Agency of Autistic Children in Technology Research—A Critical Literature Review

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Autistic children are increasingly a focus of technology research within the Human-Computer Interaction (HCI) community. We provide a critical review of the purposes of these technologies and how they discursively conceptualise the agency of autistic children. Through our analysis, we establish six categories of these purposes: behaviour analysis, assistive technologies, education, social skills, therapy and well-being. Further, our discussion of these purposes shows how the technologies embody normative expectations of a neurotypical society, which predominantly views autism as a medical deficit in need of 'correction'. Autistic children—purportedly the beneficiaries of these technologies—thus become a secondary audience to the largely externally defined purposes. We identify a lack of design for technologies that are geared towards the interests, needs and desires of autistic children. To move HCI's research into autism beyond this, we provide guidance on how to consider agency in use and explicitly allow for appropriation beyond externally driven goals.

CCS Concepts: • **Human-centered computing** → Participatory design; *Interaction design process and methods*; **Accessibility design and evaluation methods**;

Additional Key Words and Phrases: Autism, agency, children, participation, literature review

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1 INTRODUCTION

Human-Computer Interaction (HCI) and overall computing communities have, in recent years, shown an increased interest in designing, developing and evaluating technologies targeted at

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autistic children.[1] However, it is, thus far, unclear how these technologies discoursively conceptualise autistic children as their target audience or how the fields understand the limits of the design space for such technologies.

Previous reviews of research into autism and HCI have provided useful overviews of the type of technologies in this space [144], or investigated a specific context of use such as serious games [277], interventions for reading comprehension [141], speech generation [163] or social robotics [191]. While these reviews map out the technological space, they do not critically discuss the impact these technologies may have when incorporated into children's lives, or explore who defines the nature of interactions between these technologies and the children. Other reviews have examined, more generally, methods and approaches when designing for children [30, 190]. We agree with the authors of these works that including autistic children in the design process offers the opportunity to not only create more suitable and acceptable technologies, but also allow users to potentially shape technologies according to their needs and desires. At the same time, there is a need to look closely at the way autistic children can participate and how much they can shape the purpose of a given technology design.

Complimenting previous work, our review focuses on the *purposes of these technologies* and the subsequent *power dynamics* they invoke in conceptual and actual use. Describing larger trends about which types of technologies are typically developed and *how they relate to the agency of autistic children*, we provide insights into how the technologies may affect the realities of the people who are intended to interact with them. As a critical review, this article also contributes to an understanding of how technological research for autistic children conceptualises various involved stakeholders (e.g., parents, teachers, peers and therapists). Finally, the review uncovers some of the inherent effects the technologies have on these stakeholders across the board, particularly autistic children themselves, and argues for a change in perspective when it comes to designing and creating technologies for autistic children. This shift in perspective then opens up new opportunities for the design of novel technologies.

After detailing our understanding of autism as a disability—a stance core to the perspective from which we conduct our analysis—we detail the methodological approach, a mix of thematic and discourse analysis. We then present our corpus and each of the different purposes in detail. Our discussion centres on the notion of the ideologically charged concept of autistic children as 'other' as embodied in the technologies and re-engages with the question of who the audience effectually is. We close with brief deliberations of how researchers may reflect on these issues in their work.

2 AUTISM AS A DISABILITY

Several models are in play when it comes to constructing and conceptualising disabilities. Being disabled can either be understood as internalised, individual and embodied classification (the 'medical model'), or as something conceptualised and reinforced by society (the 'social model') [169]. The medical model has been criticised for normalising particular bodies, identifying deviances from these norms as inferior to that norm and, ultimately, putting an emphasis on understanding disability as a *deficit* rather than understanding the disabled person as an equally valid individual with different needs and strengths [183]. The social model, which understands disabilities as solely established through external barriers, has been criticised for neglecting the embodied experiences and physical realities that manifest themselves in quite drastic manners for the individual [221]. In short, the medical model places a disability as a deficit within the individual, whereas the social model argues for societal responsibility in removing barriers to participation. These

[1] Due to a slight preference of autistic people to use identity-first language[140], we opt for this variant of disability-related language.

models matter for technological research as they come with assumptions about how technologies might impact the lives of disabled individuals [12]. In this context, calls have been made for the participation of disabled people in the technological research about them, and for approaches that consider them as multi-faceted individuals who are not solely defined by one label, as opposed to people defined by their disability and in need of 'fixing' [167].

2.1 Medical Model

About 1 in 59 children in the United States of America are diagnosed with autism [54], although a reported increase in diagnoses might at least partly result from a recent change in diagnostic criteria [120]. 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 [taken from 149]. The International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO), in its 11th revision (ICD-11), requires that symptoms appear in early childhood for a diagnosis to be made. Further, they identify 'persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests' across all levels of language acquisition [taken from the icd.who.int website[2]]. 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 autism as a condition within the individual that needs medical attention and correction for the person to fit better into dominant society.

Alongside this kind of understanding, several theories have attempted to explain the etiology of autism. The condition is currently assumed to stem from a combination of genetic and environmental influences [85], but ultimately, no definite cause has been identified. There are several different cognitive theories available that aim at explaining differences [200]. One of those theories claims that autistic children lack 'theory of mind', the skill set to understand how other people feel and process emotion; a necessary precursor to empathy [21, 239]. Further development of this theory is the 'extreme male brain theory' [20]. It presumes that male brains are more prone to systemising whereas female brains are more inclined to empathising.[3] This theory, though widely cited, overlooks how autism presents in women and non-binary people 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 [153], which are tied to the necessity of a medical diagnosis. It has also been critiqued as unsupported by the body of scientific work into autism and hormonal influences on behaviour, with psychologist Cordelia Fine describing it as 'neurosexism' [89].

A theory of executive dysfunction [185] 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 [200]. The language of dysfunction also normalises a certain neurotypically presenting form of functioning as ideal, effectively posing autistic people, again, as 'abnormal' [95].

Yet another hypothesis is titled 'Weak Central Coherence' theory [121], through which autism is explained as predominantly perceiving the world with an attention to detail instead of generalising perceptive input. The approach suggests that any cognitive theory on autism might be necessarily unsuited to explain all differences for all individuals who share the diagnosis, which indicates that a purely medical conceptualisation of the condition will never lead to a holistic understanding.

[2] Specifically https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/437815624.
[3] While we understand gender as a continuum [50], we refer to the binary dichotomy here as the literature discusses it.

Another theory on autism has suggested that autistic people lack cognitive empathy, but possess a surplus of emotional empathy [228], which then makes interaction with other people extremely uncomfortable and exhausting. Others see in autism an account of decreased social motivation rooted in heightened fear of social rejection [58], where such an approach would be extremely counterproductive.

This discourse shows that within a medical account of autism, it remains unclear what are appropriate ways to interact with autistic individuals. To this extent, preferences of individuals might just be that: individual. Hence, technology research is ill-advised to consider people sharing the same diagnosis as a homogeneous group with assumed shared desires and needs. However, the drive to slot autistic individuals in different levels of functionality as is done by the DSM-5 (Diagnostic and statistical manual of mental disorders, fifth revision) [15] is not aiding a differentiation of individual needs as it is a further externally driven form of differentiation of experiences instead of an approach to encounter an individual as such. Instead, 'HFA [high-functioning autism] and LFA [low-functioning autism] are attempts to technologize autism—and not positively, either' [274] and aid as rhetorical devices to inhibit self-representation as either 'not autistic enough' to count as a valid experience or 'too autistic' to be able to communicate one's needs. Further, a medical model based on the notion of perceived deficits, as all functioning labels are [274], readily buys into a notion of finding a cure, which is vehemently rejected by autistic advocates [193].

