

Co-designing with adult people with ASD: A review on applied tools and techniques

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In recent years, more and more research has been contributed in regards to the autistic spectrum disorder (ASD), which has provided new approaches to support individuals that are diagnosed in such a way that specific needs and challenges are becoming acknowledged, yet along with this process further complexity is added to the requirements for suggested solution concepts. In response, HCI has taken a further interest in researching with regarded 'vulnerable groups of individuals, in which individuals with ASD has been recognized for its potential within the field, where new possibilities for assistive technologies are being developed on. However, how closely researchers and designers involve participants of the demographic during the design process of the development is in some cases unclear. Moreover, when facilitating activities that call for collaboration with the participants, usage of appropriate co-design tools are frequently applied, yet documentation of how these tools were chosen during preparations are often lacking. In order to gain a better understanding of why this may be the case in ASD-related studies, this paper aims to establish an overview of tools and techniques applied within these studies, as well as a comprehensive implication of what areas of ASD the field of HCI is engaged to make contributions for. In establishing this overview, the paper presents a scoped literature review that surveys accepted papers from high regarded HCI conferences, in which the review started with 267 papers and filtered down to 8 relevant papers. The review resulted in six categories of applied tools and techniques: *observations, interview, make tools, design workshop, prototyping and survey*, as well as four domain areas of ASD-oriented research: *social skills capabilities, practical challenges, need for assistive technologies and personal well-being*, which are elaborated on in the findings and then reflected in the discussion. The paper then concludes with no future implications in regards to domain areas of ASD-related research, as findings showed an equal distribution of contributions in the established categories. In contrast with tools and techniques findings, it provides a starting point for future research, where the need for more reflective decision making is addressed needed when choosing appropriate tools and techniques for collaborating with ASD individuals.

Additional Key Words and Phrases: autism, co-design, scoped literature review

ACM Reference Format:

Jacob Hjulskov Ravn. 2023. Co-designing with adult people with ASD: A review on applied tools and techniques. 1, 1 (January 2023), 15 pages. <https://doi.org/10.1145/nnnnnnn.nnnnnnn>

1 INTRODUCTION

Autism Spectrum Disorder (ASD) is classified as a neurodevelopmental disorder and are characterized by symptoms that affect the sensory, perceptual and cognitive senses to a varying degree depending on the individual person. The outcome of the diagnosis may lead to challenges regarding communication, expression, sensory perception and socializing

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Manuscript submitted to ACM

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53 with others, where in order to cope with these challenges, strategies that involve creating familiar and repetitive
54 patterns that contribute to the creation of structure are required [3]. However, while this description address what
55 could be considered 'vulnerable' flaws, at the same time, many individuals on the autistic spectrum shows signs of
56 being intelligent, creative, deeply invested and motivated to certain interests in such a way that they can contribute
57 substantially, as long as the necessary support is accounted for [16]. In past years the demographic of those who have
58 been diagnosed have been facing marginalization in that it has been viewed as a sickness and have been trying to 'fix it'
59 i.e. through dietary means or even worse, through surgical procedures. However, recent developments report that this
60 is thankfully not the case anymore, as the general perception of the disorder has shifted towards a more accepting
61 behaviour [13]. While the disorder is described as a spectrum, it means that other related diagnoses such as Asperger's
62 syndrome, ADHD, OCD etc., may be found in addition to the prior ASD diagnosis for some individuals. However, when
63 seeking psychological treatment, most therapists begin with targeting symptoms and challenges that are related to
64 autism, then branching out to the other diagnoses afterwards.

65 In terms of the magnitude of the disorder, according to the Center for Disease Control and Prevention (CDC), it is
66 estimated that about 1 per cent of the entire world population (the equivalent of being about 75000000 people) have been
67 diagnosed with ASD. Moreover, research suggests that boys are four times more likely to be diagnosed with ASD than
68 girls, yet a resurgence in recent studies suggest that diagnosing females is becoming more accessible when they enter
69 the early stage of their teen years, which is where they show signs of the disorder [6]. The general estimation is further
70 supported by WHO (World Health Organization), who suggest that about 1 out of 160 children is diagnosed with autism
71 [19]. In terms of how many individuals that are not diagnosed or are in their later years is entailed by the disorder is
72 unknown, but the number presumably is presumably higher than anticipated. However, as more research goes into
73 autism, more is known about the disorder in regards to providing early diagnostics as well as early interventions
74 and better solutions. In contrast, the outcome of this progress may result in more complex challenges and require an
75 immense amount of effort in developing appropriate solutions that reduce the significance of individual hardships.

