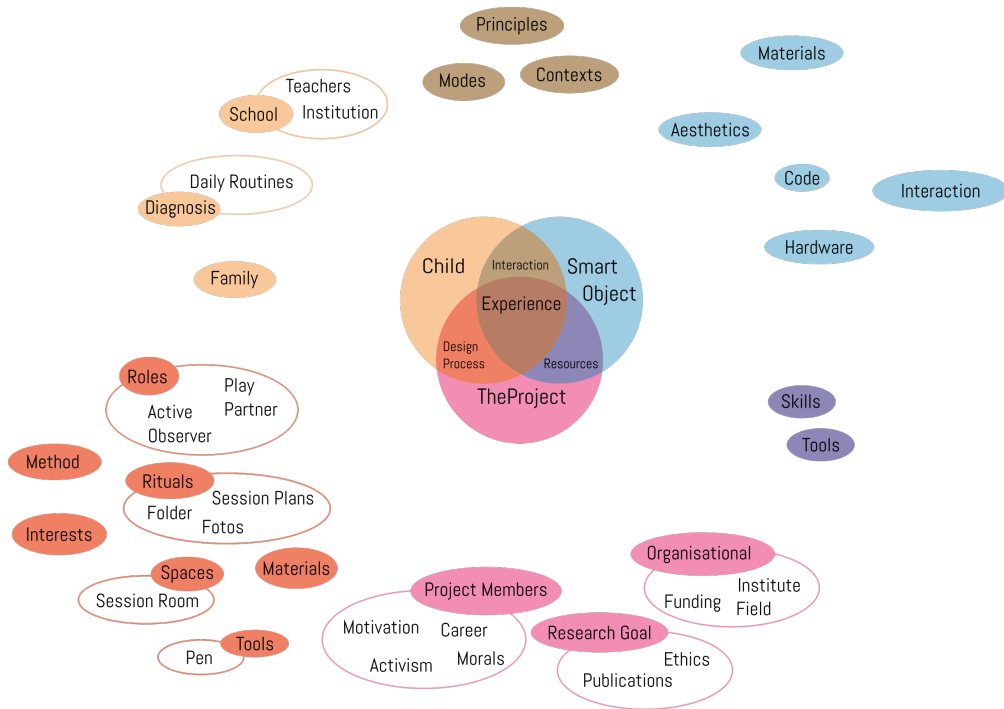
Figure 10: Actor-Network of Stable Actors

Other Networks

General Starting Point
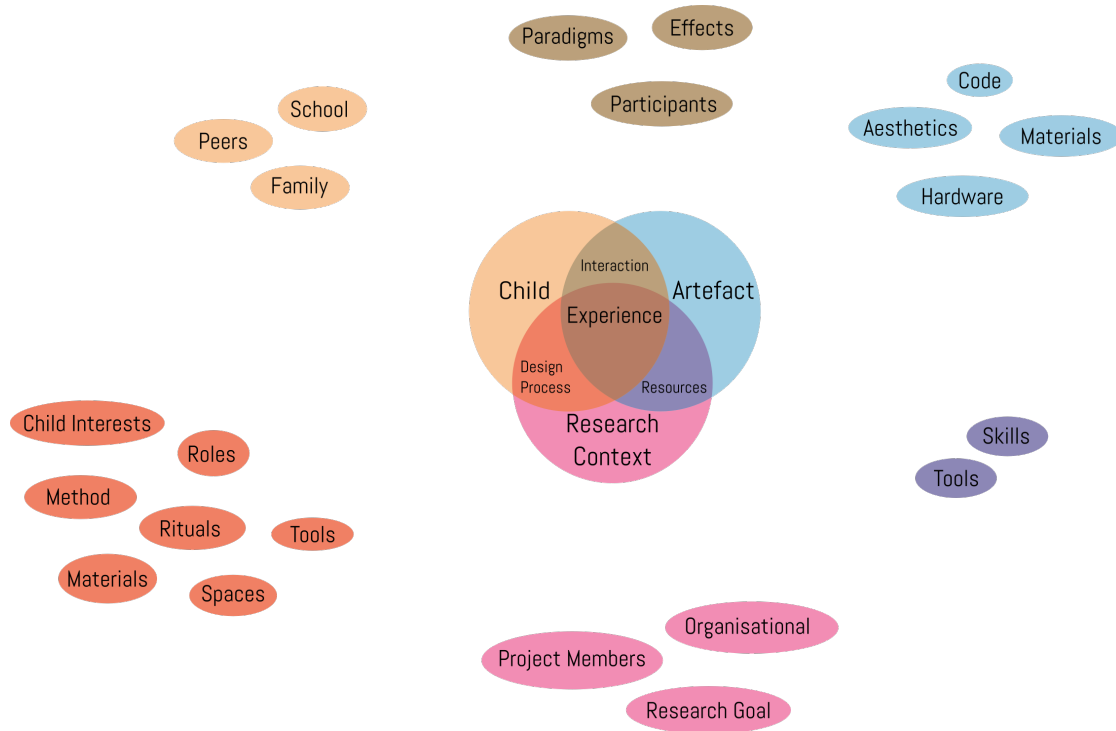
Figure 11: Schematic for Actor-Networks Describing Experiences of Children in PD Projects

Figure 12: Actor Network for Gus' interaction with Siri

Group Setting

Figure 13: Actor-Network for a Group Context

Appendix C: Initial Coding for Literature Review

The following pages illustrate the results from the initial coding process for the literature analysis in Section 2.3.