2.2 Social Model

A social model of disability proclaims that it is predominantly a lack of accommodation that disables individuals. Prominently attributed to Oliver (1983) [184], it has led to accessibility considerations becoming a part of policy making in areas such as education, work and website development. The social model of disability has been criticised for downplaying the individual impairments and their actualised effect in the embodied experience of disabled people [221]; however, Oliver (2013) [183] 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 in a society that assumes a lack of any disability as a default norm [177].

Practising the social model for visible disabilities, such as removing physical barriers for wheelchairs, can be reasonably straightforward and, if implemented consistently, creates equitable access. However, when a disability is invisible, as is the case with autism, disabled people rarely find their needs met outside of constant re-affirmation and disclosure 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 et al. (2017) [269] suggests that the primary social barrier for autism is the negative language surrounding the diagnosis. While Hollywood 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 [26]. Hence, the social model, while being very useful for people with visible disabilities for making their needs heard, is only marginally effective for autistic people—predominantly because requirements for access are flexible, situated and highly contextual.

2.3 Alternative Approaches to Autism

Alternative accounts of autism aim at a more holistic and embodied [73] or phenomenological and pragmatic understanding [237]. According to De Jaegher (2013) [73], different ways of processing sensory input lead to different sense-making, which influences the assignment of meaning.

When meaning-making is based on different perceptual grounds between two people interacting, participatory sense-making becomes a challenge. It requires flexibility from allistic people[4] and interpretation to make communication happen.

A more critical understanding of autism (and other mental conditions), *neurodiversity*, is relatively recent. The term has been coined by Singer (1999) [226], an autistic self-advocate. The concept refers to neurological conditions that are commonly identified by the process of medical diagnosis and 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' [69, 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 but not negated in its embodiment. Within such a discursive approach, many writers conclude that the categories of disability could be removed, as, in their reading, they become meaningless. This leads to some people proposing that 'everyone is a little autistic', which negates any differences in lived experiences. Watson [263] 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 [263] lumps the critique over all authors inspired by Critical Theory stemming 'Foucault, Butler, Derrida and Deleuze and Guitarri' (p. 197). This move of equalising these authors with other scholars who reference them ignores that all of them critically engaged with the formation of the categories.

Neurodiversity does not refer to a single coherent movement. While the academic part 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, such a conceptualisation ignores the genuine needs some autistic people have to be able to navigate life in a predominantly neurotypically shaped society, in which arguments have to be made by those who are already able (albeit with difficulties) to make themselves heard [130]. Hence, we adopt an interpretation of neurodiversity, which 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.

Especially in the area of technologies intended for disabled people, there is a further push to view the design space less with a medicalised view but rather understanding disability as a consequence of individual and societal parameters interacting—a critical realist perspective [97]—or a dedicated focus on abilities [266]. In a different vein, understanding disability as a discourse 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 92]. This understanding is found as well in the field of Critical Disability Studies [223]. These perspectives can be operationalised differently for technological research: critical realism broadens the understanding how technology can be meaningful for disabled individuals and ability-based design shifts the focus of attention. However, understanding disability also as discoursively established and re-affirmed is especially useful for a review of existing literature as it provides a conceptual frame for understanding previous work in the area as contributing to said discourse in this particular case, how autism is re-affirmed as a disability through technology research.

2.4 Representation of Autism

While it might be most beneficial to some disabled people to not explicitly self-identify as *disabled* [262], disability is an identity label that can be positively reclaimed [177]. Such an action of

[4] *Allistic* people are people who are not autistic [165].

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 HCI—about the technologies in their lives. 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' [220].

It then becomes a question of whose expertise is valued when it comes to autism? Pop cultural representation often fails to provide examples that resonate well with autistic experiences. Nevertheless, autistic authors receive less attention than those using Autism as a fictional prop. Burks describes this conundrum as follows:

> 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. [49, p. 295]

Hence, it matters who speaks about the experiences autistic children make. We do not claim that autistic children cannot express their needs, rather we come from the perspective, that there is limited acknowledgement of giving the things they have to say value and taking them seriously, which is just one shared experience they have.

2.5 Experiences of Autistic Children

According to De Jaegher, different processing of sensory input of autistic people leads to different sense-making that 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 [73]. Sharing experiences in a mode De Jaegher 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 [73].

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 19], who are limited to giving their interpretations of the children's experiences or through observation and ethnography [e.g., in 10]. We define this as an *indirect* perspective. Alternatively, researchers also conduct interviews with autistic adults [e.g., in 55, 253], who can provide a hindsight view on their experiences as a child.

Allistic researchers find it additionally challenging 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,

Table 1. Sources for the Literature Review and How Many Items in the Corpus They Yielded

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	April 7th, 2017
hcibib http://hcibib.org	autis* & child*	255	243	April 11th, 2017
Disability and Rehabilitation: Assistive Technology+	autis* AND child* AND technolog*	41	41	April 20th, 2017
Journal of Intellectual & Developmental Disabilty+	autis* AND child* AND technolog*	79	58*	April 20th, 2017
Autism+	child* and technolog*	140	115*	April 24th, 2017
Autism Research+	child* and technolog*	159	150*	April 24th, 2017
Developmental Disabilites Research Reviews+	child* AND technolog* AND autis*	84	75*	April 24th, 2017
Focus on Autism and Other Developmental Disabilities+	child* AND technolog* AND autis*	257	234*	April 24th, 2017
ingenta connect http://www.ingentaconnect.com	child* AND autis* AND technolog*	44	38*	April 25th, 2017
Journal of Applied Research in Intellectual Disabilities+	child* AND technolog* AND autis*	111	101*	April 25th, 2017
Journal of Autism and Developmental Disorders+	child* AND technolog*	624	514*	April 25th, 2017
Research on Autism Spectrum Disorders+	child* AND technolog*	208	207*	April 26th, 2017
Journal of Child Computer Interaction+	autis* AND technolog*	15	13*	April 26th, 2017

+ Journal; * Excluded Book Reviews, News, Letters to the Editors, Call for Papers, Lay Abstracts, Editorials and similar items not representing an original research paper.

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., 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 [150]. We have also aimed at providing methodological support for HCI researchers [233]. As an alternative approach to eliciting first-person perspectives Satchwell and Davidge [215] co-created stories that allow insight into how a person might understand their autism for themselves. These findings support de Jaegher's theory about sense-making of autistic individuals [73].

3 CORPUS SELECTION

The focus of the review was the purposes technologies for autistic children have and how the children are supposed to engage with them. A secondary lens then looks at how the children are included in the research processes to understand how they and their condition are conceptualised in connection to the technologies designed for them. This means, we aim at identifying which kinds of technologies for which kinds of purposes are dominantly shaping the field and which consequences this has for discursively establishing (or neglecting) the agency of autistic children.

Table 1 shows the search items for each venue and how many items the search yielded. This resulted in a total of 2,083 initial items. We then read all abstracts to see how the article fitted to the focus. There were several criteria for keeping a paper in this review round.

— the paper describes a technology that is supposed to be used by autistic children under 10 years old.
  In some publications, teenagers or adolescents are also referred to as children. Hence, we set a firm boundary at the entry of teenage years.
— the paper is of sufficient length (longer than five pages)
  Focusing on full papers made the corpus more manageable and functioned as an indicator for the depth of a paper.
— the paper covers either the design or the evaluation process and focuses on the technology
  We excluded papers describing early ethnographic studies for the elicitation of design requirements without a concrete design idea.