76 As more interest has been exhibited from the community of HCI in working on studies that involve 'vulnerable users'
77 and current views on ASD being more prominent in today's society, it has led to a growing attraction in developing
78 assistive technologies for demographic, where various contexts are presented and are addressed in either a wide-range,
79 i.e. "one-size-fits-all"-solutions or more determined to solve one particular aspect of the disorder [16, 18]. However, how
80 researchers proceed to include the demographic in contributing to their solution is seen to a varying degree of success,
81 where preparations and documentation regarding their approach to the collaboration are brought into question in this
82 scoped literature review. Hence, the practice of co-design plays a pivotal role in examining this aspect of ASD related
83 research due to its suitable view in intimately involving users in the design process of developing appropriate solutions.
84 Moreover, in which specific areas of ASD is the field of HCI attempting to make a contribution and what other areas
85 may be neglected in this purse. As an outcome of this consideration, this paper is primarily focused on answering the
86 following research questions:

87 *RQ1: What ways have co-design been used in research within the field of HCI with adults with ASD?*

88 *RQ2: Which problem domains are focused on in the field of HCI?*

89 The paper starts by outlining work related to prior ASD-related studies within HCI to establish a mutual understanding
90 of the primary intention behind those studies and establish the co-design principles in terms of why it is applied and
91 when it is used. After that, the scoped review begins by selecting literature from highly regarded conferences within
92 HCI, which is then followed by two filtering phases with established criteria toward a final data corpus. Subsequently,
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105 the result of the review is presented in the findings and are later reflected on in the discussion, then concludes with
106 future design implications for researchers who may be interested in pursuing ASD-oriented HCI studies in the future.
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109 1.1 Motivation

110 As an interaction designer, who is particularly diagnosed with Autism at the age of 14, which is still present at this time
111 of writing, my motivation for this kind of scoped literature review is two-folded.
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113 First, by being a part of this demographic, my approach going into this may be somewhat biased as I draw on
114 my own experience, observations and understanding, as well as that of close friends and acquaintances who are also
115 placed on the spectrum to the varying degree of being high-functioning or the case being much more severe, where
116 the focus is shifted towards of being on the spectrum and it following challenges and benefits that are present on
117 a "day-to-day"-basis. Knowledge regarding this perspective may involve referring to particular situations that are
118 most cumbersome or strategies that may or may not be acknowledged by professional therapists or other relevant
119 stakeholders as it can be comforting for individual cases.
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121 The second perspective is that of the interaction designer, which adopts the knowledge and willingness to improve
122 the quality of life of target populations through their experience and use of technology that contributes to shared
123 understanding in the field of HCI among peers.
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125 In summarizing how the two perspectives interchange, as a designer, I seek to ease accessibility for work with this
126 particular demographic by providing the level of tangible knowledge that is necessary for peers to make their own
127 contributions. Whereas in contrast to being part of the demographic, I want to secure an approach that is not being
128 interpreted as invasive of one's personal life, which asks for complex and detailed descriptions, which to some might
129 be overwhelming and ensue more disruption rather than solutions, improvement or empowerment in the given case.
130 Hence, comfort in venturing into unknown territory, creating familiarity from where there were otherwise none prior
131 to this area and providing a shared space of mutual understanding between designer and user is the highest priority
132 going into this review.
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136 1.2 Contribution statement

137 This paper contributes to the body of knowledge of ASD-oriented design research by establishing an overview of
138 current trends on the usage of a selection of tools and techniques in regards to co-design practices, as well as what
139 domain areas of ASD does recent HCI-related studies seek to make a contribution within. As the findings of the review
140 are two-folded, the first part suggests that while some tools and techniques such as interview are highly utilized, other
141 formats such as design workshops and prototyping are however outperforming in comparison; Second, the established
142 domains from the review are almost evenly distributed in their respective domain, which resulted in no further effort
143 to draw any meaningful implications of which areas of ASD-related studies receive noticeably more attention and
144 which does not as part of the process. By the end of the paper, I found that not many studies reflect on their choice of
145 appropriate tools and techniques in terms of collaborating with individuals diagnosed with ASD, which lead to the
146 main contribution of the paper that raises questions in regards to what is required by appropriate tools and techniques
147 for ASD-related studies to be viable co-design tools? as well as what are desirable traits for specific tools and techniques
148 to be chosen over others given the context? And finally, how are co-design tools used in the occurrence of unforeseen
149 events during sessions?
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2 RELATED WORK

For this paper, two main areas are relied on prior to conducting the review, mainly that of how autism is understood within HCI and how they are generally involved as well as establishing what co-design is and how its practices are utilized.

