

# Involving Autistics in User Experience Studies: A Critical Review

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## ABSTRACT

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by various sensory perceptual and cognitive issues that lead to far-reaching challenges in autistics' social and daily lives. Research in HCI is inclined to take an important role in providing support to autistic individuals. However, due to the sensitivity of this user population and the HCI research community's lack of experience in working with neurodiverse users, researchers struggle while conducting and reporting on user studies with autistics. Aiming at analyzing autistics' involvement in design processes and the struggles encountered, here we present a critical review of user experience studies with autistic users conducted between 2010 and 2016. Using qualitative and quantitative approaches together, we revealed common practices and major problems. We provide a two-fold contribution to the HCI field: A guideline for conducting studies with users with autism as well as suggestions on how to report these studies.

## Author Keywords

Autism, neurodiversity; human factors; interaction design, user experience; design process; review.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation:  
Miscellaneous.

## INTRODUCTION

Autism spectrum disorder (ASD) is a broad range of neurodevelopmental conditions that affect humans' sensory-perceptual and cognitive systems to varying degrees and throughout their lives. ASD is portrayed through problems in socializing, communication, sensory-perception as well as repetitive and restricted behavior patterns [2]. Although not much can be explained on the disorder's complete causation mechanism, an interaction of

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genetic, biological, developmental and environmental factors is thought to be the main reason [18]. The recent estimation of global ASD prevalence is 62/10000 [18] with a remarkable increase over the years.

With the increase in autism prevalence and the recognition of technology's benefits in autism intervention, involving this population in design processes has become a crucial part of developing products, systems and frameworks for autistics. However, involving this user group in design processes has emerged as a challenging issue mainly due to (1) socially demanding nature of design activities where autistics may struggle to interact with the researchers [24], (2) researchers' lack of experience in working with neurodiverse (ND) users, (3) lack of collaboration opportunities with autism schools or centers and (4) a general unwillingness among potential study participants within the population (including their caregivers) in taking part in such studies.

In HCI field, recent aim is to create models for including ND users and their contributions in design processes [9, 38]. Yet these studies mostly focus on the ND children or specific technologies. Contrarily, psychology studies involve ND population from varying ages, yet a considerably little amount report design practices. Besides, transferring the experiences in study conducting from one field to another may not always be suitable due to differing natures of the two fields.

We believe that bridging this methodological gap between HCI and psychology would be beneficial not only for the sake of better research conducting and documentation, but also for the target population's content both during their active involvement in and after the research. Deriving from this motivation, in this paper we present a critical review of user experience (UX) studies conducted with autistic users from any age group within the last 7 years. The primary focus of our research lies on the following questions:

- Why and when do researchers encounter problems during UX studies with autistics?
- How can researchers avoid these problems prior to conducting and/or during these studies?

To answer these questions, we extracted the following information from the publications we reviewed:

- How and when the autistics are involved in UX studies,
- What kind of problems researchers encounter while conducting UX studies with autistics,
- How the actors such as parents, teachers and caregivers are involved in these studies,
- How study participants interact with the prototyped, developed and/or tested products, and
- The existing guidelines and suggestions for involving autistics in design processes.

Before discussing our insights regarding each research question, we first summarize the current stand of leading research that focus on HCI studies involving autistic users.

#### **BACKGROUND: NEURODIVERSITY AND HCI**

Neurodiversity is a movement advocating different cognitive and perceptual capacities than what is normative, in other words, neurotypical. When the term was first coined in 1999 [51], the initial idea was to advocate autistic people's rights. Through the support of populations with other neurological conditions such as ADHD (Attention Deficit Hyperactivity Disorder) [17], Dyslexia and Tourette's Syndrome, the movement has become much diverse in the last two decades.

Recently, academics seek to create neurodiversity awareness in HCI both in terms of recruiting ND users in their studies and collaborating with ND researchers and practitioners in the field [17]. Several frameworks have been developed to engage ND individuals in participatory design (PD) through bringing out their creative potential by focusing on their strengths and supporting their difficulties.

Benton et al. [9] propose a guiding framework, named Diversity for Design (D4D), to adapt PD for ND children by taking their strengths and difficulties into account. They utilize previous structured teaching programs for autistic children and highlight the importance of adding minor situational modifications to the environment in order to meet each ND participant's individual needs for a better participation. They further suggest that both 'structuring the environment' and 'providing supports' should be realized after understanding the characteristics of the specific ND culture and tailoring both the environment and the support measures considering each participant's personality, abilities, interests, strengths and difficulties.