Reasons for rejecting a paper included the technology was only used as a research instrument (e.g., eye tracking, computerised task), the main topic was video modelling,[5] no technology was present, other conditions were included alongside autism, it was not written in English, the paper was a review paper or the reference to autism was used off-handedly to describe a potential, but not intended or tested use of a technology. These parameters meant that, for example, purely ethnographic work on existing platforms (i.e., [204]) was excluded. After this round, 318 papers were left in the corpus. All of these papers received a skim read to assess how they related to the focus. For example, the age of participants was not always clear from reading the abstract alone. Comparisons between two technologies were also excluded as they did not address the individual design or evaluation context, which was usually already present in other publications. In the end, the remaining 185 papers were read in full and built the basis for the analysis we present in this article.

4 METHOD

To get a handle at the amount of data, we first conducted the initial five steps (Familiarisation, Initial Coding, Theme Search, Theme Review, Naming and Definition) of Thematic Analysis according to Braun and Clarke [43]. Before we prepared the report, we additionally drew on Discourse Analysis as a method for making sense of themes across a range of texts [134]. This method originates from the works of Foucault on how norms are established within society [93, 94]. Foucault was concerned with understanding how knowledge is constructed through texts and language. Consequently, *statements*, *syntax* and *semantics* within a *dispositive* (the situational context) are in the centre of any discourse analysis [46]. Our analysis aims 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 research, we limit our selection to research publications, even though we could have also included popular news outlets or app store reviews in our overview. A discourse itself is established by how something is constructed through language and practice. Our work focuses on the dominant purposes of technologies for autistic children and how these influence how the field conceptualises autistic children as active or passive users of these technologies. We provide an intertextual understanding of what is discursively established across these publications. While our work can be classified as descriptive discourse analysis [106], we augment this with a critical discussion on how autistic children appear as stakeholders in the technology research concerning them.

Discourse analysis has been used in HCI to understand concepts within the field and how it constitutes its discourse about these concepts across several texts. This has led to an increased understanding of environmental discourses in HCI as well as directions for future research [111], a discussion of how ageing is negotiated [251] and an analysis of the effects of the shift from 'user'

[5]For example, video materials explaining expected social behaviours in certain situations.

Table 2. Projects with More Than One Publication within the Corpus

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%	OutsideTheBox	6	3.2%
COSPATIAL	2	1.1%	TouchStory	2	1.1%	ECHOES	10	5.5%
FaceSay	2	1.1%	Walden	2*	1.1%			

Note that this does not indicate whether projects have published more than one overall. In cases, where the number is denoted with *, there exist publications for that project that discuss more than once.

to 'maker' on HCI research [210]. Hence, Discourse Analysis constitutes a suitable method when aiming at an understanding of how technology and its use contexts are designed and constructed through certain texts within an area of HCI.

As a set of interpretative methods, Thematic Analysis and Critical Discourse Analysis require 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. For example, two of the authors were involved in designing technologies in participatory processes with autistic children, notably within the OutsideTheBox[6] project. Our motivation for this review comes from trying to understand how our work differed systematically from existing work with the desire to have a rigorous argument for our own approach, but also to identify potential future directions technology research can take to serve this population in the best way possible.

5 OVERVIEW OF SELECTED PAPERS/RESEARCH PROJECTS

In our final analysis, we included 185 papers across 148 research projects. Research projects that have published their findings more than once are denoted in Table 2. Notably, the ECHOES project[7] leads the table with 10 publications within the narrow search parameters of this survey. While the first mention of computing technology being a suitable way to engage autistic children in tasks can be found much earlier [62], the first concrete project in our corpus was published in 1990 [202]. As can be seen in Figure 1, until 2003, there were only single papers published discussing technological projects for autistic children, until a short increase wave around 2005 with a larger trend between 2012 and 2016, which appears to still be going strong (considering that for 2017, we only took the first quarter of the year into account). This shows, that papers on technologies for autistic children hold great interest within the community, which makes it all the more important to construct an overview describing larger trends about how these technologies discursively negotiate the agency of autistic children.

In an analysis of the author keywords (see Table 3), we grouped individual keywords that were similar (e.g., Autism, ASD and ASC) to create a succinct description for how the papers in the corpus situated themselves. We noticed that social interaction is the most referred to keyword-class next to autism. This comes as no surprise given that differences in social interaction is one of the core defining characteristics of autism. Other keywords target use context (therapy, game), design, technology (tablet, VR, technology) or application domain (language, emotion recognition).

[6] http://www.outsidethebox.at.

[7] In the interest of full transparency, we point out that the second author of this paper was involved in both the ECHOES and the OutsideTheBox projects and the first author was directly involved in the OutsideTheBox project.

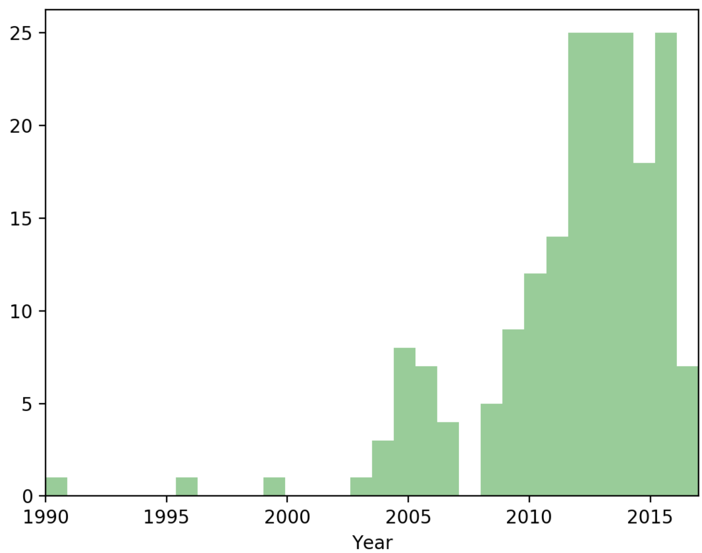

Fig. 1. Histogram for papers in the corpus along the years in which they have been published.

Table 3. Keyword Categories that Occurred More Than 10 Times within the Paper Corpus

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%

Notably, the keyword category of 'children' (including 'autistic children') is mentioned comparatively less considering the search parameters of this review.

Subsequently, robots appear to be one of the most commonly used technologies as can be seen in Figure 2. Other popular approaches are game-based or rely on screens (either stationary or mobile). Only about a fifth (18.4%) of the papers deal with more ubiquitous technologies, such as interactive environments or tangibles.

Table 4 presents the list of publication venues 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 papers in the most common venues are ultimately from Psychology and the others stem from general (13), children-related (14) or accessibility-oriented (14) HCI venues.

While not necessarily our primary focus, analysing which types of design processes are prevalent within the corpus provides us with an initial perspective on how autistic children might be involved from the start. Their participation in defining *what* they might need and *how* it should look like gives an indication on how the field acknowledges and validates their unique expert knowledge of their lived experiences. A vast majority of the papers (76.2%) take on a so-called 'informed' design approach. The authors reviewed the associated topic to their subject of interest

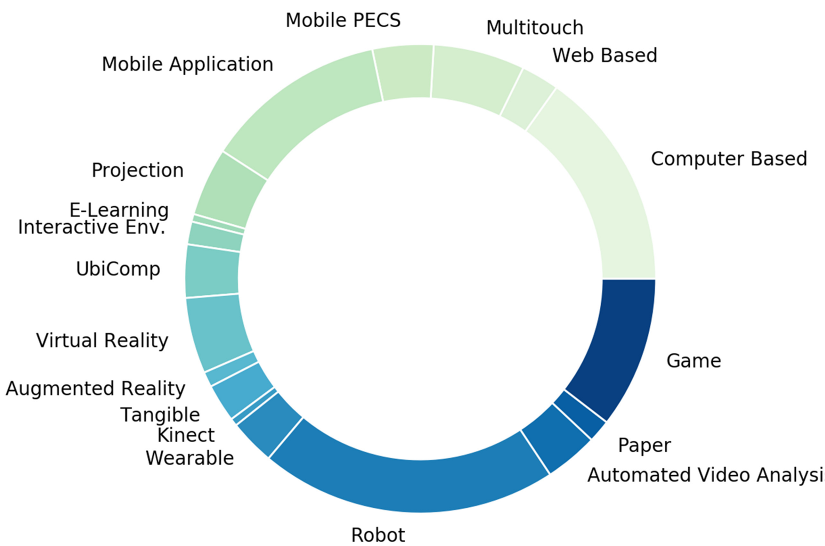

Fig. 2. Technologies used throughout papers in the corpus.