2.1 Autism in HCI

According to Waycott et al., the HCI community have a growing interest in researching in sensitive settings and include the involvement of participants that are considered "vulnerable", which ranges from a variety of diverse groups that experiences being marginalised, disadvantaged or particular groups, i.e. people who are homeless. Among one of these groups stands psychological disorders such as autism, who among many others, face common challenges in handling complex issues in terms of complex emotions, social isolation and mental well-being. In their work, they conducted a series of case studies for different groups with the intention of designing technology to aid the given demographic in some way. However, when they performed their study with autistic participants, the focus was shifted from creating a novel device to emphasising behavioural use of technology and learning in social settings, which were the targeted context [18]. This particular development could be considered to be contributing towards empowerment, which seems to be a common theme within other related studies that focus on research that includes autism. To elaborate on this, the study of Dijk et al. took a specific approach in exploring new ways of empowering young autistic adults in a home setting, which were done through the use of an IoT system. The system prototype that they used would help their participants in self-managing domestic activities to specific needs, i.e. transitioning from being in a working mindset to taking a break and vice versa. Their results of the study would then contribute with four reframings of 'empowering technology', which were mentioned as follows: 1) From 'planned reminder' to 'situated attention grabber', 2) From 'supporting action' to 'scaffolds for developing own supportive routines' and 4) From 'assistive product' to 'co-design tool in a larger transformational process'. Aside from their profound findings in relation to their work, their approach to their project was aimed to go against a possible dismissive trend in developing assistive technologies for this demographic. They had observed that most technologies were developed with the goal of creating 'one-size fits all' solutions, which is based on generic traits of ASD due to the influx of cognitive and social challenges, but with this process, it comes with the cost of ignoring individual interests, talents and contexts [16]. Addressing why this neglect is present in some case studies may be difficult to understand to its fullest from the HCI researcher's perspective. However, the study of Corlu et al. aimed to analyze this perspective regarding the struggles encountered in studies with the involvement of autistics. From analyzing 98 papers in a literature review, they were able to identify more than 50 problems of significance, which were summarised into five conventional parts for reducing the amount of intertwining issues; the parts were focused on the following: 1) user sampling, 2) actors, 3) environment, tools and materials, 4) tasks, techniques and instructions and 5) data analysis. While all of these parts highlights critical flaws with HCI related problems in ASD studies, the third and fourth part is of particular interest for this paper. The third part elaborates on the feeling of anxious behaviour of the participant while being exposed to an unfamiliar environment, context and materials, which may contribute to unwillingness for the participant to continue further into the study. In addition, if not considering factors such as physical ergonomics (i.e. size) in regards to tools and materials, it may prevent the participant from performing the desired task. The fourth part delves into misunderstandings during tasks in terms of cognitive and attentive capabilities as well as the expected outcome. This is exemplified in multiple ways, but most notably is that while specific tasks may seem simple, understandable and engaging to the researcher, it may

209 not be the case for the participant as in they may experience it as too simple, too complex or even dull to complete.
210 Following actions to counteract these experiences were described as either adjusting the tasks to the participant's
211 cognitive capacity or ending further study sessions. By the end of the study, established guidelines were provided to
212 include strategies involving training stakeholders prior to conducting the study if it required for them to carry it out, as
213 well as letting the users familiarize themselves with the facilitators and the environment [3]. While this paper does not
214 present new solutions to the chosen parts as mentioned above, it further extends them to provide further detail of what
215 prompts the thought processes of selecting appropriate tools and techniques. In addition, it provides an established
216 overview of what aspects of ASD that the field of HCI is taking particular interest in to conduct researcher to the benefit
217 of the demographic.
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223 2.2 Co-design in HCI

225 Co-design is described by Sanders and Stappers as the collective creativity that is being applied throughout a design
226 development process, which involves the efforts of both designers and non-designer who may formerly be considered
227 to be 'end-users', but should be referred to as co-creators. The premise of doing this collaboration between these parties
228 is to understand the situation in which the design takes place, explore new possibilities while gaining insights and
229 understand the impact it has on the targeted demographic, moreover which alternatives and challenges emerge as an
230 outcome of a design project[11]. The practice utilize methods that emphasize visual, creative and expressive, which blend
231 into physical and tangible mediums that contribute to a design narrative of storytelling while keeping it playful, fun and
232 ambiguous, as well as being personal, reflective or subjective. This interaction allows for a deeper understanding and
233 accessing tacit and latent knowledge but also requires the cooperation and willingness of the individuals participating
234 [12]. These mediums can be referred to as 'Make tools' in which there exist many examples such as photographs,
235 symbolic shapes and other pictorial forms that lend themselves to a 2D or 3D format. Having a selection of a few make
236 tools combines into a toolkit determined by factors such as time, budget, context etc., but can also be used in adopting
237 particular themes such as eliciting emotions from the past of good and bad experiences or cognitive ones that express a
238 relationship between ideas or components. In terms of when co-design is utilized in the process of a design project,
239 Sanders and Stappers suggest that it can be used at any time while referring to five distinct stages, which are as follows:
240 1) Pre-design, 2) Discovery, 3) Design, 4) Making and 5) Marketing. To describe each of these phases in short, pre-design:
241 is where research is conducted and defines the context of a problem; discovery: identifies opportunities within a study,
242 which then transfers over from being research to being design; design: continues in exploring but this time happens
243 through the initial stage of developing on a design; making: producing or building a more concrete concept that is
244 fit for future release; marketing: focuses on sales and/or distribution as well as the implementation of the idea [11].
245 In this paper, the focus of the review will revolve around the first four stages in which they are used in examining
246 the preparations and decision making from the researcher's perspective before conducting the study; which approach
247 they employ to make a contribution within a specific area of ASD as well as observing the use of their chosen tools
248 and techniques in practice and what implications the outcome of their study may bring. Furthermore, as make tools is
249 seemingly a popular tool in co-design processes, it will serve to sample different kinds of tangible artifacts as mentioned
250 above when going into the review, in which it will receive its own category in which the chosen make tools will be
251 elaborated on.
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3 METHODOLOGY

The collected papers were gathered that for this review were submitted and accepted at highly regarded HCI-conferences, which would ensure the quality of the review as there is a concordance from established peers in the field that have considered the work as a significant contribution. The two sections below further detail the methodology in accordance with selection criteria of literature and the results of the phases in regards to tools and techniques, as well as the domain of context, which will be elaborated in the findings section.