Makhaeva et al. [38] propose the concept of "Handlungsspielraum" and argue that creative spaces for PD sessions should be constructed within "structures" and "freedoms". They suggest that maintaining a balance between "structures" and "creative freedoms" will bring out the creative capacity of the participant. The term structures entails social, physical, mental and methodological structures in which participants feel comfortable and are able to participate. Creative freedoms accompany these structures through providing different kinds of possibilities that would encourage participants to contribute their ideas during the PD process.

These PD frameworks are useful, guiding and enlightening in terms of engaging ND participants in design processes and expanding their contribution limits. Yet we believe that there is also a need for better UX conduct with this population due to the variety in contexts, materials, techniques and roles in UX studies.

Apart from the PD frameworks, we identified four research works that deliver a review of studies conducted with ND participants (including autistics). All four research works center around designing for and with ND individuals. Benton and Johnson [7] attribute following process elements to a design process and expect to contribute within the sphere of these elements: technology, ND individuals, other actors (e.g. parents, caregivers, teachers), outcomes and reporting. The researchers analyze the roles and responsibilities ND children take over and assess the impact of these on the process outcomes along two dimensions: first, upon the designed product and/or system; second, on the children themselves – in other words, the intended users of the designed product and/or system.

Grynszpan et al. [26] focus on a single element in design process: technology. They measure the efficacy of chosen technologies and perform a meta-analysis among studies that entail computerized systems that allow for an active interaction with its users. The researchers excluded non-interactive systems such as video modeling from their analysis and provide recommendations on "developing technology-based applications for interventions with various goals for those with ASD".

Similar to Grynszpan et al. [26], Fletcher-Watson [22] focuses on technology and design process and defines her research objective around identifying best practices for the design, implementation and evaluation of computer-assisted learning systems (CAL) through evidence for CAL systems' value in autism education. It is important to note that CAL systems do not necessarily exclude training measures that enhance the life and/or social skills of individuals. Fletcher-Watson [22] draws attention to this aspect and excludes non-computerized systems (such as video modeling) like Grynszpan et al. [26]. In addition to video modeling, Fletcher-Watson [22] excludes systems including robotics in her review, arguing that users do not interact "in the traditional sense" with robots in robotics studies as the research field is "still in its infancy".

Börjesson et al. [12] let us zoom out and view the whole design process at a distance by giving an overview of research works that include recommendations for involving 'developmentally diverse' children during design.

To our knowledge, there is a lack of research that reviews empirical studies made exclusively with autistic participants. Besides, most work focusing on reviewing existing research conducted with ND study participants and formulating best practices based on them strive to cover a wide range of ND participants and refrain from focusing on

autistics. With our research, we hope to contribute to the HCI research community's and our own understanding of conducting research for and with autistics by considering and carefully reviewing research conducted with autistic individuals. It is important to note that we are not excluding any studies made with any specific technologies and/or age groups from our review.

## METHOD

The aim of this study is to reveal how autistic users from any age group, are involved in UX studies focusing on developing HCI solutions for this specific user population. We mainly focus on the methodological approaches and practices for conducting studies with autistic users and explore the nature of these studies. Following an iterative critical analysis approach comprised of 4 steps, we analyzed published studies from a wide range of disciplines. The first three steps were about data collection (searching the databases and elimination of papers) and the last step was for the data analysis using the selected papers.

### Step 1: Retrieving Publications

*Databases and Search Query:* Publications from ACM Digital Library, IEEE and ScienceDirect (SD) were retrieved based on the search query illustrated in Table 1. Due to slight differences in search skills of the given databases, the following search procedure was applied respectively: 1) Combinations of the primary and secondary terms (See Table 1) were searched using the search engines, and 2) tertiary terms were scanned manually among the retrieved results of (1). In IEEE and ACM, the primary and secondary terms were searched in metadata (title, abstract, keywords). However, such a restriction was not provided by SD, so the primary and secondary terms were searched in whole text. The tertiary terms were searched only in titles in all databases (Table 1).

*Timeframe:* The HCI studies involving autistic users have prominently started increasing after 2010 (e.g. in Börjesson and colleagues' literature review of studies between 2003 to 2014 [12], 42 out of 55 papers including autistic users were published after 2010). So, the search was limited to seven years (from January 1st 2010 until October 31st 2016).