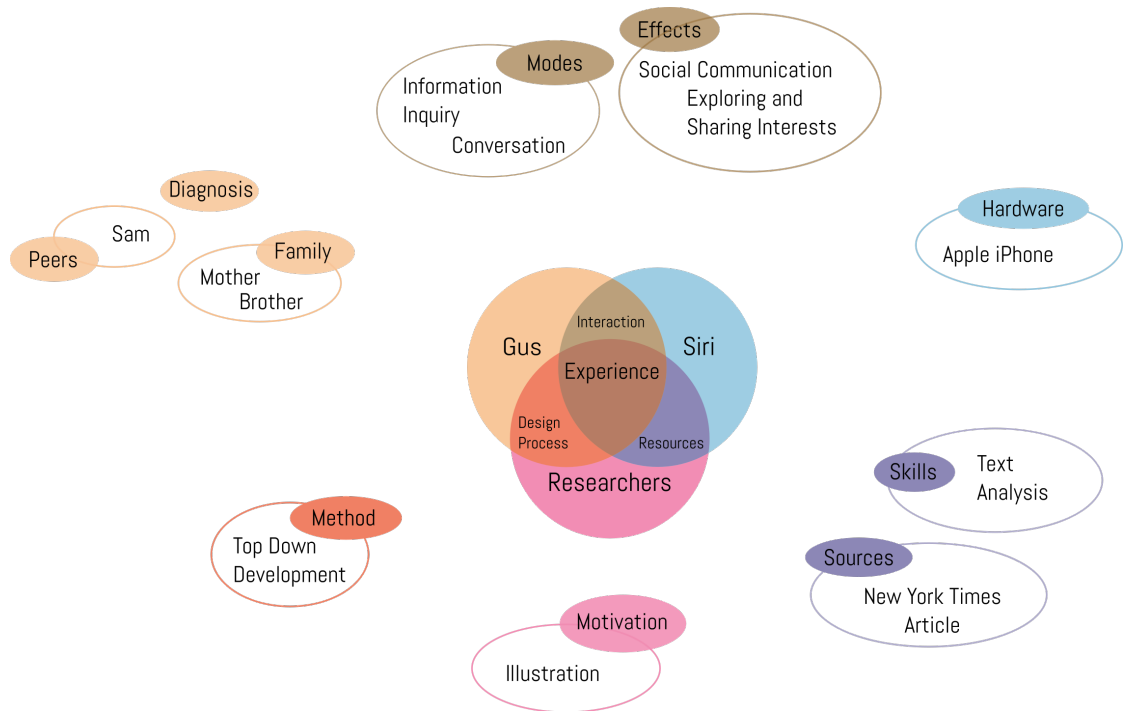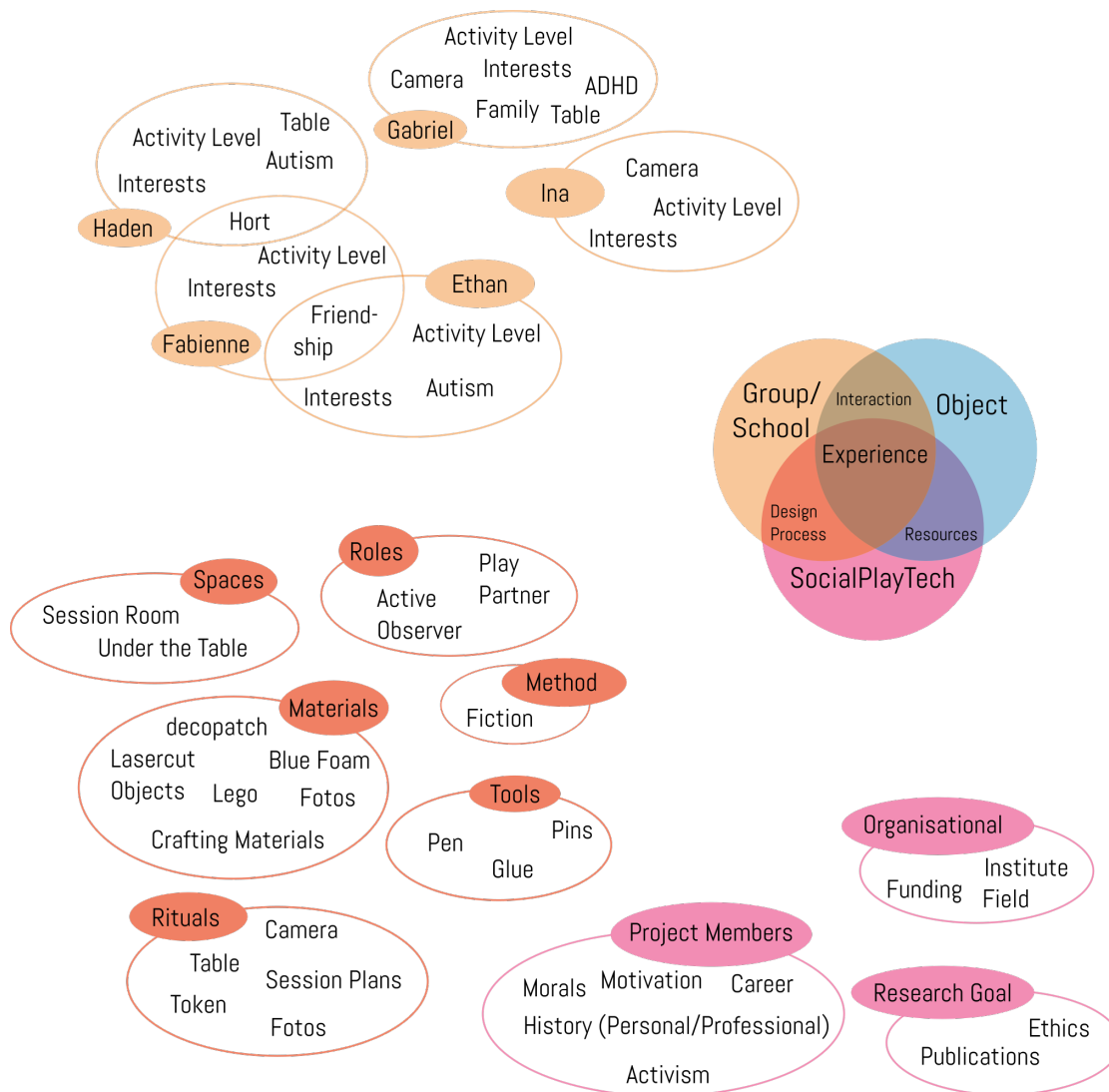| Paper	Type of Technology	Class of Technology	Purpose	Audience	Participants	Design Process	Evaluation		Project
Abaris: Evaluating Automated Capture Applied to Structured Autism Interventions	automated capture	Automated Video Analysis	monitoring + therapeutic review (DTT)	therapists working with children	one parent, three therapists, one lead therapist, a consultant around a 7 year-old -- informants	not described; probably top down	deployment around the child; only therapists/adults contributions; observations	observations, interviews with adults	Abaris
Accessible Education for Autistic Children: ABA-Based Didactic Software	eLearning tool, computer based	E-Learning	education + monitoring + therapeutic review	autistic children & their ABA therapists	therapists, parents -- informants	not described; probably top down	not described	not described	ABCD SW
Accessing Peer Social Interaction: Using Authorable Virtual Peer Technology as a Component of a Group Social Skills Intervention Program	authorable virtual peer; computer based	Computer Based Programm	social skill expansion	children	children as testers (no age given)	not described; probably top down	quantitative analysis of task performance and questionnaires	task performance, questionnaires	AVP
Achieving Dialogue with Children with Severe Autism in an Adaptive Multisensory Interaction: The "MEDIATE" Project	multi-sensory interactive environment	Interactive Environment	well-being/enjoyment, fun/relaxation	children	high-functioning children as proxy informers (no age given)	not described; informant design indicated	120 session with 90 children -- observations and interview with parents (no age range given)	observations, interviews with adults	MEDIATE
A Communication System on Smart Phones and Tablets for Non-verbal Children with Autism	smartphone based communication	Mobile Applications	learning to communicate	mainly the children, configurable by carers	autistic children (around eight years old)	PD with one eight year old boy and one parent; highly dominated by the parent	24 autistic children + teachters; measured learning rates and correlated them with their behavior traits	task performance	AutVisComm
A computational simulation tool for training autistic reasoning about mental attitudes	computer based mental model simulation	Computer Based Programm	rehabilitation	children	12 children between 6 and 10 years old	apparently top down	quantitative analysis; knowledge acquisition	task performance	NL_MAMS
A Computerized System for Neurologic Music Therapy	web based system	Web Based	therapy	children during therapy	none	apparently top down	none described	not described	no specific one
Acquisition of Social Abilities Through Musical Tangible User Interface: Children with Autism Spectrum Condition and the Reactable	tangible/reactable	Tangible	social interaction acquisition	children	nine children (5-11) as testers	top down	checking for increase in social interacction	change in social interaction	Reactable & Autism
Activity Analysis and Detection of Repetitive Motion in Autistic Patients	wearable	Wearable	detection of repetitive movements	children, passively; medical personal & therapists	none	top down	none described	not described	no specific one
Adapting a robotics program to enhance participation and interest in STEM among children with disabilities: a pilot study	LEGO robot	Robot	engage youth's interest in STEM	children and carers together	18 youth (aged 6–13), 12 parents and 11key informants	top down	mixed methods pilot study; did the interest increase, did the children enjoy?, questionnaire, interview, only one direct quote, otherwise mostly parents	questionnaire, interviews	FIRST
Adaptive Body Gesture Representation for Automatic Emotion Recognition	motion capture with kinect	Automated Video Analysis	emotion recognition; learning and recognising emotions	children	none	top down	not described	not described	ASC-Inclusion
Adaptive robot design with hand and face tracking for use in autism therapy	interactive games with a hand and face tracking robot	Robot	therapy	children	typically developing children (4-11)	top down	proof of concept test	proof of concept	CHARLIE
A Digital Storytelling Approach for Fostering Empathy Towards Autistic Children. Lessons learned	Digital story (computer based)	Computer Based Programm	empathy in a mixed population classroom	kindergarten children	12 children (4/5), two with ASD	top down	participatory observation; interest in feelings of joy, sadness, anger and fear	observations	no specific one
A low-cost socially assistive robot and robot-assisted intervention for children with autism spectrum disorder: field trials and lessons learned	toy-like robot prototype	Robot	robot-assisted intervention	children	8 nt, 3 asc	top down	clinical questionnaires; efficacy of robot and intervention	questionnaires, efficacy	CHARLIE
A microcomputer system used for evaluative and experimental behavioural research in mental handicap	computer based application	Computer Based Programm	ABA Data collection	ABA therapists	none	top down	none described	not described	PCS?