3.1 Selection of Literature

In order to retrieve pertinent literature, an advanced search was conducted on ACM digital library on nine different HCI-related conferences using the Title, Abstract and Author Keywords with relevant tags as seen in table1.

autis*	Ensures to capture every kind of wording that is related to autism, i.e. autistic or autists
ASD	Common acronym for Autistic Spectrum Disorder
Asperger	Included as Asperger is sometimes referred to in relation of high-functioning Autism

Table 1. The three search words used in this review and their respective descriptions

Out of the nine included conferences, only six of them returned had any results, whereas the three that was excluded were NordiCHI, PDC and DIS. The following bullet shows the included conferences for this review along with the number of autism-related papers with the total being 267 studies:

- CHI - 101 papers
- HRI - 66 papers
- ASSETS - 47 papers
- OZCHI - 16 papers
- CSCW - 11 papers
- UBICOMP - 26 papers

3.1.1 Phase 1. After the initial retrieval of literature, all bibliographical information was presented in a Google Sheets document from which the titles, as well as abstracts were used for sorting out relevant data for this study. In this sorting, a set of inclusion criteria were established in order to set a scope and extract meaningful data of the research domain. When doubt of relevance to a given study would occur, a selective reading through 'Introduction', 'Methodology' and 'Results' or 'Findings' sections was conducted, then making a note of what was significant about the paper to later be peer-reviewed. By the end of this process, the data corpus resulted in 16 papers that satisfied the criteria to be included in the review. The criteria set for the sorting were described as follows:

- (1) The study must not include or implicate the involvement of children
- (2) Associated stakeholders and their practices should not be the sole focus of the study
- (3) The participants should be high-functioning enough to be communicate and participate in the given study

The first criteria were included based on within HCI there is a seemingly high interest in creating an early intervention for autistic children, where one study from Vellank et al. motivates this direction by stating: "in autism, early intervention is crucial, but support is sparse in even developed countries. Without assistance children may face lifelong cognitive and social disability" [17]. However, when carefully reading through a selected few of these study a pattern is seen regarding the participation of this sub-group to be fuzzy in some cases as stakeholders sometimes include parents,

313 teachers and caregivers to assume the source for feedback depending on the child's ability to provide a response, i.e. if
314 they are hindered by being non-verbally or have other forms of hindrance in communication. Hence they are excluded
315 from this review. For the second criteria, stakeholders as previously mentioned may sometimes be included in HCI-ASD
316 related studies, where they either participate on their own dependence or on behalf of their ward's feedback. Their
317 participation in this particular review is partially irrelevant, as this review mainly focuses on individuals with ASD, but
318 the population is included provided that their feedback addresses insightful areas of the diagnosed person in ways
319 that the person is not able to provide themselves. The third criteria is an extension by the two previous criteria, and it
320 goes without saying that this review is intended in the context of participatory design and co-design, which means
321 that the participating individual should be mentally capable of communicating their own thoughts and emotion in a
322 given design process, which unattainable with people on the extreme end of the spectrum without the assistance of
323 stakeholders. One instance of this is shown in a study by Hornof et al., which were conducted with people diagnosed
324 with Rett syndrome - a severe kind of developmental disorder that affects communication and motile functions, which is
325 classified on the autistic spectrum - and their families [8, 9]. In their study, four out of five participants were not able to
326 speak, whereas the only able participant to do so their interactions were described as "conversations are atypical and
327 consist of ... slowly answering familiar questions with practiced communication partners such as ... mother". To say that
328 these kinds of participants should be ignored entirely from a participatory design process is an understatement. It is
329 perceived that it is possible to involve these kinds of individuals, yet would require a significant effort for facilitating
330 the process with this kind of population. Hence they are excluded from this particular review but could be involved in
331 future research. By the end of this phase, 16 studies satisfied the criteria.

337 *3.1.2 Phase 2.* After the first phase of sorting through the papers, the second was more of a comprehensive sorting
338 examination of the papers in regards to Co-design practices and the context they were used in. To this, the examination
339 would focus on two criteria that would determine whether a paper should be included in the final data corpus or not.
340 The criterias are described as follows:

- 341 (1) The age range of participants
- 342 (2) The level of participant involvement

343 In detail, the first criteria is a continuation of the previous criteria in phase 1 of excluding children from the data
344 corpus, which captured most studies that related to this sub-population. However, in some papers of the data corpus
345 that included participants considered to be 'adolescent' or 'young adults' there were conflicting definitions whether
346 or not it could actually still be considered children, which would then influence the integrity and the outcome of the
347 paper. Hence, it was decided by the author to put a minimum age of inclusion to 16 as this was marginally closer to
348 considering the participants as young adults. Additionally, the second evaluates the degree to which the participants
349 were involved in the study and the influence of their feedback being considered, and was done through a score of one
350 to three. One exemplified a minimal use of participant involvement, i.e. one interview for insight gathering but did
351 not encourage further interactions or if there was not an attempt at all. In contrast, the second criteria also illustrate
352 continuous and close collaboration with the participants through multiple workshops and significant findings that
353 were included for further implication for either future designs or facilitation of working with the user demographic.
354 While looking at these criteria of co-design, the context of which these methods and theories were also examined to
355 deduce emerging trends within this field of study. The criteria and contexts would contribute to an overall score of
356 relevancy between one and five for the given paper. Papers that had an overall score below two were excluded from the
357 review, leaving the final data corpus at eight conference papers.