Table 4. Prominent Publication Venues (Five or More Times Listed in the Corpus)

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%

and then designed and often developed a technology based on that survey. In 11.0% of all papers, a Participatory Design (PD) approach is described. As this includes the two projects which have published the most papers within the corpus, this number has to be adjusted; then, only 7.3% of all projects applied a PD process.[8] Of the 21 projects involving stakeholders in design (as in: User-Centred Design, Informant Design and PD), 10 involved the children supposed to use the technology directly in the design processes. Other stakeholders included teachers (9), therapists (6), family members (9) or various other professionals dealing with autism from a research or practitioner perspective (4). Note that one project might involve more than one type of stakeholder. However, it is telling that about half of the projects actively allowing non-researchers to participate in the design processes did not consider the perspective of the children themselves in the design of their technologies.

[8]The distribution of PD methods across the purposes identified below is fairly even: all of them have one to four projects involving stakeholders in design, only the category *Behaviour Analysis* does not hold any participatory projects.

Table 5. Types of Evaluation Performed in Projects Involving Technologies for Autistic Children

Evaluation	#	%	Evaluation	#	%
Observations	71	37.2%	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	14.1%

We list common evaluation methods in Table 5. In total, 37.2% 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. Hence, a wide variety of evaluation techniques are represented within the corpus with a focus on analysing autistic children's behaviours with a technology through an outside (most likely neurotypical) view. It should also be noted that across the corpus, if the gender of participants is indicated at all, it is strictly binary,[9] there is no explanation of how it was assigned (presumably externally) and the overall distribution of boys to girls included is 9:1. This means, research into autism and technology is heavily skewed towards male participants as the general epidemiology indicates a ratio of 2:1 for diagnoses [48] and even those show a heavy gender bias [64].

Across the 185 papers in our corpus, we find a range of projects, technologies as well as design and evaluation methods. We now show how we analysed these technologies along the purpose to understand how they conceptualise the agency of autistic children more generally.

6 PURPOSE OF TECHNOLOGIES

We assigned the purposes to each paper in the corpus through inductive coding. In cases where more than one code fit, we assigned both codes to the paper. Figure 3 shows all final codes and subcodes in relation to each other. Our aim was to make the codes abstract enough to cover a core concept expressed in a paper, even though some of the concepts (e.g., 'Educating Classmates') only have one reference to show (compare also occurrence counts in Table 6 and Figure 4). These papers then have a unique purpose not seen in other papers within the corpus and through that offer opportunities for further development in that area. The high-level categories can be understood as *themes* of the technologies.

If the technology itself has a different purpose than strictly discussed in the accompanying publication, the paper has been coded for the purpose of 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 [e.g., 105]. Hence, the overall sum of individual instances for each purpose (199) exceeds the number of papers within the corpus (185).

After introducing each high-level purpose and illustrating them through examples, we discuss how they shape the resulting technologies and the agency of autistic children in interaction. Our 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 and the discourses they form through their purposes about the agency of autistic children.

[9] Doing so is likely to ignore queer identities (which children tend to express early on [179]) as indicated by research looking into gender variance among autistic people [135].

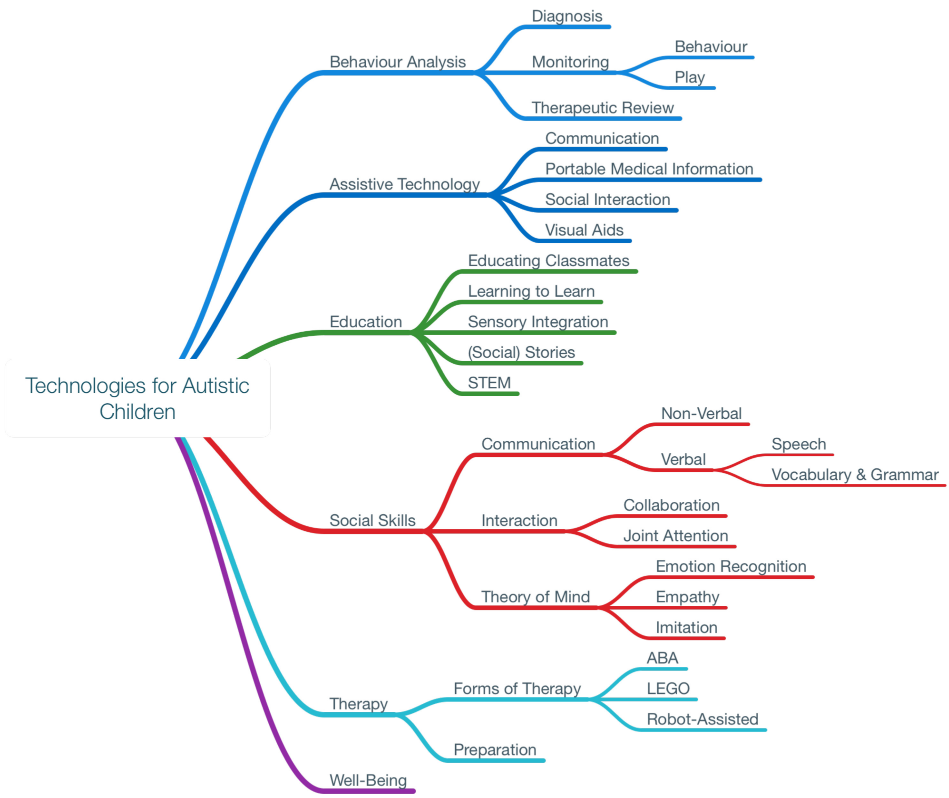

Fig. 3. Purpose of technologies for autistic children.

6.1 Behaviour Analysis

The purpose of a technology lies in behaviour analysis, if the focus is on recording data on an aspect, analysing the data and presenting its interpretation. Out of all papers in the corpus, 13.6% (or 26) follow this goal. These technologies predominantly rely either on video analysis or wearables that record movement patterns. The resulting observations classify behaviour to infer a potential diagnosis, monitor progress (with a special focus on behaviour during play activities) and reflect on therapy sessions for continuous improvement.

Different agendas drive the desire for technologies concerned with the analysis of autistic children's behaviour. Some aim at providing *diagnostic* information through a computer-based game [219], 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 [143].

Monitoring technology can be more generally focused on behaviour or, more specifically, behaviour during play activities. Some of the technologies monitor the children's development, e.g., through a portable audio/video recorder [255]. When focusing on the behaviour of children, the resulting technologies might use, for example, sensors in smartphones [61] or use cameras embedded in computers to analyse the children's attention while they interact with a program [175]. All projects monitoring play behaviour use social robots to do so [35, 96, 268].