A mixed-method evaluation of the feasibility and acceptability of a telehealth-based parent-mediated intervention for children with autism spectrum disorder	Internet-based, parent training intervention for autism spectrum disorder	Web Based	parent training intervention	parents	28 parents (+ kids, passively)	top down	improvement in child's social skills and parent competence; mixed methods	change in social interaction	ImPACT Online
A Multimedia Social Story Intervention: Teaching Skills to Children with Autism	social stories in a computer based format	Computer Based Programm	learning social behaviours and interactions	children	three boys with autism (7-9)	top down	observation; interviews with professionals	observations, interviews with adults	no specific one
A Multimodal and Multilevel System for Robotics Treatment of Autism in Children	humanoid social robot-assisted behavioral system	Robot	therapy, improving eye contact, joint attention, symbolic play and basic emotion recognition	children	3 hfs children (8-13)	top down	statistical differences/ 'improvements'	change in social interaction	Nao Robot
An Alternative Design Perspective for Technology Supporting Youngsters with Autism	paper prototyping	Paper	including children in design activities	children	3 4-year old children + 2 therapists	participatory	none described	not described	CAPES
An Analytic Tool for Assessing Learning in Children with Autism	web application for data aggregation and visualisation	Web Based	reflection on therapy sessions	ABA therapists	none	top down	none described	not described	ABCD SW
An application of interactive game for facial expression of the autisms	interactive game	Game	game-based learning approach to improve the ASD children's ability to express facial emotion and communicate with others in social activities	children	college students & graduate students as well as researchers	top down	qualitative expert evaluation; expert heuristic	expert heuristic	FaceFlower
An Effective Neurofeedback Intervention to Improve Social Interactions in Children with Autism Spectrum Disorder	social mirroring game with neurofeedback	Game	improve behaviour, cognition and emotion regulation	children	13 children with ASD (6-17)	top down	testing of paradigms	proof of concept	no specific one
An inclusive design approach for developing video games for children with Autism Spectrum Disorder	Kinect-based video game	Game	elicitation of social initiation behaviours	children	10 children with ASC (between 4-6)	PD with experts and children	field observations & video analysis; acceptance of the children, behaviours	observations	Pico's Adventures
An IoT-based System for Supporting Children with Autism Spectrum Disorder	Internet of Things (IoT) and P2P technology	Ubiquitous Computing	supporting learning and improving the quality of life	children	one child — maybe?	top down	effect of the system on children's skills	learning outcomes	SmartBox
A Nonintrusive System for Behavioral Analysis of Children using Multiple RGB+Depth Sensors	rgb+depth (rgb+d) sensors	Wearable	monitor and reconstruct the play and interactions of preschoolers.	preschoolers (passively), analysis by therapists, medical experts and so on	none	top down	experimental results of trying out the system (two boys running through the classroom)	proof of concept	no specific one
A Participatory Approach for Game Design to Support the Learning and Communication of Autistic Children	games	Game	learning and communication support	children	6 children (3-10), parents & therapists	PD with therapists	usability and accessibility tests (videos and such)	observations	no specific one
A Platform for Creating Adaptive Communicators	augmentative and alternative com- municator which runs on a Pocket PC	Mobille PECS	communication assistance	children (age unspecified)	none	top down	none described	not described	Sc@ut
A Portable Audio/Video Recorder for Longitudinal Study of Child Development	portable version of the embed- ded audio/video recording technology	Mobile Applications	Recording child behavior daily	families, diagnostic medicinal personel, therapists	four households with 2 year olds, one with ASC	top down	exploratory proof of concept	proof of concept	Speechome
A robot-assisted behavioral intervention system for children with autism spectrum disorders	robot	Robot	assisting in intervention	children and therapists during therapy	eight children (3-5)	top down	performance evaluation; system effectiveness	effectiveness	no specific one
A single case design evaluation of a software and tutor intervention addressing emotion recognition and social interaction in four boys with ASD	computer software (Mind Reading:The Interactive Guide to Emotions)	Computer Based Programm	Learning to recognise emotions	children	4 boys with ASC (7-11)	top down	improved ER scores and social interaction	change in social interaction	Mind Reading
A Smart Environment and Heuristic Diagnostic Teaching Principle-based System for Supporting Children with Autism During Learning	Internet of Things (IoT), P2P tech- nology	Ubiquitous Computing	identifying learning abilities in mathematics and creative traits	children (passively), teachers, parents, therapists in data analysis	none	top down	planned	planned	SmartBox
A Smart-Phone Application and a Companion Website for the Improvement of the Communication Skills of Children with Autism: Clinical Rationale, Technical Development and Preliminary Results	Smart-Phone Application and a Companion Website (PECS based) for windows mobile	Mobile PECS	Improvement of the Communication Skills	children	three children (no age given)	UCD with proxy users (teachers)	usage and communication happening	observations	PixTalk
A Smart Tutoring Aid For The Autistic	Smart e-Learning environments	E-Learning	learning	children	three children (8-9)	top down	usage possible (self guidance)	observations	Smart Tutor
Assistive technology application for enhancing social and language skills of young children with autism	mobile application and objects identifiers	Mobile Applications	learning language and social skills	children (guided by parents)	two children (3.5/4.5)	top down	number of words learned; comparing smart watch and smart phone; enjoyment reported through parents	learning outcomes, interviews with adults	Let's Play
Assisting Speech Therapy for Autism Spectrum Disorders with an Augmented Reality Application	Augmented Reality	Augmented REality	communication intervention	children	four boys (6-10)	top down	qualitative study (observation), suitability of software use, behaviours extibited	observation	no specific one
Assistive Technology for Children with Autism - Lessons for Interaction Design	AutVisComm, an assistive communication system developed on ubiquitous tablets, and Autinect, a set of activities to teach social skills to children with autism that use Microsoft Kinect as a controller	Mobile PECS	learning to communicate	children	three boys, one girl (around 8 years)	participatory design with proxies (teachers & parents)	usability study	usability study	AutVisComm and Autinect
A SUNNY DAY: Ann and Ron's World an iPad Application for Children with Autism	iPad Application	Mobile Applications	therapeutic aid, presenting structured tasks	children (passively), therapists structure it	doctors, teachers, and parents	top down	with doctors, teachers, and parents (system improvements)	proof of concept	A SUNNY DAY
A trial of an iPadTM intervention targeting social communication skills in children with autism	iPad APP	Mobile Applications	social communication skills	children	54 children (under 6)	top down	impact on real-world social communication skills	learning outcomes	no specific one
Attention Analysis in Interactive Software for Children with Autism	computer software	Computer Based Programm	attention analysis	children	none	top down	planned	planned	AutiSTIC
Audio-augmented paper for therapy and educational intervention for children with autistic spectrum disorder	audio-augmented paper	Paper	therapy and educational intervention	children during therapy	four children (male, 8-12)	UCD with children and therapists	pilot study, observation of usage	observations	COSPATIAL
A Usability Study on Natural Interaction Devices with ASD Children	Microsoft Kinect	Kinect	social skills	children	four children (male, 8-13))	top down	usability study	usability study	Autinect
A User Trial Study to Understand Play Behaviors of Autistic Children Using a Social Robot	social robot	Robots	learn play and interaction	children	five children (one female, 5/6)	top down	observations of behaviours, inference of enjoyment	observations	Rofina
Autism and tablet computers in Turkey: Teaching picture sequencing skills via a web-based iPad application	web based iPad app	Mobile Applications	teaching sequencing skills	children	three boys	top down	observation of reactions and effectiveness	observations	no specific one

Title	Technology	Category	Aim	Target group	Study/Participants	Design approach	Evaluation focus	Evaluation type	System name