3.2 Results

While examining tools, techniques and domains for each paper, emerging patterns were established into general categories, which would then be counted if being utilized and compared in order to gather meaning from current trends for co-design activities within the field of HCI in conjunction with ASD related research. It should be noted for the final results that each paper could include multiple uses of various techniques and domains and were satisfied to a varying degree yet is seen as generally as equivalent for comparability. In table 2, it describes the tools and techniques that were applied in the different papers in the data corpus. Similarly, in table 3 different domains regarding current trends in ASD related research is illustrated.

Tools and techniques	Total uses
Observation	7 [1, 2, 4, 5, 7, 10, 14]
Interview	6 [1, 2, 4, 5, 7, 20]
Make tools	6 [1, 5, 7, 10, 14, 20]
Design workshop	5 [4, 5, 7, 10, 14]
Prototyping	4 [1, 7, 10, 14]
Survey	1 [5]

Table 2. Table on tools and techniques used in the papers from the data corpus and the amount of uses across each study

Domain	Total mentions
Social skill capabilities	4
Practical challenges	3
Need for assistive technologies	3
Personal well-being	3

Table 3. Table on defined domains of ASD related studies within HCI and their respective amount of mentions from the papers of the data corpus

4 FINDINGS

The following sections describe the two categories of tools and techniques as well as problem domains with their respective subcategories from the results of the data corpus.

4.1 Tool and techniques

When conducting co-design related activities with people on the spectrum, the techniques can be required to be modified to account for certain factors to improve the quality of the feedback to the ability that the individual is capable of. To this extent, it can be paramount to be attentive to the setting being comfortable for the participants when requiring their deliberate effort to contribute to the study. This slight matter will be one of the focal points in the following sections when going through each topic, along with reflection on what seems to be frequent approaches in the process of collaboration as well as how these techniques are ranked compared to each other.