<b>Primary term</b>	<i>autism</i>
Searched in metadata (IEEE, ACM) or in whole text (SD)	
<b>Secondary terms</b>	<i>design, usability, UX</i>
Searched in metadata (IEEE, ACM) or in whole text (SD)	
<b>Tertiary terms</b>	<i>evaluation, participatory, presence, 3D, collaborative, virtual reality, augmented reality, mixed reality, develop, video, game, tool, app, iPad, case-study, application, system, user, interface, robot, interactive, device, mobile, technology, design, wearable, device, tablet</i>
Manually searched in title (IEEE, ACM, SD)	

**Table 1. Search query using AND between rows, and OR between terms in each row.**

*Results:* The search resulted in 606 publications (Table 2; ACM=238, IEEE=177, SD=191). All papers were imported in PDF format into a local drive accessible to all the authors for further elimination.

### Step 2: Appropriate Papers

In this step, the papers that were not appropriate for the review were eliminated by one of the authors based on the exclusion criteria below:

- Papers written in another language than English
- Review papers, dissertations, thesis, demos and workshop calls
- Papers not including any studies with autistic users
- Papers not published even though they were already in press during the retrieval.
- Papers describing the same study including the same group of users or papers from the same project (paper and study duplications)

*Result:* The first elimination resulted in 258 papers (Table 2; ACM=182, IEEE=53, SD=23).

### Step 3: Thorough Elimination

To ensure an unbiased selection, the remaining papers were scrutinized by two of the authors together based on the exclusion criteria below:

- Papers not describing the studies in enough detail and/or impossible to extract data regarding our study
- Papers not having explicit HCI implications for further studies, specifically in their discussion or conclusion sections
- Papers not focusing on the design of technologies and/or participatory methods for autistic users (e.g. medical studies).
- Papers not focusing on the autistic users primarily (e.g. interface design for special need education teachers)

*Result:* The last elimination by two authors resulted in a final list of 98 papers (Table 2; ACM=62, IEEE=25, SD=11) to be included in the study we present here. The 98 publications selected for this analysis are listed in a document on: <http://bit.ly/2obfRPK>

### Step 4: Analyzing the Papers

Quantitative and qualitative data were extracted from the papers and gathered in a database. The qualitative analysis of each substudy included the following information: (1) users (diagnosis, age and recruitment method) and (2) actors involved, (3) the roles they took, (4) the design phases in which a substudy took place, (5) substudy types, and (6) data collection techniques used, (7) where and (8) how long a substudy took place. We extracted the main intervention point of the studies and type of the product being designed as well. We will briefly mention the former in our analysis in the next section, however we leave the latter for our future studies. Qualitative data such as problems encountered and suggestions for further studies were analyzed using grounded theory methodology where

the authors discussed emergent topics throughout the analysis.

Note that we separately extracted studies and substudies (the methods/techniques used within a study such as interview, think aloud etc.) from the papers to be able to see which substudies were used together in different studies. This process resulted in 153 studies and 253 substudies reported in 98 papers. In the following sections, we present statistical data based on the total number of substudies, not the papers.

**User types and actors:** To examine the involvement of the autistic users in the studies, we first specified the types of user groups and actors. We specified three different types of user groups: **ASD**, **TD** (typically developed) and **non-ASD** (conditions and disabilities other than ASD, e.g. ADHD, dyslexia and intellectual disability). A user group indicate the *primary users of a product* (any kind of design outcome, e.g. interface, PD framework) or a *control group* to compare the outcomes of a product primarily designed for the autistic users. Actors on the other hand, are the people surrounding the users such as their parents, teachers or the people who are involved in the process of product's design for autistics such as designers. Although in some cases actors are also the primary users of a given product, they are still defined as actors due to their *daily roles in autistics' lives*. We categorized the actors under two groups: **caregivers** (teachers, parents, psychologists, therapists, and other experts and workers in education and therapy of autistics) and **design experts** (product designers, interaction designers, experts from different areas of HCI). We keep the researchers in the studies as separate entities.

**Age range:** We examined user groups' ages in 4 stages: **preschooler** (age 0-4), **child** (5-12), **adolescent** (13-19), **adult** (20+). In few studies neither the users' age range nor the developmental stage was specified. We categorized them under 'not specified'.