Automatic Childhood Autism Detection by Vocalization Decomposition with Phone-like Units	speech signal processing technology	Mobile Applications	analyze and monitor a child's natural language environment and the vocalizations/speech of the child	children (passively), clinicians	via audio samples: 76 td children, 30 with language delays, 34 with ASC (between 8 and 48 months)	top down	correct detection of autism in child	error rate	LENA
Avatar Assistant: Improving Social Skills in Students with an ASD Through a Computer-Based Intervention	computer based intervention	Computer Based Programm	Improving Social Skills	children	49 children with ASC (6-15, mental age 6-10)	top down	attending to eye gaze, discriminating facial expressions and recognising faces and emotions, and inferred from that social skills	learning outcomes	FaceSay
A Virtual Reality Application with Autistic Children	virtual reality	Virtual Reality	learning	children	two children (7/9, girl/boy)	top down	helmet acceptance, immersion, motion, generalisation, learning, etc.	learning outcomes	no specific one
Building an Intelligent, Authorable Serious Game for Autistic Children and Their Carers	intelligent, authorable serious game	Game	supporting social interaction	children and their carers	none yet	top down	planned	planned	SHARE-IT
Building Autonomous Social Partners for Autistic Children	autonomous virtual agent	Multitouch	credible social partner	children	19 children (age unspecified)	top down with 'input from users'?	efficacy in response time, initiations	efficacy, task performance	ECHOES
Can Robotic Interaction Improve Joint Attention Skills?	robot	Robot	administering and adjusting joint attention problems		six children (3-5)	top down	better joint attention	observations	Nao Robot
Collaborative Puzzle Game: a Tabletop Interactive Game for Fostering Collaboration in Children with Autism Spectrum Disorders (ASD)	tabletop puzzle game	Game	fostering collaboration	children	70 typically developing children (around 9 years old), 16 boys with asc (8-18)	top down	completion time, enjoyment, engagement,	task performance, questionnaires	COSPATIAL
Collaborative Tablet Applications to Enhance Language Skills of Children with Autism Spectrum Disorder	tablet apps	Mobile Applications	developed with an aim to enhance language skills, could also enhance social behaviors such as collaboration, expression and appreciation for pair activities	children	4 proxies	proxy design (teacher, parents, grandparent)	evaluation with proxies	proof of concept	I Know and I Can Tell
Collaborative Virtual Environment Technology for People With Autism	Virtual Environment	Virtual Reality	emotion recognition (skills)	children	34 participants (7-16)	top down	how emotions were recognised	learning outcomes	no specific one
Combining Ludology and Narratology in an Open Authorable Framework for Educational Games for Children: the Scenario of Teaching Preschoolers with Autism Diagnosis	authorable framework for educational games	Computer Based Programm	education	preschoolers	none	top down	none described	not described	IOLAOS
Comparative efficacy of the Picture Exchange Communication System (PECS) versus a speech-generating device: Effects on requesting skills	PECS vs. speech generation	Mobile PECS	communication	nonverbal children	three elementary school children	top down	differences between the systems in socio-communicative behaviour	change in social interaction	no specific one
Comparing Acquisition of AAC-Based Mands in Three Young Children with Autism Spectrum Disorder Using iPadÒ Applications with Different Display and Design Elements	ipad application	Mobile Applications	taking up AAC	children	three children (1-3)	top down	differences in acquisition of AAC skills	learning outcomes	no specific one
Computer-Assisted Face Processing Instruction Improves Emotion Recognition, Mentalizing, and Social Skills in Students with ASD	computer program	Computer Based Programm	affect recognition, mentalizing, and social skills intervention	children	31 children (5-11)	top down	improved their affect recognition and mentalizing skills, as well as their social skills	learning outcomes	FaceSay
Computer-based intervention for inferring facial expressions from the socio-emotional context in two children with autism spectrum disorders	computer program	Computer Based Programm	inferring facial expressions from the socio-emotional context	children during therapy	2 children (4/8)	top down	children learned the relationships and improved their performance with untrained stimuli	learning outcomes	no specific one
Computer mediated imaginative storytelling in children with autism	computer program	Computer Based Programm	explore expressive writing ability	children	10 pairs of children (always td + asc, 7-9)	top down	task competency, length of narrative, bubble use, etc.	task performance	Bubble Dialogue
Conversing through and about technologies: Design critique as an opportunity to engage children with autism and broaden research(er) perspectives	annotation overlay	Multitouch	support children in design critique	children in PD processes	7 children	participatory design	SCERTS	efficacy, task performance	ECHOES
Creating a Spoken Impact: Encouraging Vocalization through Audio Visual Feedback in Children with ASD	audio and visual feedback on vocalizations	Projection	encourage vocalisations	children	5 children (3-8)	top down	hypothesised questions, vocalisations	observations	Spoken Impact Project
Creating Creative Spaces for Co-Designing with Autistic Children - The Concept of a "Handlungsspielraum"	ubiquitous/smart objects	Ubiquitous Computing	enjoyment, holistic sense making in the children's lives	children	4 children (6-10)	participatory design	none described	not described	OutsideTheBox
DayByDay: Interactive and Customizable Use of Mobile Applications in the Cognitive Development Process of Children with Autistic Spectrum Disorder	mobile apps	Mobile Applications	support tool	children (8-12)	seven caregivers, 1 psychologist, 1 pedagogue	informant design (psychologist, pedagogue)	questionnaire, use by proxies	questionnaires, proof of concept	day-by-day
Design and application of an immersive virtual reality system to enhance emotional skills for children with autism spectrum disorders	immersive virtual reality system	Virtual Reality	improve and train emotional skills	primary scholl children (7-12)	40 students (7-12)	top down	which system is better (ivrs vs. desktop vr)	comparison	no specific one
Design and Evaluation of Applying Robots to Assisting and Inducing Children with Autism in Social Interaction	card games with robots	Robots	assistance and inducing of social interaction	children	5 children (8-12)	top down	task completion, 'happily involved', generate basic social behaviour	task performance, observations	no specific one
Design and Evaluation of Mobile Learning Applications for Autistic Children in Pakistan	mobile app	Mobile Applications	culturally specific learning to encourage social interaction	children	8 children (8-12)	top down	pre-/post evaluation questionnaires, video observation, development of socio-emotional skills	questionnaires, observations, learning outcomes	no specific one
Designing ABA-Based Software for Low-Functioning Autistic Children	computer program	Computer Based Programm	didactic software along ABA principles	children (2-6 years)	none	top down	none described	not described	ABCD SW
Designing and Evaluating Touchless Playful Interaction for ASD Children	kinect game	Game	monitoring improvement	children (and subsequently, therapists)	19 children and 18 specialists; 10 more children (6-8)	top down	clinical and performance variables	effectiveness	M4All
Designing Capture Applications to Support the Education of Children with Autism	automated capture	Automated Video Analysis	tracking in educational and learning settings	children (passively), caretakers, educators	not sure	informant design with proxies (teachers, researchers, parents)	none described	not described	Abaris, walden monitor, care log
Designing for Interaction Immediacy to Enhance Social Skills of Children with Autism	mobile app	Mobile Applications	supporting social communication	children	fourteen children (8-10)	top down after observational study	none described	not described	Mosoco (mobile social compass)
Designing for young children with autism spectrum disorder: A case study of an iPad app	iPad APP	Mobile Applications	social skills learning (attending to others & following social cues)	children	41 pre-schoolers with autism	user centred design with relevant stakeholders (including children)	expert evaluation & pilot testing	expert heuristic, proof of concept	Running Head
Designing Motion-Based Activities to Engage Students with Autism in Classroom Settings	kinect game	Game	student engagement in classrooms	children	2 teachers & 18 students (8-19)	iterative prototyping	teacher feedback, video recording	observations, interviews with adults	no specific one
Designing ReduCat: Audio-Augmented Paper Drawings Tangible Interface in Educational Intervention for High-Functioning Autistic Children	audio- augmented paper drawings tangible user interface	Paper	support educational intervention, collaborative story telling	high-functioning children diagnosed with autism spectrum disorder (ASD)	4 children (8-17)	observation & iterative prototyping	observation	observations	ReduCat