417 4.1.1 *Observations*. Conventionally, observations can be used independently to capture participants non-verbal cues
418 and authentic interactions, i.e. when testing out a prototype of an interactive product or when asked performed, yet it
419 is commonly utilized in conjunction with techniques that require giving some sort of response or feedback, that being
420 usually being interviews and workshops. Why this particular category had the highest amount of applications within
421 the papers of data corpus might be reasonable, as it can be speculated that some participants may struggle to react to
422 tasks that require them to think aloud or talk while they interact with the artifact. In the paper from Burke et al., they
423 highlight two particular hardships in regard to thinking flexibly as well as processing non-literal language, which can
424 be a part of turn-taking in social communication [2]. Observation can be a great approach to captivate an authentic
425 experience, as illustrated in the work of Boyd et al., which focused on face-to-face conversations with the assistance of
426 wearable technologies and found major findings in making people with ASD aware of their speech prosody sounding
427 negative and in making aware of processing necessary information for the sake of performance were both being the
428 established through the use of observations [1].
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432 4.1.2 *Interviews*. Interviews were one of the second-highest techniques applied in all of the papers, which generally
433 followed a semi-structured form for the majority of the papers and were used mainly for gathering insights about the
434 demographic and validation for proof of concepts. The argument why most semi-structured approaches to interviews
435 seem to be the frequent approach has been described in Hong et al. where they stated: "*we acknowledged structured*
436 *interviews alone are not suitable for individuals with cognitive difficulties because they struggle with recalling and describing*
437 *their experiences*" [7]. To elaborate on this statement, structured formats in interviews might be intimidating and invasive
438 to some extent for the ASD individuals when they are asked formally about their daily lives, further for the approach
439 itself can be complicated to structure in such a way that captures the variety of difficulties in what each individual
440 is presented with on a daily basis. In regards to why open formats are not considered to be utilized more, it can be
441 speculated that it relates to the researchers own comfort facilitating interviews in that they might feel they have no
442 control over what they can expect from the session, whereas semi-structured allows for general topics that can further
443 be elaborated on in-depth and that there is an opportunity to let participants know of these topics before conducting the
444 interview. The setting from which the interviews can also be questioned in regards to the comfort of the participants
445 to optimize their feedback quality. From Burke et al. in ethical considerations before the interviews, they decided to
446 conduct the session in the home of the participants as it would allow for greater control over environmental stimuli
447 and add to the contextual validity of the study [2]. An additional finding from Hong et al. was also noted in terms of
448 involving stakeholders in interviews and their influence on their client's answers to the questions, which they held
449 separate to minimize this effect [7].
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456 4.1.3 *Make tools*. As 'Make tools' artifacts have already been established in the related work chapter in the co-design
457 section, this section of the practice will not go further in detail of what it is and rather focus on how they have been
458 applied of what was examined in the data corpus [11]. In the paper from Hong et al., they state that "*visual support is*
459 *particularly beneficial to individuals with autism because it helps make abstract concepts concrete and capitalizes on their*
460 *inherent visual learning strength*", a statement which can be used in relation to make tools and its benefits for people
461 with ASD to participate in creative activities[7]. An example of how make tools are used in ASD related studies is
462 illustrated by Simm et al., where in the early phases of their process, they had their participants ideating on developing
463 a wearable technology that would alleviate anxiety. They used materials such as playdoh, pipe cleaners and 3DP 'sensor
464 mimics', which resulted in 13 different prototypes in which the researchers were able to draw general thematic patterns
465 related to context and modality type, i.e. public speaking and auditory triggers. Further in the paper, they give a chosen
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469 concept more and more depth making it more concrete as the study progresses, which illustrates a sort of natural
470 progression in making abstract ideas to be more tangible towards a final prototype [14]. Hong et al. also made use of a
471 particular make tool that they called "life skills card", which were pictures with descriptive texts that explained specific
472 situations and used in reflection of a developed prototype [7]. Of all the papers in the data corpus, make tools that
473 involved sketching or drawing activities saw the most usage through the majority of the paper. However, none of them
474 discloses the choice of why this is so.
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477 *4.1.4 Design workshops.* From the data corpus, design workshops were utilized fewer times in comparison to interviews
478 as it only had been applied in five of the papers, which is an interesting finding in that it shows a trend that researchers
479 tend to prefer having participants involved in one-on-one sessions rather than have a large gathering of participants
480 collaborate with researchers. While no singular explanation was able to be drawn from the papers, from observing the
481 structure of some of the papers, it could be speculated that the ethical considerations had an influence on the decision
482 going into a project, as only a few papers addressed them. From a facilitators point of view, gathering a particular
483 medium to large group of diverse individuals, who might have challenges in different areas that can prevent them from
484 participating optimally, it can be difficult to assure that the environment and requirements are satisfied universally.
485 However, in the article from Cha et al., they established three instructions to their participants, which were described
486 as follows: 1) The study was not a clinically validated therapy, 2) the participants was free to ask questions comfortably
487 if they had any, and 3) if the participant decided to leave in the middle of sessions, there would be repercussions as it is
488 voluntary [4].
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493 *4.1.5 Prototyping.* Prototypes can be presented in two types, either as low-fidelity (lo-fi) or high-fidelity (hi-fi), which
494 both aids in illustrating the notion of the finished product's interactable elements, shape and capabilities. Lo-fi prototypes
495 utilize inexpensive materials like the ones previously mentioned in the section above, but hi-fi prototypes are generally
496 software-based and closer to what the final product may look like. Both types can target different phases of designing a
497 concrete product when considering collaborating with participants, where lo-fi typically is applied in the early phases of
498 generating ideas and alternatives and hi-fi. In contrast, it leans towards validating the concept's features and functions.
499 In the paper from Salai et al., an example of the latter was presented, where they used a hi-fi prototype in the form of
500 situated buttons placed at different locations that proactively trigger video prompts for certain tasks such as making
501 lunch or doing laundry. Throughout the paper, they held two validation workshops where the first was aimed as a
502 proof of concept and the second was exploratory towards other user segments and measuring established factors such
503 as 'ease of use' and experience of being 'independent' [10].
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507 *4.1.6 Surveys.* From the data corpus, surveys had the lowest amount of uses with only one paper it was applied in
508 when compared to with the others. However, there might be a reason for this. Traditionally surveys are perceived to be a
509 tool to gather a large pool of data to validate certain pieces of hypothesis for a given user group, then using quantitative
510 methods such as ANOVA in order to do so. Subsequently, if the researcher wishes for more in-depth feedback, the
511 survey can serve as a means to scour for participants that fulfil specific requirements to then be recruited. From Chapko
512 et al., the researchers who themselves are on the spectrum investigated public attitudes towards learning disabilities
513 (LDs), where they describe and evaluate the creation process of making offline and online surveys being accessible for
514 people with LDs. They elaborate that a major factor in difficulties in using a survey with these demographics stems
515 from being purely text-based, which demands a lot of cognitive effort when it particularly comes to the use of language,
516 which can result in confusion. Furthermore, as they followed up with tests of survey design with their own concept,
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521 they discovered emerging themes in regards to public perception of they understand LDs, recognizing the pride in
522 regards to skills and being an individual with an LD and framing exchanging questions between the two parties. The
523 result of their study partially finds that surveys that want to include people with LDs often times end up ridiculing
524 them for their diagnosis instead of helping them and providing essential features for making it more accessible to them,
525 i.e. make use of modalities such as pictures, audio or video [5].
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528 **4.2 Problem domains**