Table 6. Occurrence Count of Purposes of Technologies for Autistic Children along Instances of References in the Corpus

Purpose	References	#
Behaviour Analysis		25
Diagnosis	[219]	1
Monitoring	[24, 123, 139, 142, 143, 145, 146, 181, 182, 255, 259, 271]	12//20
Behaviour	[8, 61, 151, 175, 182]	5
Play	[35, 96, 268]	3
Therapeutic Review	[14, 23, 143, 202]	4
Assistive Technology		22
Communication Aid (AAC)	[1, 38, 105, 107, 160, 212, 217, 246, 254]	9
Visual Aids	[1, 22, 126, 279]	4
Social Interaction	[118, 178, 211, 243, 245, 273, 275, 278]	8
Portable Medical Information	[136]	1
Education	[6, 13, 14, 51, 152, 157, 249]	7//25
Educating Classmates	[42]	1
Learning to Learn	[34, 78, 84, 115, 197, 238, 240, 256]	8
Sensory Integration	[28, 137, 205]	3
(Social) Stories	[7, 45, 71, 72, 77, 173, 241]	7
STEM	[82, 131, 162, 214, 227, 241]	6
Social Skills	[2, 17, 29, 60, 76, 83, 90, 110, 129, 147, 244, 252, 281]	13//89
Communication	[5, 91, 117, 119, 125, 128, 197, 213, 224]	9//23
Non-Verbal	[187, 208, 242, 247]	4
Verbal	[257]	1//9
Vocabulary & Grammar	[40, 104, 131, 170, 265]	5
Speech	[199, 225, 267]	3
Interaction	[3, 31–33, 98, 108, 116, 159, 195, 196, 206, 209, 250, 280]	14//31
Collaboration	[25, 41, 44, 86, 87, 102, 124, 132, 207, 258, 270]	11
Joint Attention	[4, 27, 222, 234, 235, 261, 282]	7
Theory of Mind	[103, 128]	2//21
Emotion Recognition	[11, 59, 66, 138, 156, 164, 171, 176, 187, 192, 203, 216, 218]	13
Empathy	[56, 180]	2
Imitation	[57, 79, 101, 128]	4
Therapy	[6, 53, 100, 122, 194, 272]	6//31
Forms of Therapy		22
ABA	[14, 23, 51, 143, 202, 248]	6
LEGO	[18, 132]	2
Robot-Assisted	[18, 36, 37, 39, 65, 67, 70, 109, 112, 132, 147, 148, 172, 201, 236, 276]	15
Preparation	[63, 218]	2
Well-Being	[47, 99, 166, 188, 189, 230, 232]	8

Even if worn directly on the body,[10] these technologies fade into the background of the lives of autistic children as they do not interact with them directly. Instead, the technologies ambiently

[10] The popular use of wearable technology appears problematic considering that studies tend to be geared to 'children [who] would be likely to tolerate wearing a device' [168], which ignores the different sensory processing [73] and sensitivities autistic children often express overall including their clothes [174].

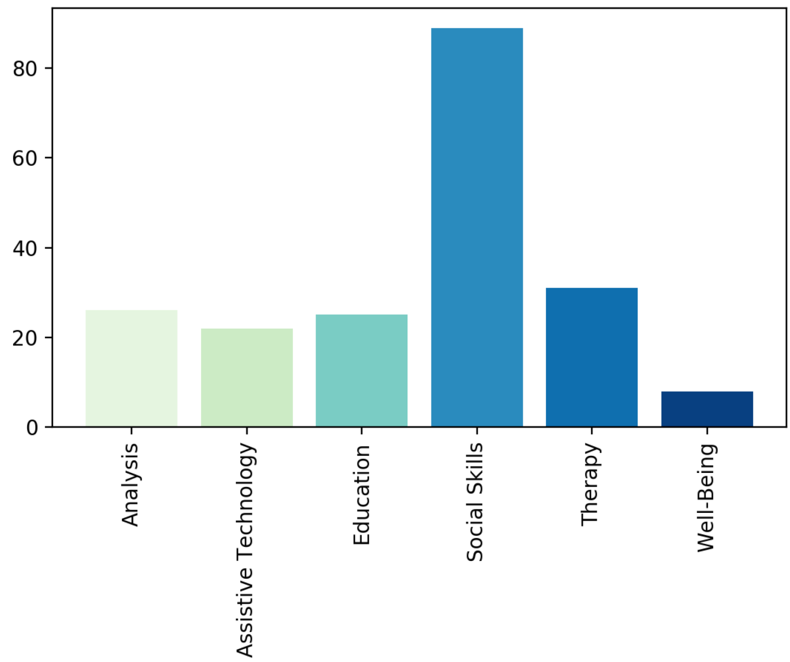

Fig. 4. Distribution of purposes of technologies for autistic children.

observe the children. Especially the part that is focused on analysing their behaviour is hidden and ephemeral to them as it does not require active engagement by or explicit assent of the children. Rather, they are reduced to data sources providing input to the systems that are then used by others to make meaning about the behaviour and condition of the children. An exception—to some extent—is the monitoring of behaviours during play as this is facilitated by social robots. However, the monitoring part is not obvious 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 presumed play partner, they do so for an external purpose, namely monitoring their play behaviour. The children's motivation of playing is different than researchers' or parents motivation of observing them. Hence, these robots have to fulfil the desires of two different agendas that are in place in that context, where not all intentions are explicit to all participants.

Hence, autistic children are *secondary users* when it comes to technologies for behaviour analysis. Even when interacting directly, e.g., with a robot, they do not initiate, choose or intend all ongoing activities, but rather do so embedded in the desires of adults around them to understand more about the children. 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. The technologies act here as mediators for the adults' interpretation of the children's behaviour and facilitate further decision making that impacts the lives of autistic children.

6.2 Assistive Technology

Strictly assistive technologies aim at 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 11.5% (22) fall into this category, 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 one provides a system for portable medical information.

Following a medical notion of assistive technologies as mitigators of functional limitations assigned to the children, AAC devices primarily use pictures and associated audio output (e.g., in [246]) to enable nonverbal children to communicate in a way that the adults around them can comprehend. Already existing physical devices with buttons can be expanded with tremendously more options (and even at a later point) when digitally implemented so that different buttons can take on different functions that change according to context. Visual aids (e.g., [279]), 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 socially appropriate (e.g., [278]), to understand more about the current social-emotional context as established by others and one self (e.g., [211]) or prompt them to initiate social interaction, for example, through vocalisations (e.g., [118]). Finally, the application providing portable medical information to autistic children [136] can communicate certain needs to those assisting in crisis situations, where a child might not be able to express them otherwise.

The technologies extend autistic children's abilities [158] or function as a lens into their environment. They use them whenever their modes of expression fail or, inversely, to make sense of what the environment is telling them when it fails to make itself understandable to autistic children. As the technologies are conceptually tied to a notion of failure, 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. Hence, these technologies incorporate a medical model of autism. The potential refusal of such assistive technologies can then become a revolutionary act of defining and conceptualising the self as a powerful, but different entity (akin to, e.g., refusing to use Facebook, [198]). Subsequently, these technologies also imply that neurotypically oriented communication is a desired norm instead of trying to aim for a more mutual understanding (with one exception further below).

While autistic children are the *primary users* of assistive technologies, the use of these technologies happens out of a joint desire for understanding between autistic children and allistic adults/environment. The communication is inherently limited to aspects that designers of these technologies have implemented. As autistic children are sometimes included in the design of these technologies, 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 as a need of the child.