Designing Smart Objects with Autistic Children Four Design Exposés	smart objects	Ubiquitous Computing	holistic wellbeing	children	4 children (6-10)	participatory	none described	not described	OutsideTheBox
Designing technology for children with special needs: bridging perspectives through participatory design	virtual environment	Multitouch	development of children's social skills	children	30 typically developing 6-year-olds and a social skills training group of three children with special needs (two boys with HFA and a girl with undiagnosed social and language difficulties)	participatory	none described	not described	ECHOES
Design of a Computer-Assisted System for Teaching Attentional Skills to Toddlers with ASD	computer program	Computer Based Programm	teaching attentional skills, specifically responding to one's name	toddlers	5 typically developing (TD) children with the average age of 1.38 years and 5 children with ASD with an average age of 2.26 years.	top down	prompt level needed, time spent to hit target	task performance	no specific one
Developing a Robotic Platform to Play with Pre-school Autistic Children in a Classroom Environment	turn-taking games with a robot	Game	educational companion to encourage social interaction skills	children (pre-school)	5 children (pre-schoolers) (5-6)	top down	behavioural data (eye gaze)	eye tracking	no specific one
Developing technology for autism: an interdisciplinary approach	technology-enhanced learning environment	E-Learning	acquisition and explo-ration of social skills by typically developing (TD) children and children with autism spectrum disorders (ASDs)	children	30 typically developing 6-year-olds and a social skills training group of three children with special needs (two boys with HFA and a girl with undiagnosed social and language difficulties)	participatory	planned	planned	ECHOES
Development and Evaluation of a Computer-Animated Tutor for Vocabulary and Language Learning in Children with Autism	computer-animated tutor	Computer Based Programm	teach vocabulary and grammar	children (under teacher guidance)	seven children (7-12)	top down	acquisition of language, effectiveness	learning outcomes	Baldi
Development and Study of Support Applications For Autistic Children	PDA app	Mobile PECS	voice output communication aid	children	1 8 year old boy	top down	clinical observation	observation	Let's Talk
Development of Software that Supports the Improvement of the Empathy in Children with Autism Spectrum Disorder	software application on multi-touch devices	Multitouch	enhance empathy	children	group of children (8-11)	UCD through consultation of allistic stakeholders and observation of autistic children	heuristic evaluation, user test, interviews (with mother/teachers)	expert heuristic, interviews with adults, usability test	no specific one
Development of symbolic play through the use of virtual reality tools in children with autistic spectrum disorders	virtual reality environment	Virtual Reality	educational intervention, teaching pretend play and understanding imagination	children	two children (8/15)	top down	effectiveness through observation	observations	I am going to act as if . . .
Development of Therapeutic Expression for a Cat Robot in the Treatment of Autism Spectrum Disorders	cat robot	Robot	early therapeutic treatment to improve social interactions	children	none	top down	experimental tests on the robot	experiments	no specific one
Dimensions of Collaboration on a Tabletop Interface for Children with Autism Spectrum Disorder	suite of tabletop games	Games	support social competence training	children	two therapists and eight children (9-12)	top down	observational field study	observations	no specific one

Title									
Discrepancies in a Virtual Learning Environment: Something "Worth Communicating About" for Young Children with ASC?	Virtual Environment	Multitouch			eight children (5-8)			planned	ECHOES
Does appearance matter in the interaction of children with autism with a humanoid robot?	robot	Robot	support interaction skills	children	four children (5-10)	top down	comparison of interaction in different appearances	comparison	Aurora
Do Sensory Preferences of Children with Autism Impact an Imitation Task with a Robot?	robot	Robot	facilitate imitation	children	12 children (8-17)	top down	effect of sensory preferences on imitation task	task performance	Nao Robot
ECHOES: An intelligent serious game for fostering social communication in children with autism		Multitouch						planned	ECHOES
Edushare, a Step beyond Learning Platforms	web based learning environment	E-Learning	cognitive remediation, facial emotion recognition	children under supervision/guidance of a teacher (no ages given)	none	top down	none described	not described	edushare
Effects of a Computer-Based Intervention Program on the Communicative Functions of Children with Autism	computer based application	Computer Based Programm	enhancing communication functions	children	five children (7-12)	top down	variables: delayed echolalia, immediate echolalia, irrelevant speech, relevant speech, and communicative initiations. transfer of knowledge, and focus of sentences	observations	no specific one
Effects of a Story-Mapping Procedure Using the iPad on the Comprehension of Narrative Texts by Students With Autism Spectrum Disorder	iPad App	Mobile Applications	teaching story element definitions	elementary school children	3 children (8-10)	top down	identification of story elements	learning outcomes	no specific one
Effects of computer-assisted explicit instruction on map-reading skills for students with autism★	computer program (computer-assisted explicit instruction package)	Computer Based Programm	teaching social studies	elementary school children	3 children (9-10)	top down	acquisition of knowledge	learning outcomes	no specific one
Effects of synthetic speech output on requesting and natural speech production in children with autism: A preliminary study	speech generating device	Mobile PECS	alternative communication method	non-verbal children	5 children (8-10)	top down	requesting and natural speech production	change in social interaction	no specific one
Efficacy of Handheld Electronic Visual Supports to Enhance Vocabulary in Children With ASD	tablet based visual scripts	Mobile Applications	language therapy	children (via therapist)	three children (8-14)	top down	increased use of verbs or nouns with the treatment materials	change in social interaction	no specific one
Efficacy of TeachTown: Basics computer-assisted intervention for the Intensive Comprehensive Autism Program in Los Angeles Unified School District	computer assisted instruction	E-Learning	language and cognitive support	children (via teacher)	47 children (3-6)	top down	improvement overall on language and cognitive outcome measures	change in social interaction	TeachTown: Basics
Embedded capture and access: encouraging recording and reviewing of data in the caregiving domain		Automated Video Analysis						not described	Abaris
Embodied Companion Technologies for Autistic Children		Ubiquitous Computing						planned	OutsideTheBox
Embodiment and Cognitive Learning – Can a Humanoid Robot Help Children with Autism to Learn about Tactile Social Behaviour?	Humanoid Robot	Robot	teaching tactile social behaviour	children	not exactly specified how many (two special needs schools), or which age (photos indicate elementary level)	top down	observation	observations	Roboskin/Kaspar
Emotional Robot to Examine Different Play Patterns and Affective Responses of Children with and without ASD	robot	Robot	social assistance, ultimatelyy	children	12 children + 15 nt	top down	different child/robot interactions & characterising differences in play and affective responses within-group (ASC)	change in social interaction	Sphero
Engaging Autistic Children in Imitation and Turn-Taking Games with Multiagent System of Interactive Lighting Blocks	interactive blocks	Games	establish elements of cooperative play	children together with adult caregiver	five children (4/5)	top down	number of distractions, concept understood	observations	no specific one
EnGaze: Designing Behavior Visualizations with and for Behavioral Scientists	visualization-based Web tool for dyadic communicative behavior	Web Based	highlights commonly discussed features of joint attention	clinicians, researchers, children only passively	five participants, clinicians and researchers	top down after observation	usability by clinicians/researchers	expert heuristic	EnGaze
EnhancedTouch: A Smart Bracelet for Enhancing Human-Human Physical Touch	wearable (bracelet)	Wearable	measure human-human touch events and provide visual feedback to augment touch interaction	children/adults	six children (5-8)	top down	response time evaluation, observation, touch duration	usability study, observations	EnhancedTouch