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530 While observing applied tools and techniques, the context of which was also regarded in terms of emerging problem
531 domains that receive recognition and tells about the general focus of HCI research wants to contribute to in relation to
532 the area of autism. It should be noted that these domains are defined by the author through careful reading in order to
533 categorize and not through quantitative means, such as counting the individual instances of what could be considered a
534 domain. It should also be mentioned that the domains may overlap with each other in papers that address multiple
535 problems in regards to ASD.
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538 *4.2.1 Social skill capabilities.* This domain describes specific challenges in regards to social situations for the individual
539 with ASD that calls for certain skills such as identifying non-verbal cues, keeping eye contact, being aware of speech
540 prosody etc. It is described by Boyd et al. that individuals with ASD who face struggles with their social skills have
541 a harder time developing peer relationships as well as recognizing emotions, further it can lead to social isolation,
542 low rates of employment and significant mental health concerns such as developing severe depression or anxiety [1].
543 However, few articles elaborate on developing technologies in which that can help the user in their social life, whether
544 it be training prior to engaging in social interactions, i.e. practicing turn-taking in conversations or devices that makes
545 the user aware of certain occurring skills that they lack in their social interplay. In the case of Boyd et al., they employ
546 the latter through Google glass that presented visual information to make the user aware of atypical sounds or rhythms
547 in their speech when hitting a certain pitch, also called prosody, which can range from the use of body language and
548 expressing as well as interpreting emotions. Their findings of using such devices intervening in social settings suggest
549 a positive experience that weaves naturally in situ to the conversation. However, it was mentioned that deciphering
550 alerts and presenting them to the user required more context as it would target either the user itself or the partner that
551 they were in a conversation with [1].
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557 *4.2.2 Practical challenges.* Practical challenges are defined as challenges that may happen on a general or individual
558 basis, i.e. having more severe sensitivity issues such as olfactory and photosensitive or even other neurological diagnoses
559 such as Rett's syndrome added to the initial ASD diagnosis. The challenges are presented as hardships the ASD individual
560 may encounter on a regular basis, which contributes to preventing them from fully independent living independent, as
561 well as relying on the consistent care of stakeholders to properly function. Some examples of this can be doing chores
562 or menial tasks, such as making lunch or doing laundry as previously mentioned in the study of Salai et al., but can be
563 more general tasks such as maintaining a structured routine schedule or practices of self-care. Creating independence
564 or autonomy for individuals with ASD was a particular emerging trend that a majority of the papers aimed for in
565 different aspects and with varied results. Separately, in some of the same papers, stakeholders such as caregivers would
566 be involved in providing their own understanding to further support their clients need for independence, but others
567 such as Hong et al. addresses the need to lessen the burden of dependency of the caregiver. Solutions within this domain
568 have been seen with Salai et al. situated buttons used to show certain tasks in a video format that happens at the time
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573 of need, but also with Hong et al.'s contribution of an interactive social mirror that let the individual send out questions
574 to a trusted network of family, friends and professionals [7, 10].
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576 *4.2.3 Need for assistive technologies.* Development of assistive technologies was seen in the majority of the papers,
577 which ranged with a variety of solving specific purposes that factors as a part of an ASD person's behaviour and needs,
578 such as the other mentioned domains in this paper. However, in some of the papers, it became apparent that some users
579 did not imagine their issues and needs accounted for through the use of an app or a device, but rather the solution to
580 the condition was mediated by using them, which led to diverse experiences. For instance, in papers such as Burke et al.
581 where they utilized existing technologies such as Facebook, texting and email to solve social issues, where the received
582 feedback of using these modalities returned with negative responses due to problems such as trust, disclosure and
583 captivate decisions by others [2]. By extension of this observation, the need for assistive technology for people with
584 ASD seeks to explore new technologies in which existing ones does not fulfil the exact needs of the given objectives. An
585 example of how this domain is used, as shown in Simm et al. that specifically addressed individual experiences of anxiety,
586 which were focused on developing different prototypes that would capture and present information appropriately to
587 the user [14].
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591 *4.2.4 Personal well-being.* In addition to their original diagnosis, an individual on the spectrum can be affected by
592 pervasive psychological disorders that can be found with common people, such as stress, depression and anxiety, in
593 which autistic individuals show an increased vulnerability that affects their overall well-being [15]. Due to a variety
594 of what these illnesses bring, it should be assumed that solutions should incorporate different aiding resources for
595 individual needs. However, Cha et al. pursued in making one device that could be customized to fit different goals that
596 contributed to managing daily routines, i.e. relieving stress as well as developing healthy habits such as a regular sleep
597 and morning schedule [4].
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601 5 DISCUSSION

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603 In this article, a scoped literature review was conducted to survey contributions in regards to the use of co-design
604 practices within the relation of the field of HCI and research of ASD. The first resulting topic within tools and techniques
605 would serve to gain an overview of which are generally employed and to see whether or not co-design plays a part
606 of the process, the second topic resulting topic of domains would function as an overview to establish any emerging
607 trends in terms of focus areas of ASD that HCI is targeted towards to make a contribution. In the following sections,
608 reflections are given in regards to the results of the categories, which are then elaborated upon with future implications
609 for research.
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612 5.1 Reflections on tools and techniques