**Design phases:** We examined users' involvement in 3 main design phases: (1) Requirements (R): where user requirements are elicited for designing a product. (2) Design (D): where ideation and prototyping took place. (3) Evaluation (E): where the product, as a prototype or product, is evaluated for further development (Fig. 1). In many cases, studies took place in more than one phase. So, we used combination of phases with their initials in the following sections (R, RD, D, DE, E, ER, RDE).

## RESULTS

Here we present the results in two parts: (1) A state of the art section consisting of a statistical overview of the 253 substudies, an outline of what has been largely done, and what might need more attention in the field; (2) major problems encountered while conducting research with autistic users.

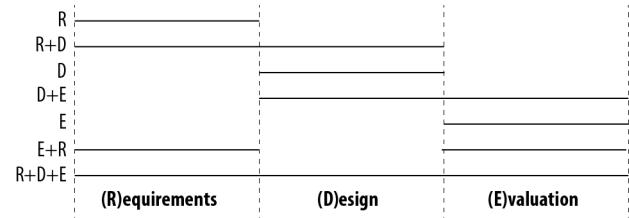


Figure 1: Design phases and their combinations we used in our analysis.

## State of the Art

Our data collection resulted in 98 paper over 7 years. We observed a significant increase in publications including autistic users (Fig. 2).

### Autistic Users' Involvement and User Sampling

Autistics were included in 173 out of 253 (68.4%) substudies and other user types (TD and non-ASD) involved only in 8 substudies (2.2 %). Actors, on the other hand, took part in 237 substudies (93.7 %). The reason why autistics were not present in all the substudies is that some substudies were conducted with actors or other types of users only. For instance, autistic kids can play with a product while their caregivers are present to observe kids' interactions. After the free play session, an interview session can be conducted with the caregivers. In such a case, first substudy is considered as conducted with autistics and caregivers whereas the second with caregivers only. And both substudies together form a study.

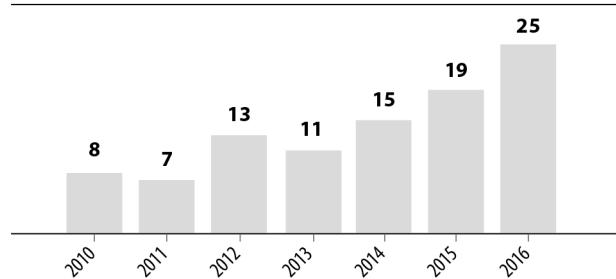


Figure 2: Number of papers per year until October 31st 2016.

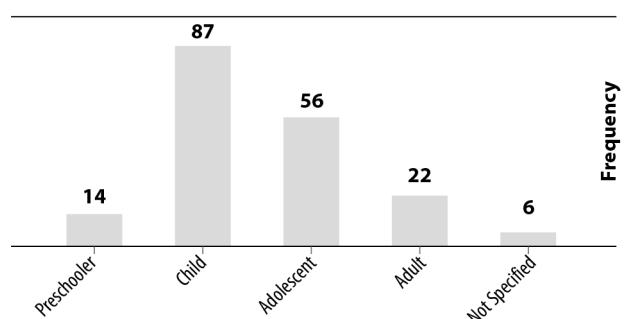
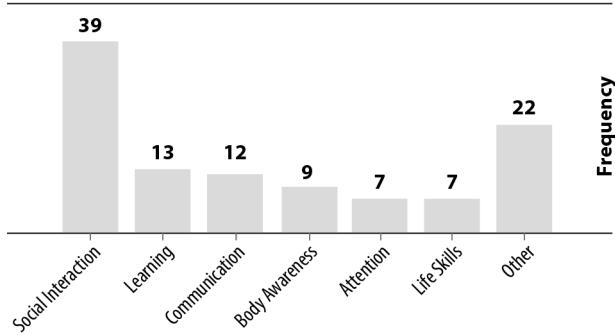


Figure 3: Age ranges of users with ASD

In most substudies ( $n=79$ ), autistics are mentioned as ‘user with ASD’ [50], yet there are substudies where the degree of autism was specified as well: 43 substudies with high-functioning autistics (HFA) [44, 15], 20 with medium/low functioning (M/LFA) autistics [19, 11] and 5 with severe autistics [33]. Among autistic users, from all developmental stages, children (47%) and adolescents (30.3%) are the age ranges most often involved in UX studies (Fig. 3). Adults (11.9%) and preschoolers (7.6%) follow them with a considerably small involvement. In 3.2% of the studies, the developmental stage or age was unfortunately not specified.