Enhancing empathy instruction using a collaborative virtual learning environment for children with autistic spectrum conditions	collaborative virtual learning environment	E-Learning	empathy instruction	children	3 children (8-10)	top down	appropriate answers, understanding empathy	learning outcomes	CVLE - 3D
Enhancing social communication of children with high-functioning autism through a co-located interface	Touch Table	Multitouch	enhancing social communication	children	six children (8-10)	top down	frequency of autistic behaviours, initiation of positive social interaction, level of shared play	change in social interaction	StoryTable
Evaluating a Collaborative iPad Game's Impact on Social Relationships for Children with Autism Spectrum Disorder	collaborative ipad game	Game	facilitate social relationships	children (also without adults ;)	eight children (8-11)	top down	social relationships, membership, partnership, friendship	change in social interaction	Zody
Evaluation, Training and Measurement System for Autistic Children	computer program	Computer Based Programm	special training	2-6 years old autistic children	none	top down	none described	not described	Squeak and eToys
Experiences of autistic children with technologies		Ubiquitous Computing						planned	OutsideTheBox
Exploring the use of a mobile robot as an imitation agent with children with low-functioning autism	mobile robot	Robot	facilitate reciprocal interaction such as imitative play	children	four children (4-5)	top down	shared attention, imitation of facial expressions, imitation of body movements etc.	observations	Tito
Facial Expression Recognition Teaching to Preschoolers with Autism: A Natural User Interface approach	Computer Game with NUI	Game	teaching the recognition of facial expressions	children	none	top down	none described	not described	no specific one
Facial Expressions and Gestures to Convey Emotions with a Humanoid Robot	robot	Robot	robotic tool used to study human-robot interactions with children with ASC	children (under research conditions)	42 children (8-10) and 61 adults (18-59)	top down	questionnaire	questionnaires	ZECA
FroggyBobby: An exergame to support children with motor problems practicing motor coordination exercises during therapeutic interventions	exergame	Game	support children with motor problems practicing motor coordination exercises during therapeutic interventions	children during therapy	eight children (7-10)	participatory design for gameful mechanisms and to explore range of body movements; with therapists and experts	video recordings, observations, interviews with teachers	observations, interviews with adults	FroggyBobby
From child-robot interaction to child-robot-therapist interaction: A case study in autism	mobile robot	Robot	augmenting therapy	child + therapist	one child (8)	top down	video observation	observations	GIPY-1
From Isolation to Communication: A Case Study Evaluation of Robot Assisted Play for Children with Autism with a Minimally Expressive Humanoid Robot	minimally expressive humanoid robot	Robot	assisted play					comparison	Aurora
From the War Room to the Living Room: Decision Support for Home-based Therapy Teams		Automated Video Analysis						not described	Abaris
Handheld "App" Offering Visual Support to Students with Autism Spectrum Disorders (ASDs)	iOS app	Mobile Applications	Caregivers use the application to create and present visual schedules, visual countdown timers, and visual choices, to help individuals with ASDs stay orga- nized, understand upcoming events, and identify preferences	caregivers, children passively	29 teachers with 88 students (5-16)	top down by HandHold Adaptive, LLC,	9 question evaluation with teachers, observation, focus group (with teachers)	questionnaires with adults	iPrompts
IIAM (important information about me): a patient portability profile app for adults, children and families with neurodevelopmental disabilities	mobile app	Mobile Applications	communicate and organize healthcare information for people with neurodevelopmental disabilities (NDD	children (passively)	7 parents of children (3-22)	top down	usability oriented	usability study	IIAM
Improving Autistic Children's Social Skills Using Virtual Reality	virtual reality	Virtual Reality	improving social skills	children (5-16)	10 children (5-16)	top down	usability and reception	usability study	no specific one
Improving Collaborative Play Between Children with Autism Spectrum Disorders and Their Siblings: The Effectiveness of a Robot-Mediated Intervention Based on LegoÒ Therapy	robot	Robot	robot mediated intervention based on lego therapy to improve collaborative play between children and their siblings	children and their siblings	three pairs (5-13)	top down	collaborative behaviours, social validity	change in social interaction	no specific one
Incorporating a robot into an autism therapy team		Robot						not described	Aurora
Informing the Design of an Authoring Tool for Developing Social Stories	authoring tool (computer software)	Computer Based Programm	developing social stories	therapists	therapists,	informed design	with therapists on usability and functionality	usability study with adults	ISISS
In My Own Words: Configuration of Tangibles, Object Interaction and Children with Autism	tangible toys	Tangible	support of cooperative play	children	children (9-13)	top down	amount of cooperative play	observations	Augmented Knights Castle
Interactive Educational Games for Autistic Children with Agent-Based System	computer games	Game	diagnosis and training	children (under supervision)	none yet	top down	planned	planned	Autism Project
Interpreting Input from Children: a Designerly Approach		Multitouch						planned	ECHOES
Jumru 5s – A Game Engine for Serious Games	web based Game Engine/game	Game	therapy/emotion recognition	children (5-12)	none	top down	functionality	proof of concept	Jumru5/EmoJump
KASPAR – a minimally expressive humanoid robot for human–robot interaction research		Robot						observations	KASPAR

Title	Technology	Type	Purpose	Users	Participants	Design Approach	Measured	Method	Name
Learning Environment for Autism Spectrum Disorders: a universal approach to the promotion of mathematical reasoning	computer program	Computer Based Programm	promotion of deductive reasoning	children	7 boys (8-12)	PD	execution ability, motivation, exhaustion through observation	observations	LEMA
Lehigh Instrument for Learning Interaction (LILI): An Interactive Robot to Aid Development of Social Skills for Autistic Children	Interactive Robot	Robot	Development of social skills	children (no age given)	none	top down	planned	planned	LILI
LIFEisGAME Prototype: A Serious Game about Emotions for Children with Autism Spectrum Disorders	iPad Game	Mobile Applications	promote emotional understanding	children	11 children (5-15)	top down	motivation to play and game usability, and also participants' emotional recognition abilities and technology usage; video observation, parent questionnaires	usability study, observations, questionnaires with adults	LIFEisGAME
Long-term LEGO therapy with humanoid robot for children with ASD	humanoid robot	Robot	LEGO therapy	children	six boys (8-12)	top down; they mention a co-design component for the therapy, but I'm not quite sure how	social interactions	change in social interaction	nao robot
MOSOCO: A Mobile Assistive Tool to Support Children with Autism Practicing Social Skills in Real-Life Situations	mobile app	Mobile Applications	support in practicing social life skills	children	6 children (8-11), 3 of them TD	top down	video recordings, interviews with participants; use and adoption, behaviour and performance, skill	observations, interviews, task performance	MOSOCO
Multimedia and Virtual Reality in the Rehabilitation of Autistic Children	multimedia and virtual reality software package	Virtual Reality	rehabilitation	children	some children' (no age given)	top down	usability	usability study	no specific one
Multimodal Human-Robot Interactions: the Neurorehabilitation of Severe Autistic Children	robot	Robot	neurorehabilitation	children (in therapy)				observations	GIPY-1
Multimodal Interfaces and Sensory Fusion in VR for Social Interactions	adaptive virtual reality-based social interaction platform	Virtual Reality	learning sensory integeration	children	10 children (no age given) and 10 td children	top down	physiological signals and questionnaire for therapist	physiological signals, questionnaires with adults	no specific one
MyCalendar: Fostering Communication for Children with Autism Spectrum Disorder Through Photos and Videos	visual calendar app	Mobile Applications	communicate about their own activities and interests across the settings of home and school.	children	four teachers, ten parents and eleven children (5-7)	participatory design with children, parents and teachers	better communication	change in social interaction	MyCalendar
NoProblem! A Collaborative Interface for Teaching Conversation Skills to Children with High Functioning Autism Spectrum Disorder	multi-user interface	E-Learning	teach social conversation and social interaction skills	children (after setup from therapist)	nine boys, one girl (9-13) + 22 (around 9.75)	top down	intervention success & enjoyment through questionnaires	questionnaries	NoProblem!