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614 The results of tools and technique interviews and observations had the highest amount of applications used in articles
615 from the data corpus, but for both categories, it is highly debatable in terms of how they fair in co-design. First, as
616 observations is a technique that involves the facilitators minimally, there is a lack of guidance and perhaps a lack of
617 understanding in what is to be expected to be given by the participant. An exception might be made if the technique is
618 used in settings that focus on how ASD individuals work together on a concept for an ideal solution but otherwise lacks
619 in other areas of co-design as a practice. In terms of interviews, it depends on the goal of what is wanted to be achieved.
620 If it wants to incorporate the practice of co-design, the process should happen during idea generation or design phases
621 in order to align. However, the acquired papers in the data corpus all focused on either gathering insights on specific
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625 topics related to ASD or evaluating a proposed concept. Additionally, when comparing interviews with the score of
626 design workshops, it indicates that there might be a preference in regards to how researchers approach collaboration
627 with people with ASD. Specifically, it assumes that having participants in one-on-one sessions are more favourable than
628 a larger gathering. Although no explanation is given to this, it can be argued that it relates to the ethical considerations
629 for inclusion, as a couple of papers such as Burke et al. addresses the need for control over environmental stimuli,
630 which is hypothesized to be complicated with an increasing number of participants with their own individual needs [2].
631 In contrast, only one paper from Cha et al. details ethical considerations in regard to design workshops and establishing
632 principles for user participation, which can be seen in the design workshop section of the findings. Their understanding
633 of their work could serve as a foundation in which future consideration of technique could be utilized [4].
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636 Looking at specific tools that would fit for either interviews or design workshops, make tools had the highest amount
637 of appliances in the papers, followed by prototypes and then surveys. In terms of the least utilized tool, survey finds
638 itself in a cumbersome position as it is difficult to say if it has a part to play in relation to co-design due to most survey
639 platforms not designed appropriately towards ASD individuals as indicated by Chapko et.al in the survey section
640 [5]. Although survey are most commonly utilized in gathering large amount of data from user demographics, with
641 adjustments they might at least serve as a desirable tool to participants to in-depth co-design processes i.e. if the survey
642 could for instance employ resources to find common traits among participants to optimize quality of the targeted
643 area. Regarding prototyping, out of the four papers with the exception of Simm et.al utilized hi-fi prototypes in their
644 study, where in those paper the approaches that employed focuses on evaluating them in a given context in order
645 to either gather insights for implications for future research or make iterations of adjustments on a device to better
646 fit the solution as much as possible . However, in terms of co-design participants has constrained influence over the
647 direction of the design of the prototype as it can be intimidating proposing a completely new direction, especially by
648 individuals with ASD can be very anxious and embarrassed in giving a response i.e. in fear of being judged for doing
649 something wrong. In contrast, the study of Simm et.al implies that lo-fi prototypes benefited the authors remarkably by
650 allowing participants to be able customize a prototype that fitted into their specific needs, which resulted in a variety
651 of solutions that covered different aspects of interaction [14]. Finally in relation to make tools, a notable finding was
652 found in relation to describing why they were chosen, specifically referring to the suggestion made by Hong et.al in the
653 respective section of the findings [7]. Following this, a reexamination were conducted on other papers within their
654 respective paper, but did not return with any noteworthy results. Although this particular finding is based a single
655 statement, it raises multiple questions regarding ASD related studies that utilize co-design practices within HCI, which
656 may result in new emerging areas of research. At the end of reflecting on both co-design and tools within the practice,
657 serves as an answer to RQ1 as stated in the introduction.
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664 5.2 Reflections on domains

666 When looking at the results of the various domains, an almost evenly distribution is presented with the exceptions
667 of social skill capabilities, which had one more mention in compared to the others. Due to this moderate amount of
668 resulting paper in this review, it is hard to draw any indication in regards to current trends within HCI-related ASD
669 studies, as well as disclose in research areas that are lacking in their contribution. However, concise findings were found
670 while looking at the papers of the corpus in general, which were that all of them included participants with ASD to
671 varying degrees, i.e. involve them in a physical setting or online with certain criteria set. By the very least, this shows
672 when it comes to the empowerment of people on the spectrum; HCI researchers let their participants have control
673 over their own contribution and help define their needs for themselves and those alike. Moreover, some papers had
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677 mentions involving stakeholders or minor diagnoses, i.e. anxiety to that of ASD, which in some cases would leave some
 678 contributions unclear in terms of which demographic they were targeted towards. However, the majority of the papers
 679 take a proactive in keeping the focus on the individuals with ASD, such as in the study by Zoloyomi et.al. In their work,
 680 they focused students with ASD on higher education in terms of partaking in student teams with non-autistic students,
 681 where both parties of participants benefitted from the efforts being made in regards to factors such as group identity
 682 and team conflict, the primary focus remained in empowering the autistic students [20]. While this review did not
 683 present a domain that specifically references co-design, future research could involve taking an in-depth examination
 684 of how individuals on the spectrum can function optimally within these practice settings. In summary, domains of
 685 current emerging trends in ASD related studies within HCI were established; while the answer may be limited by the
 686 scope of the review, it serves as an answer to RQ2.

690 5.3 Future research implications

692 This paper presents a variety of themes as a result of the conducted scoped literature review, specifically examining the
 693 practices of co-design used within the field of HCI with the psychological disorder of autism as the primary focus. The
 694 presented themes show different utilized tools and techniques as well as domains of the study in the papers from the
 695 data corpus, all to different extends of what the recruited ASD participants are capable of. While some contributions
 696 were shown in regards to the findings, i.e. that survey platforms are not optimally designed to include the demographic
 697 or that make tools benefit the participants significantly in collaborative sessions. The main contribution of this paper
 698 leaves the following questions for future research implications:

- 701 • What is expected for tools and techniques to fit into co-design practices with people on the spectrum?
- 702 • Why are certain tools chosen over others?
- 703 • How are they utilized in unexpected situations?

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