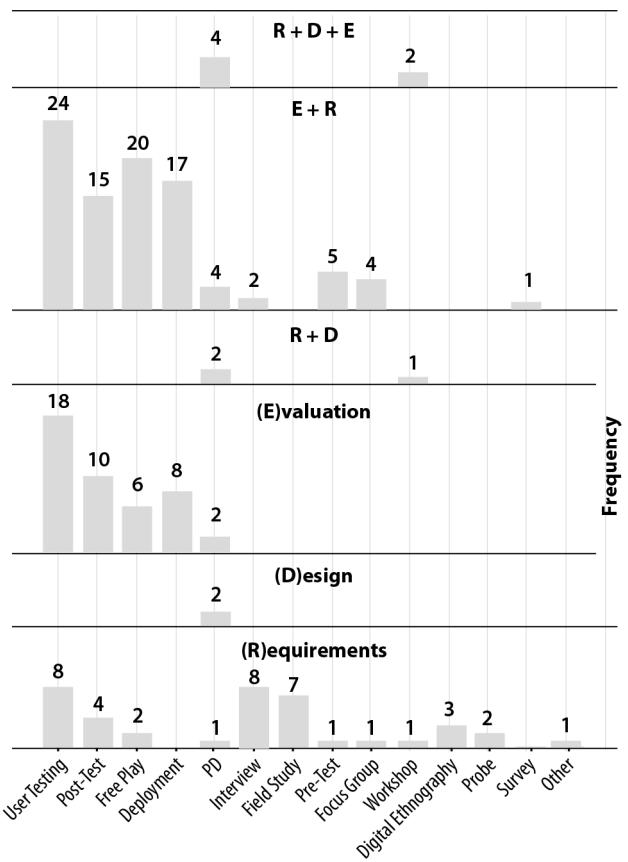
In terms of intervention, 39 out of 98 studies predominantly aimed at overcoming issues related to social interaction such as emotion and expression recognition and reciprocal interaction (Fig. 4). Following this, learning (e.g. improving the learning capacity) ( $n=13$ ) and communication (e.g. speech, word recognition) ( $n=12$ ) were prominent intervention points.



**Figure 4: Intervention points of the 98 papers. Other includes intervention points such as attention, anxiety and routines.**

The techniques that were the most commonly used in substudies with autistics were (Fig. 5): **(1) User testing & free-play** ( $n=78$ ): In user testing the researcher follows a predefined procedure through which the user performs several tasks. In free play on the other hand, user is expected to interact with the product without any procedure or task [4, 5, 43]. Especially in substudies with preschoolers and children with autism, free play is a common technique; **(2) Post-test survey** ( $n=29$ ): After these 3 techniques, users fill out a post-test survey which usually consists of a Smileyometer (a Likert-like scale to rate an experience with smileys ranging from sad to happy) [39] and/or simple questions. In some cases where the researchers develop PD models [8], users’ experiences are elicited through post-test surveys regarding the PD session; **(3) Deployment** ( $n=25$ ): Especially in educational settings [28, 20], product deployment for a long period is a common technique to be able to measure its effects on the students over time.

During the R phase, interviews ( $n=10$ ) with autistics were commonly used. In interviews, evoking materials such as pictures of daily situations were used to facilitate users’



**Figure 5: Techniques used in substudies including autistics, based on the design phases**

ability to recall and express experiences [30]. Digital ethnography ( $n=3$ ) and digital probes ( $n=2$ ) were also presented by several studies as a fruitful information resource especially when investigating daily experiences and social networks [29, 31, 46]. In D phase, where the autistics were least involved, PD sessions ( $n=14$ ), workshops and focus groups ( $n=9$ ) took place [9, 21, 30, 49]. Most of the PD sessions were actually the studies where a model or concept was being established for including autistics in the design process [33, 38], but not a product for their direct use. We counted these studies in all RDE phases since they are used iteratively for the the model development throughout each session.