On-line Behaviour Classification and Adaptation to Human-Robot Interaction Styles		Robot						not described	Aurora
Participatory Design Strategies to Enhance the Creative Contribution of Children with Special Needs	kinect game	Game	fostering social initiation skills	children	four children (9-10)	participatory design	none described	not described	no specific one
Pervasive Computing and Autism: Assisting Caregivers of Children with Special Needs		Automated Video Analysis						not described	Abaris, CareLog and Wearables
Pervasive multimedia for autism intervention	portable platform, multi-touch (iPad)	Mobile Applications	pervasive delivery of early intervention therapy	children (along set lessons)	7 children (4-8, 14)	top down	system functionality, individual performance, survey from parents	proof of concept, task performance, questionnaires with adults	no specific one
Pilot clinical application of an adaptive robotic system for young children with autism	humanoid robot	Robot	administering and automatically adjusting joint attention prompts to a small group of preschool children	preschool children	12 (6 of those nt) (2-5)	top down	gaze, target success, hit frequency	eye tracking, task performance	Nao Robot
Planning-based social partners for children with Autism		Multitouch						planned	ECHOES
Playful interaction with Teo, a Mobile Robot for Children with Neurodevelopmental Disorders	mobile robot	Robot	therapy driven game based activities as well as free play	children	2 therapists and 11 children (3-10)	top down	behavioural variables, video analysis	observations	Teo
Playing with Virtual Peers: Bootstrapping Contingent Discourse in Children with Autism	virtual peer	Computer Based Programm	collaborative narrative	children and their (human) peers	six children (7-11)	top down	increase of contingent discourse, improved topic management	change in social interaction	Sam
Potential Clinical Impact of Positive Affect in Robot Interactions for Autism Intervention	wizard of oz robot	Robot	interventions	children	24 children (4-12)	top down	positive affect, engagement	observations	Pleo
Project Communicate	augmented reality mobile app// kinect game	Game	learn and communicate effectively	children and their caregivers (no age given)	none	top down	none described	not described	Project Communicate
Promoting Joint Attention with Computer Supported Collaboration in Children with Autism	collaborative gesture-based application	Computer Based Programm	promote joint attention	children (no age given)	ten children (no age given) in evaluation and two in design as well as nineteen school specialists, three parents	user-centered design approach	observable improvements in social interaction with typically developed peers, (b) the opportunity to customize and individualize intervention to cater to a large spectrum of children and (c) the potential opportunity of reducing fears of certain objects.	observations	Balloons
Promotion of creative activity in children with severe autism through visuals in an interactive multisensory environment.		Interactive Environment						observations, interviews with adults	MEDIATE
RACHEL: DESIGN OF AN EMOTIONALLY TARGETED INT	Embodied conver- sational agent	Computer Based Programm	elicit and analyze complex, structured, and naturalistic interactions and to encourage affective and social behavior	children	two children (6/12)	empirically informed top down	pilot study, usability oriented	usability study	Rachel
Read my lips		Computer Based Programm						learning outcomes	Baldi
Read, Play and Learn: An Interactive E-book for Children with Autism	web-based interactive e-book	Web Based	teach children novel vocabulary, counting, identifying numbers and colors, and responding to inference questions.	children (3-12)	none	top down, inspired by an existing analogous copy	none described	not described	The Wolf in Love
Reversal Learning Task in Children with Autism Spectrum Disorder: A Robot-Based Approach	robot	Robot	ultimately, being part of robot based therapy	children/therapists	40 TD children and 41 children (4-13)	top down	learning/video coding	learning outcomes	Keepon
Robotic Animals Might Aid in the Social Development of Children with Autism	robotic dog	Robot	aid in social development	children	11 children (5-8)	top down	words spoken/engagement/interaction	language	AIBO
Robotic assistants in therapy and education of children with autism: can a small humanoid robot help encourage social interaction skills?	humanoid robot	Robot	therapy & education	children (mediated)	4 children (5-10)	top down	longitudinal study, Based on the video material documenting the interactions, a quantitative and qualitative analysis was conducted.	observations	Aurora
Robotic Social Therapy on Children with Autism: Preliminary Evaluation through Multi-parametric Analysis	robot	Robot	social therapy	children (mediated)	5 children and 15 td children (6-12)	top down	accuracy	task performance	FACET
RoDiCA: a Human-Robot Interaction System for Treatment of Childhood Autism Spectrum Disorders	robot	Robot	therapy	children (mediated), more like therapists	apparently, but I don't know how many or what age	top down	what the child does, reliability of motion comparison	obsrvations	Zeno/RoDICA
Seeking Independent Management of Problem Behavior: A Proof-of-Concept Study with Children and their Teachers	wearable watch	Wearable	detect 'problem behaviour'	children (mediated), teachers for notifications	21 children (7-17)	top down	detection reliability and what the teachers did	observations	no specific one
SensoryPaint: A Multimodal Sensory Intervention for Children with Neurodevelopmental Disorders	multimodal system on large displays	Multitouch	sensory integration therapies	children (in therapy)	15 children with neurodevelopment stuff and 4 (4-12)	top down?	interviews with psychologists and parents and observations	observations, interviews with adults	SensoryPaint
SketchUp-: A Technology Tool to Facilitate Intergenerational Family Relationships for Children with Autism Spectrum Disorders (ASD)	freeware 3D design programme	Computer Based Programm	intervention	children with other family members	7 boys (8-17)	top down (technology taken from somewhere else)	focus groups with parents and grandparents	focus groups with adults	SketchUp
Smart objects to support the discrimination training of children with autism	tangible smart objects	Tangible	promote interactivity with a playful and engaging interaction, and are capable of the automatic recording of students' progress	student with teachers	18 students (3-8) & seven teachers	ethnographically informed	impact on teachers workload to keep students on task, facilitating recording, and burden with giving instructions	observations	T3
Smartphone Based Autism Social Alert System	smartphone app	Mobile Applications	facilitate the study of the autistic children's behaviors by recording and analyzing data collected from embedded sensors in smartphones	children passively, more researchers and therapists	4 "healthy" students	top down	accuracy of classification, functioning of the prototype	observations, proof-of-concept	SASA
Social benefits of a tangible user interface for children with Autistic Spectrum Conditions	Tangible User Interfaces	Tangible	support social play	children	six boys (8-11)	top down (technology taken from somewhere else)	video observation	observations	Topobo
Social communication between virtual characters and children with autism		Multitouch						planned	ECHOES
Social Robots as Embedded Reinforcers of Social Behavior in Children with Autism	social robot	Robots	reinforce social behaviour	children	24-children (4-12)			observations	Pleo
Speech development of autistic children by interactive computer games	visual displays and physical robots	Robots	improve the speech	children	1 child (no age given)	top down	speech development	language	no specific one
StepByStep: Design of an Interactive Pictorial Activity Game for Teaching Generalization Skills to Children with Autism	computer game	Game	teaching generalisation skills	children	1 child (8)	top down	participant's mother took on the observer role in the research due to her confidence with autistic children and her experience on understanding small emotional and behavioral changes of her child	observations	StepByStep