6.3 Education

Educational technology provides autistic children with classical educational content that does not target their social skills. Overall, 25% of the papers in the corpus had an educational purpose, where seven of them do not address a specific topic as such, but are more generally concerning education. About a third sets the context for learning and assists autistic children in acquiring meta-skills essential to learning more generally. Other papers focus on sensory integration (3), storytelling and social stories as a way to understand narrative and social interaction (7) as well as topics of science, technology, engineering and mathematics (STEM; 6).

Most of these technologies discuss different forms of content provision (e.g., [152]) or show how different therapeutic principles can be adapted (e.g., [13] for Applied Behavioural Analysis (ABA)). To elicit empathy for autistic peers Bratitsis used digital storytelling [42]. Supporting autistic children in learning to learn is based, for example, on Internet-of-Things (IoT) devices ([240], augmented reality [84] or a visual game for generalisation skills [115]. 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 [28], tangibles [137] or body capture on a projected screen [205]. Narration and storytelling also receive extra attention, especially when it comes to social stories [e.g., 72]. These technologies are all screen-based. Finally, several papers focus on STEM-topics by providing learning environments [e.g., 214, 241], interactive e-books [e.g., 131] or robots [e.g., 162].

Educational technologies offer autistic children new opportunities to learn more about the world and the social contexts they live in. While this potentially allows them to then 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 regular routine, but rather singular in use (see for a discussion on anxiety induced by change of routine [186]).

The children engage with these technologies directly and are *primary* users in that they are supposed to learn from what the technologies provide. However, the content is either given by the system or set by teachers around them. Autistic children cannot use these technologies to actively investigate their own interests. The strict boundaries in which they can engage with these technologies are extrinsically defined as is the educational context they are embedded in. We are not trying to argue that autistic children should not be educated or that these technologies are not appropriate for them. However, the children engage with them mostly through being directed to the interaction by a teacher or other carer. The technologies are more tied to curricula and external learning goals than supporting intrinsic interests or 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. While this might be similarly the case for allistic children, the particular power relationships autistic children are embedded in exacerbate this issue.

6.4 Social Skills

The majority of technologies for autistic children aim at Social Skills; be it acquiring them, facilitating social situations or supporting the children during these moments. In total, 48.1% of papers fall into this category. This comes to no surprise seeing as technologies in this section directly engage with the core characteristics of the condition as ingrained by a medical model understanding of autism. Among the skills are communication skills (25.8%), including non-verbal and verbal aspects, where verbal aspects are again split into formal (vocabulary and grammar) and informal (speech) elements. Further, the papers discuss parameters of interaction (34.8%), concrete collaboration and joint attention. Finally, 23.6% of papers specifically address Theory of Mind. In this subcategory, most technologies concern themselves with emotion recognition, followed by imitation and only two target empathy directly.

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 [76]. In one of the rare cases of PD, Porcino et al. created a game through which autistic children can engage more with communication [197]. Robots are used to teach the more nuanced aspects of non-verbal communication (e.g., [187]), whereas verbal components such as vocabulary [104] and speech patterns (e.g., pronunciation) [267] tend to use more classical forms of screen-based interfaces—on either mobile or stationary devices. Interactive technologies tend to be mobile (e.g., [3]), or—as is the case for most cooperative technologies—facilitated via large displays (e.g., [124]) or physicalised technologies (e.g., tangibles [250] or robots [207]). Whenever joint attention is the subskill autistic children are meant to acquire, technologies facilitate this in different ways, e.g., combining rhythm and robotics [235], embedding robots within a larger technological system [27] or, again, using screen-based methods [282]. Technologies addressing theory of mind use narration [103] and—chiefly when focusing on emotion recognition—virtual or realistic facial representations (e.g., [176, 216]). Rarely, the concept of emotional expressions on the entirety of a human body is conveyed (examples include [4]). Empathy is taught only (through virtual reality [180] and computer software [56]) and not facilitated in action. Finally, robots are often used to encourage (and observe) autistic children imitating others (e.g., [101]).

Autistic children might express their social skills differently, especially compared to allistic adults. Hence, these technologies are a source of learning and encountering new aspects about how to interact with others in a predominantly neurotypical society. This means they can be a source of social anxiety [155], but they might also enable autistic children to learn strategies for coping in such an environment. However, different to education, these technologies are very one-sided. As such, the children are required to learn the modes of interaction that are deemed as appropriate by neurotypical adults without the adults having to learn about how autistic children might want to engage or reflect on the notion of withdrawal as a social interaction. This way, interacting with the technologies happens in a space where autistic children are required to engage with something that they might feel genuine pain with as first-person accounts of autistic people indicate (e.g., for eye contact [113]).

While autistic children are the *primary* users of this type of technology, allistic people around them and as predominant group in society at large are secondary users. The content of these technologies is driven by the perceived functional deficits that comprise a diagnosis of autism and the particular social expressiveness of the condition. Hence, the efforts are at teaching autistic children how a neurotypical society expects them to engage instead of (also) teaching neurotypical people about the many ways in which autistic children might prefer to communicate and how to be attentive to find out this out for a specific child.[11] While learning contexts and disciplining technology for facilitating social interactions in-situ are very dominant, we also found many games and play scenarios aimed at improving the social skills of autistic children. However, in such a context play is associated with an extrinsic purpose. It is not conceptualised as positive experience lead by an intrinsic desire of an autistic child, but embedded into the extrinsic agenda of their social environment.

6.5 Therapy

In total, 16.8% of papers in the corpus discuss technologies specifically for therapeutic settings. While technologies in other categories might be part of an intervention, the ones in this category follow a specific medicinally driven therapeutic approach. 'Robot-assisted' therapy, though, is not a formally recognised approach that follows a strict path. It is still included here as the robots are meant to augment and further support traditional approaches. Other therapies such as Applied Behaviour Analysis (ABA)[12] and LEGO[13] based activities consist of formal paths. Only three papers assist carers in preparing therapeutic sessions.

The technologies show no orientation on a cohesive therapy or commonalities on a technological level. For example, Alessandrini et al. suggest the use of audio-augmented paper for therapeutic sessions [6], whereas Caro et al. created an exertion game engaging in motor coordination exercises [53] and Pickard et al. discuss how a physically absent therapist can be enabled to

[11] Notably, though, one exception in this corpus exist [42].
[12] A rigorous approach of analysing and reinforcing desired behaviours [16].
[13] An approach based on collaborative construction using LEGO building blocks.

guide parents through an intervention [194]. When it comes to ABA, most of the technologies are computer-based and support either structured learning (e.g., [23]) or constant monitoring of therapeutic efforts (e.g., [143]). Both papers concerning LEGO therapy [18, 132] use robots as well as all papers concerning robot-assisted therapy[14] (e.g., [172, 276]). 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 [63] and a game engine for serious games [218] are available.

We found it notable to see how many of these projects try and involve robots in therapy. Mostly, this stems from the notion that autistic children appear to appreciate structure and predictability [62]. Hence, incorporating robots might be a gateway for interaction with neurotypical people, and ultimately preferable from the viewpoint of autistic children. The context in which these technologies are embedded in might be more relevant than the potential enjoyment with them as they are.

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, 114], 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 [229] 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) [154]. Seeing as the approach requires up to 36 hours of weekly intervention [80], 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 [75]. This emphasises a change in the autistic child at such great expense that it presupposes that the child is implicitly conceptualised as an entity that is in need of 'correction' and 'improvement', without including a notion of acceptance of different ways of being in the world.

6.6 Well-Being

In the category of 'Well-Being', we grouped seven (3.8%) papers describing fun, engagement or, more generally, the facilitation of positive experiences especially tailored to the needs and interests of autistic children as the main purpose of a given technology. As these seven papers are spread across only three projects, we deemed it unfeasible to add subcategories.