As discussed before, the way autistics were involved in design processes varied according to the phases and techniques used. The types of involvement we observed in our analysis is as follows:

- **Requirements:** **(1)** Talking about [30] or recording [31] their daily experiences and needs, regarding or regardless of a specific product. **(2)** Being observed by the researchers or the actors in a daily setting [46] or in a product use setting [52]. Observations can be done

open (e.g. when the researcher participates in therapy sessions), or remotely (e.g. digital ethnography [46], when the researcher elicit information through online platforms) and with or without informing the user. Observations can be done. **(3)** Being recorded as a quantitative data source (video, physiological signals etc.) in order for the researchers can establish measures that will be used in their following studies.

- **Design:** **(1)** Developing a prototype either for a product they eventually will use [45] or for a model the researchers are developing [23]. **(2)** Ideating or giving feedback on a prototype to further develop it.
- **Evaluation:** **(1)** Using a product actively (e.g. in educational settings; where the product operates through user interaction) [11]. **(2)** Using a product passively (where the product operates without direct user interaction but with e.g. physiological input) [36]. **(3)** Being observed or recorded (open, remote or hidden). **(4)** Sharing personal or baseline information before product use [27]. **(5)** Sharing experiences after product use regarding self or the product [37].

#### *Actors' Involvement*

As mentioned, actors took part in 237 substudies (93.7 %). with changing roles within studies and throughout the design process. For instance, a teacher can collect data, facilitate and moderate product use, or convey information to the researcher throughout a deployment study. Similarly, parents of the autistic users can collect observational data [41], use a product together with their child [31] and develop prototypes [45] through R and D phases. In many cases, even if the overall study includes users, actors are involved in substudies (n=72) without users' involvement. This kind of single involvement mostly occurs in R in ER phases.

Actors' role were very similar to the users' when they were involved in the study as a user. The roles they took *differently than autistics* in each phase were:

- **Requirements:** **(1)** Providing information (e.g. general characteristics, daily experiences, needs, interests) about a group of autistics or a specific individual with autism, regarding or regardless of a specific product [25, 21]. **(2)** Facilitating data collection (e.g. using an app with the autistic so that the researcher can explore social interaction between the autistic and the actor [31]) or directly collecting data (e.g. observation).
- **Design:** **(1)** Facilitating autistics' design contributions in prototype development, and **(2)** developing prototypes [45].
- **Evaluation:** **(1)** Providing consents for autistics' participation in the studies [56]. **(2)** Conducting clinical assessment prior to studies where before and after conditions were measured. **(3)** Representing the autistics e.g. if they are non-verbal [53]. **(4)** Using a product with the autistic users [1]. **(5)** Moderating an e.g. user testing study with autistics. **(6)** Accompanying

the autistics by being passively present or active only when needed [9].

Besides caregivers and design experts, a new actor emerged through our analysis: virtual therapist or robot therapist. We will discuss this in the following sections.

#### *Environment, Tools and Materials*

33 substudies were conducted in a place where the autistic users were not initially familiar with (e.g. research lab [50], gallery [48]). 30 of them didn't mention whether the autistic users were familiarized with the environment (or the people included in the setting) or not. Only in 3 of these substudies (e.g. [44]) familiarization process was explicitly mentioned.

#### *Data collection*

Data collection was mostly the researchers' (n=164) responsibility, yet there were cases where the actors or the physical setup itself (e.g. sensors, eye-tracking) collected data. Moreover, in rare cases the actors analyzed the data, especially when video annotation is needed. Regardless of the techniques, the most common data collection types were open observation (n=69), video recording (n=38) and log (sensors etc.) recording (n= 22).

#### **Major Problems**

Within 253 substudies, we spotted more than 50 problems which we think have a significant impact on data collection and analysis throughout the design processes. Following a grounded theory approach, we iteratively worked on the set of problems to spot the main problem spaces. To overcome the intertwined nature of the problems, we examine them with respect to the conventional parts of UX studies: (1) user sampling, (2) actors, (3) environment, tools and materials, (4) tasks, techniques and instructions, and (5) data analysis (Table 2).

#### *User Sampling*

The only problem regarding user sampling is the lack of continuous presence of the participants. Due to different reasons, the users may not participate in all the sessions in longitudinal studies, even if they exhibit engagement in the sessions they attended [10].