Title	Technology	Category	Purpose	Target	Participants	Approach	Findings	Evaluation	System
Study on an assistive robot for improving imitation skill of children with autism	robot	Robots	improving imitation skills	children	4 children (no age given, but seem young enough)	top down	trained by executing specific tasks for improving imitation skill.	learning outcomes	no specific one
Supporting parents for in-home capture of problem behaviors of children with developmental disabilities	camera based surveillance cystem	Automated Video Analysis	behaviour capture and analysis	children (as input), parents/researchers/ therapists	8 children and their families (4-19)	top down	type of behaviours caught, potential for analysis	system correctness	CRAFT
Supporting the Design Contributions of Children With Autism Spectrum Conditions		Multitouch						planned	ECHOES
Tablets for two: How dual tablets can facilitate other-awareness and communication in learning disabled children with autism	two linked tablets	Mobile Applications	facilitates active other-awareness, incorporating imitation and communicative behaviour	children with others	8 boys (5-12)	top down	more active other-awareness	observations	no specific one
Talking Points: The differential impact of real-time computer generated audio/visual feedback on speech-like & non-speech-like vocalizations in low functioning children with ASD		Computer Based Programm						observations	Spoken Impact Project
Teaching Low-Functioning Autistic Children: ABCD SW		Computer Based Programm						not described	ABCD SW
Technology delivered self-monitoring application to promote successful inclusion of an elementary student with autism	Android application	Mobile Applications	self monitoring	children	1 9 year old boy	top down	immediate increase in on-task behavior as well as a decrease in disruptive behaviors	observations	I-Connect
The Application of a Sensory Integration Treatment Based on Virtual Reality-Tangible Interaction for Children with Autistic Spectrum Disorder	Virtual Reality Tangible Interaction	Virtual Reality	sensory integration / social skills	children (in therapy)	12 children (5/6) and 20 nt	top down	training of social skills	learning outcomes	VR-SIT
The Case for Conversation: A Design Research Framework for Participatory Feedback from Autistic Children	large scale sensory environment	Interactive Environment	sabotage/social interaction	children	2 children (5/6) and 4 NT	participatory design	interaction experience	Experience-Centred	Responsive Dome Development
The design and development of a mobile communication tool for autistic individuals – AutiSay	mobile app	Mobile PECS	social communication skills	parents & children	parents	top down	usability	usability study	Autisay
The effectiveness of using a robotics class to foster collaboration among groups of children with autism in an exploratory study	robots & programming of robots in classes	Robot	foster collaboration	groups of children	seven+ (8-14)	top down	analysis of behavioural data	observations	Lego robots
The effects of embodied rhythm and robotic interventions on the spontaneous and responsive social attention patterns of children with autism spectrum disorder (ASD): A pilot randomized controlled trial	robot	Robot	intervention on the spontaneous and responsive social attention patterns	children in therapy	36 children (5-12)	top down	the robot group decreased attention to the robot and increased attention to elsewhere	observations	no specific one
The effects of embodied rhythm and robotic interventions on the spontaneous and responsive verbal communication skills of children with Autism Spectrum Disorder (ASD): A further outcome of a pilot randomized controlled trial		Robot						observations	
The emotional hearing aid: an assistive tool for children with Asperger syndrome	portable assistive computer-based technology	wearable	identify a person's mental state and the ability to react appropriately to it	children	none	top down	accuracy	system correctness	emotional hearing aid
The narrative construction of our (social) world: steps towards an interactive learning environment for children with autism	interactive software system	E-Learning	romotes an under-standing of narrative structure	children	12 children (5-11)	top down	A correlation has been found with a real-world narrative comprehension task, and for most children a clear distinction in their understanding of narrative components.	learning outcomes	TouchStory
Three around a Table: The Facilitator Role in a Co-located Interface for Social Competence Training of Children with Autism Spectrum Disorder	co-located interface on a tabletop device	Ubiquitous Computing	support social competence training (CBT)	two children and a facilitator (therapist or teacher)	8 boys and their therapists (9-12)	top down	video recording	observations	Join-In-Suite
To enforce or not to enforce? The use of collaborative interfaces to promote social skills in children with high functioning autism spectrum disorder	collaborative puzzle game	Game	promot social skills	children	six dyads of children (8-11)	top down	Parents completed the Social Responsiveness Scale	questionnaires with adults	no specific one
TouchStory: Towards an Interactive Learning Environment for Helping Children with Autism to Understand Narrative		E-Learning						learning outcomes	TouchStory
Understanding the Challenges and Opportunities for Richer Descriptions of Stereotypical Behaviors of Children with ASD	wearable (wristband)	wearable	tacitly collect contextual data related to the individual's physiological state and their external environment, and map it to occurrences of stereotypies	children/parentes	3 children (4-7) and parents	participatory (focus groups with three children and four parents)	exploratory, formative	focus groups	no specific one
Using Affective Avatars and Rich Multimedia Content for Education of Children with Autism	computer program	computer Based Programm	education	children	school with approximately 50 people (8-50)	top down	educators' feedback	interviews with adults	ACALPA
Using Augmented Reality to Help Children with Autism Stay Focused	Augmented Reality	Augmented REality	stay focused	children	12 children (3-8)	user centred design	affective state in use and effectiveness	effectiveness	Mobis
Using tangible user interfaces in computer-based training systems for low-functioning autistic children	tangible	Tangible	teaching shape and color recognition	children	12 children (3-5) + 20 children (3-5)	top down	ease of use & learning efficacy	learning outcomes	no specific one
Virtual Reality Social Cognition Training for children with high functioning autism	virtual reality	Virtual Reality	social cognition training	children	30 children (7-16)	top down	Three primary domains were measured pre-post: emotion recognition, social attribution, attention and executive function	questionnaires	no specific one
VLEs, social stories and children with autism: A prototype implementation and evaluation	virtual learning environment	Virtual Reality	social stories for social skills problems	children	40 experts	top down	potential to be a beneficial and easy-to-use educational tool for enhancing social problem solving	usability study	VLSS
vSked: Evaluation of a System to Support Classroom Activities for Children with Autism	interactive and collaborative visual scheduling system	computer Based Programm	scheduling/reduce teacher burden	children /teachers effectively	number of teachers and educators	participatory -ish	reductions in staff effort required to use visual supports. vSked also resulted in improvements in the perceived quality and quantity of communication and social interactions in the classroom. — video observation	observations	vSked
"Where is Your Nose?" - Developing Body Awareness Skills Among Children With Autism Using a Humanoid Robot		Robot						observations	KASPAR
You Talk! – YOU vs AUTISM	mobile PECS	Mobile PECS	communication	children and adults	expert & mother	user centred design	usability mostly	usability study	YOU