Two of those projects are very similar: MEDIATE [188, 189] and Responsive Dome [47]. Both are sensory installations spanning up a large space for exploration. The third project is OutsideTheBox [99, 166, 230, 232], which two of the authors were involved in. Here, several ubiquitous smart objects were created with individual affordances for each child that the researchers designed with.

Autistic children encounter the sensory installations rarely and only have limited access to them. Large spaces are required to install them; hence, it is unfeasible to incorporate this type of technology in the home environment of most children. Engaging with these technologies comprises a special experience, which, according to the related publications, appears to be positively connotated. The experiences tied to the technologies developed in the OutsideTheBox project are situated in the individual context of child and interaction. Overall, though, we can say that the PD process is part of that experience and, hence, interacting with the technology means interacting with a design process as well leading to surprising use scenarios [231].

[14]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 [52].

As *primary* users autistic children are often in control of these technologies. They can decide whether to engage with them and regulate time and modes of interaction by themselves—within reasonable boundaries. However, as the sensory installations are special event technologies, the children rely on the adults around them to acquire access. Whereas refusal is a practical option for the children once the possibility is offered to them, initiation is difficult and cannot be achieved in a self-driven fashion. Similarly, parents and caretakers had to agree to their children participating in the OutsideTheBox project, which makes them gatekeepers between the children and the technologies.

6.7 Summary

While in most of these contexts, autistic children are the primary users, they rarely interact with the technologies in a self-determined way. Most of the technologies are driven by a medical model of autism or the requirements to coping in a neurotypically dominant environment. In their majority, the technologies are not primarily for autistic children as such, but instead focus on the needs for interaction from the predominantly neurotypical people around them. As the experiences of the autistic children are secondary to the externally driven purpose of the technologies, the children's perspectives are also secondary in the evaluation of these technologies. Room for their agency is conceptually limited, but, as we show in the next section, autistic children play a discursive role in the development and presentation of these technologies.

7 POWER DYNAMICS—AUTISTIC CHILDREN AS PARTNERS IN TECHNOLOGICAL RESEARCH

The design of technologies for autistic children encompasses several power dimensions that are often more entangled and complex than in cases where adult designers create technologies for comparatively privileged neurotypically presenting adult populations. Autistic children engage on several dimensions with adult researchers: they are considered as children and additionally as autistic. While the agency of children is more generally a complicated issue to navigate particularly in participatory research [127] and autistic adults similarly are continuously othered by a scientific gaze [260], autistic children make the intersectional experience of reduced agency not just as children or as autistic, but precisely as autistic children. Taking a lens of intersectionality [68] means that we understand the experiences of autistic children not made up by the combined experiences of children or autistic people separately, but instead create a distinct marginalisation as *autistic children* [161]. For example, most technologies for autistic children are presented within a medical model here, actively pathologising the autistic child. While technologies for the population of young children also predominantly focus on education, there is no inherent assumption that not knowing certain contents is a 'problem' of the individual child.

We now discuss the language that surrounds the research on these technologies, how autistic children are constructed as users and how they can or cannot take part in making and defining the meaning of a technology.

7.1 Autistic Children as 'Other'

The dominant language used across research detailing technologies for autistic children constructs them as different from authors or readers, as objects of research instead of subjects. This can take on different forms, for example in technologies for behaviour analysis autistic children are in the focus of observation, an 'object of interest'. Other technologies aim to 'correct' the children's behaviour, which then is conceptually the output of a given technology. One reason for this is might be that autistic children remain fairly isolated within scientific discourse and are mostly conceptualised as deviant from a given norm. Considering the portion of technologies aiming for therapeutic settings, autistic children are not only constructed as different, they are vehemently constructed as an *other*.

'Othering means turning the other into an other, thus creating a boundary between different and similar, insiders and outsiders' [74]. Such othering is not necessarily problematic. For example, by putting the focus on this population and identifying them as a group of special interest to which we as partly allistic researchers and our readers most likely do not belong, we follow here the very basic concept of othering: '[T]he idea of *othering* (...) derives from the presence of different and politically labeled minority others in our societies' [ibid]. However, across the texts within our corpus autistic children are presented as deficient and less than. 'The other is also often described through a deficit framework, that is, s/he is not as good or capable as "we" are, which leads to stereotypes and other forms of representation'. As technologies and the writing about technologies contributes to the representation of autism as a personal and societal factor, the purposes these technologies have, buy into stereotypes and potentially perpetuate them if not critically reflected. For example, the assumption that autistic children might engage with technology more productively because some might prefer structure, sameness and predictability, means that together with recent stereotyping of technology as a predominantly gendered activity for men [88], potentially reinforces the popular image of autism as a primarily male condition [153]. This on the other hand creates a barrier to access for people who do not present within this narrow (and gendered) spectrum as they are confronted with later diagnosis and continuous defense of their own difference within the autistic community [264].

As per the corpus, the children are conceptualised as external to authors and audience alike. As per the technologies that are developed, the children are further understood as 'other', which has to be observed, analysed and corrected. Even in cases framed as assistive, these technologies operate from a medical model. Researchers identify deficits compared to neurotypical strategies and then create technologies aiding in autistic children not to find their own coping mechanisms and strategies but to adopt the ones allistic adults deem suitable to them.

Additionally, most of the research above does not acknowledge children's agency in defining what kinds of technology are appropriate for them—contrary to how there are strong movements within HCI that consider how computation and the design of technologies can empower children (e.g., [133]) but entirely in line with the systematic exclusion from society they experience [263]. The need for technological intervention is defined by allistic adults. Further, the technologies stemming from this research are constructed as active solutions for predominantly allistically defined issues. This leads to the inversion of agency, where the technology is constructed as more active than the children: While the technology gives, changes and teaches, the child consumes, receives and adapts. Hence, a large portion of the currently existing research into technologies for autistic children constructs a view where the technologies become extensions of the pre-conceived notions of an allistic environment that expresses normative expectations of how the children have to develop and behave without necessarily considering their comfort and well-being. Instead, research focuses on the priorities of allistic adults, as can be seen by the overwhelming dominance of technologies for 'Social Skill' development without aiming at an understanding of how autistic children might express themselves socially [73].

In a similar vein, most papers introduce and discuss autism from a medical model perspective (see, e.g., [167] for the prevalence of this perspective in research on assistive technologies). From such a perspective, autism is placed within the individual child, who then is expected to change in ways that fit more into allistic societies. Within the corpus, only one paper presents a technology for educating classmates of autistic children about their particularities embodying such a stance [42]. Dominant understandings of autism as a *disorder*, a state, which is out of order and, hence, in need of correction, are embodied in all of the technologies in the categories of Analysis, Assistive

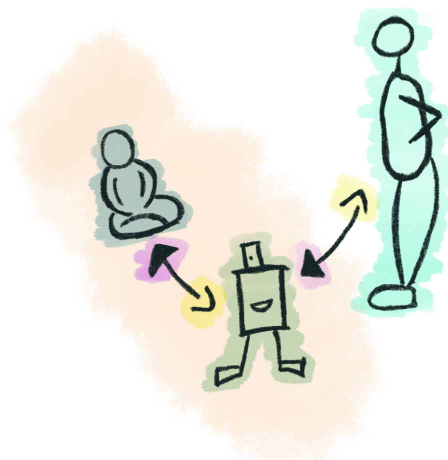

Fig. 5. Triangle of use in most technologies for autistic children. The shaded area indicates how it is predominantly presented by the research; the open arrows indicate the flow of behaviour and information, whereas the filled arrows show how neurotypical expectations are mediated to the child through the technology.

Technology, Social Skills, Therapy and to limited extent in Education. Hence, the technologies embody an understanding of autistic children as outside an expected norm, as a *deficient other*.

To avoid this 'othering' trap, we suggest that allistic designers see themselves in a partnership with autistic children. While the frame of PD might offer the most straightforward approach to achieve this, we consider this a more general stance that can be used with any methodology. Involving autistic children or adults then not only relates to them deciding the colour of a preconceived technological setup, but rather providing them with adequate agency in the process. This means that the design of technologies involves autistic children as stakeholders much earlier, when it concerns the definition of needs and desires a technology should address. Instead of defining that autistic children need, for example, to be observed and taught, technologies might then also focus on how allistic adults could be more attentive to cues. To conceptually include autistic children in the 'we' that defines the research community, allistic designers might appreciate the notion of thinking of autistic children as different but same. A useful exercise in this context might be to reflexively think of oneself as other in the research and apply othering practices to oneself to start reflecting on them and working on overcoming them.

7.2 Defining the 'User'

Not only autistic children but also their parents and carers interact with the technologies in our corpus. The latter are often discoursively hidden as stakeholders in the direct use of a given technology (see Figure 5). The technology mediates allistic expectations stemming from a neurotypical view on autism. Allistic adults one-sidedly define and determine the purpose of these technologies. The children have nominally no agency in deciding which forms of interaction are relevant to them.

From the point of view of the technologies, autistic children serve different purposes to them:

(1) they are posed as sensor input for analysis (e.g., in behaviour analysis),
(2) they are conceptualised as data output via exhibition of correct(ed) behaviour or skills learned (e.g., in therapy or social skills) or

(3) they are recipients of external information in a way that allows them to process them more appropriately to their perceptions (e.g., visual schedules)

Only in a few cases, the technologies enable self-guided interaction (e.g., in some play technologies). Devices for Alternative and Augmented Communication fall between the cracks of these distinctions: While intended to translate autistic children's communication towards an allistic audience, the design and technical limits of these devices restrict what can be said and how the children can articulate their thoughts within these narrow boundaries (see also, [9]). While allowing some agency for autistic children in use context, this agency is limited to tightly set boundaries.

The research around technologies for autistic children, hence, predominantly does not result in technologies for them, but instead targets the normative concepts and desires of their mostly neurotypical social environment. This adds to the isolation of disabled people among predominantly non-disabled individuals instead of fostering community and companionship [177]. The majority of technologies and the research around them manifest a perspective that conceptualises disabled people as passive and without agency. Autistic children in combination with these technologies conceptually establish a socio-technical construct that an allistic environment interacts with. As the technologies are designed, introduced and facilitated by allistic stakeholders, access and interaction are equally restricted and regulated.

An alternative could lie in designing technologies, which aim to be meaningful for autistic children from their own point of view and acknowledges their agency. These should allow for individually determined access of autistic children to the technologies and would not rely on an allistic environment to facilitate the interaction. That does not mean that they should exclude options for collaborative engagement between different autistic children or the children and their allistic social context. However, the research on technologies 'for' autistic children as it presents itself currently ignores how the core stakeholders are not the children, but, instead, predominantly their parents and carers.

7.3 Making Meaning of the Technology

Only a select few of the papers outside the well-being category in the corpus directly investigate the children's perspectives on an artifact or software. Instead, most of them rather inferred their perspective either from observations, via proxies (e.g., parents or teachers) or not at all (see also Table 5). Hence, autistic children have little direct say in meaning-making about a technology presumably made for them.

Including children in the design of such technologies is only a first step. Even though 7.6% of the papers in the corpus reference PD processes with autistic children as part of the development of technologies, only 1.6% include children in defining the initial purpose. Most of the projects come with a preconceived notion of the type and purpose of what should be designed and reduce the children's power to provide content for predetermined applications (e.g., [1]). While this is an important first step in broadening the inclusion of autistic children, it does little to challenge the status quo of how the technologies are embedded in the children's lives.

The call, for including disabled people more generally in the research on technologies that are intended for them, has been made before [167]. Others have shown that making space for disabled people to articulate their needs according to their interests creates design spaces that are meaningful to researchers and disabled people alike. For example, Elvitigala et al. designed an alternative for indicating start times to deaf swimmers and realised that different information is relevant for deaf swimmers [81]. An exception within the corpus can be found in our own work within the OutsideTheBox project [232]. There, we developed a Thinking Machine, which allows people to reflect on situations of high intensity (positive or negative). The idea for this concept stems from the collaboration with a then six-year-old. Hence, involving autistic children in PD and allowing space for their agency does not necessarily mean leaving out the space for more therapeutic or socially oriented technologies, but creating them in a way that is meaningful and relevant to the children instead of solely to their neurotypical environment.

As most other technologies are driven by a medical model of autism and requirements to encounter it from a neurotypically dominant environment, they are, in their majority, not actually for autistic children but instead alleviate the needs for interaction from the primarily neurotypical 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 autistic children subsequently become secondary for the technology to achieve the desired outcomes. Hence, they are also second in the evaluation of these technologies. Inquiring into these experiences means asking radically new questions about autistic children's perspectives, their meaning-making and their agency in use. Additionally, researchers need to be open for alternative ways of communication and actively engage with autistic children on their terms [233]. 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 rare so far (e.g., [230]).

8 CONCLUSION AND FUTURE WORK

Our starting point was the increased interest into technologies for autistic children in research leading to actualised technological artefacts. While, previously, design methods and technology oriented analyses have presented new avenues for understanding the design space, our lens was on the agency of autistic children surrounding the purpose of technologies.

Via a thematic discourse analysis of 185 papers, we identified six categories for the purposes of technologies for autistic children: behaviour analysis, assistive technologies, education, social skills, therapy and well-being. These categories show a predominant focus on corrective, *othering* approaches. These technologies are not directly intended for autistic children either, but embedded in social structures predominantly oriented to neurotypically presenting adults. The technologies embody and negotiate these neurotypical expectations.

8.1 Limitations

A limitation of our work is that it fails to illustrate how these relationships look like for adolescents or adults. The purposes and ideal contexts of use for the technologies might be additionally confounded by the fact that they are targeted at younger children, who are not conceptualised as having a lot of agency due to their age and dependency on their environment even when they are allistic. From our experience, we expect that the notion of othering would then shift slightly in that technologies are geared towards enabling employment and self-sufficiency as to avoid societal responsibilities in caring about autistic adults.

Further, by explicitly excluding formative work and focusing on the technologies that are physically manifest, we might not have captured those works that already strive towards more inclusion of autistic children within the design processes of technologies. However, it should be noted that it can also be problematic if the field predominantly involves autistic children in the early, fuzzy stages of design but ends up predominantly producing technologies that further their marginalisation. Additionally, simply including autistic children in design processes is not sufficient as a counterpoint if their participation is not fundamentally meaningful and shapes the type and meaning of the technology alongside more aesthetic features.

8.2 Contribution

In conclusion, HCI lacks technologies that enable autistic children to engage with them in a self-determined way. Creating and making technologies available to autistic children that matter to them can help normalising neurodiversity. Further, more technologies guiding neurotypically presenting children and adults in their engagement with autistic children provide an additional way of supporting that goal. Researchers and developers of technologies for autistic children need to carefully reflect on how their work fits into the larger field and how it might contribute to the further marginalisation of autistic children. In illustrating the current state of the field, its dominant focus on a medical model of autism and issues surrounding the agency of autistic children with the technologies meant for them, our work can guide researchers in taking the first step towards such reflections.

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