#### *Actors*

In cases where the researcher's presence is not appropriate (e.g. longitudinal deployments in schools), the caregiver becomes the researcher by moderating the procedure, facilitating the use as well as collecting data (e.g. [19]). The researcher takes the trainer role and teaches the caregiver how to utilize the given setting. The first advantage of transferring the research responsibility to an actor is that the research can take place where the product can be used in a natural and familiar environment. Secondly, data can be collected over a long time, without the researcher's direct involvement. However, depending on the novelty or complexity of the product and its technology, actors may struggle with facilitating its use. For example, in a study with Reactable (a musical tabletop interface with tangibles)

PART OF THE STUDY	PROBLEM SPACE	EXAMPLE
User Sampling	Physical participation [10]	The majority of children dropped out due to illness and absence although a few refused to continue to use ECHOES [10].
Actors	Facilitation [1, 53]	In general, the therapists appreciated the prototype and were able to use it without major problems. However, they most often used the prototype to engage the children in a description activity rather than in a storytelling activity [1].  The therapist's difficulties with technology created a frustrated interaction with children in some cases [53].
	Obtaining consents [21]	In total 20 children (ASD) took part in these activities (...) but consent forms were returned for a sample of nine and so only their data are reported and analysed here [21].
Environment, Tools and Materials	Context of use [48]	At first most children were hesitant in approaching the plants because a gallery setting was not normal for touching plants [48].
	/ Expectedness Habituation [16, 58, 59]	One of the twin girls (...) was totally not interested and refused to enter the immersive room even with her parent's mediation [16].  The sensation of wearing a watch was unpleasant for two children. C5's discomfort grew from the moment the watch was first strapped on his arm. He showed so much emotional distress at the beginning of the second session that we were unable to continue with the study [58].  Two ASD children refused to sit in the experiment chair and thus did not start the experiment [59].
	Physical ergonomics [16, 32]	Some children with autism had problems with the 3-D glasses partially because that the active shuttering glasses used in this project are designed for adults [16].
Tasks, Techniques and Instructions	Understandability [3, 4, 13, 21, 27, 30, 55]	The investigator (...) asked them to rate each reward type using a simple visual voting system consisting of a smiling face, neutral face, and sad face (...) in a row. For some children, this system was too complex and so the investigator would instead present the three reward types side-by-side on three iPad screens and ask the child to indicate their preference. In some cases this needed to be further simplified, with options presented in pairs (with checking for consistency for preference across all 3 sets of pairs) [21].  Similarly with the think-aloud, some participants struggled to talk as they remained focused and quiet whilst playing the game [27].  He took instructions literally: when the researcher told asked him to write [type] his name in the profile he started looking for pen and paper [4].
	Engagement [3, 14, 35, 47, 54]	Some participants (n=5) only engaged with one aspect of SensoryPaint (...) [47].  The children with ASD who did not complete the study stopped not because of the device but rather due to the monotony of the in-lab task [54].
	Interpretation / Result validation [23, 37]	As children speak little, they give their feedback using a cardboard chart with three different faces (I liked a lot, I liked a little, I didn't like). As the children in the study are not able to describe their experience in detail, there is no way of validating how well the evaluation results match children's subjective experience. While we had access to children's own overall evaluations of the gaming sessions, we do not know what aspects affected those evaluations [37].
Data analysis	Record quality [16, 40, 57]	Results from 3 participants from the ASD group were discarded due to poor calibration or data loss (too many head movements during reading), resulting in dramatic inaccuracies in more than 70% of the data collected from them [57].

**Table 2: Categorization of major problems encountered in 98 papers.**

[53], the autistic users' interaction with the product became a frustrating experience due to the caregivers' insufficient understanding of the product's functions. In [1], some of the caregivers could not fully utilize the product the way it was expected. Even though these findings provide insights regarding UX, the role transfer may also complicate the study structure. Another problem regarding the actors is obtaining consents from the caregivers. It is not possible to extract why caregivers refused to provide consents in the

studies we reviewed, yet we feel the necessity of reporting that as a possibility to keep in mind while recruiting limited number of users.

#### *Environment, Tools and Materials*

Participants with ASD exhibit hesitant, distressed and anxious behavior when exposed to unfamiliar, unexpected contexts, environments and materials in UX studies. Habituation to the setting and materials may not be possible even with the parents' or other actors' presence and

emotional support. For instance, there were cases where autistics exhibited refusal behaviors due to the study environment (e.g. the immersive room in [16]) or objects (e.g. the watch in [58] or the chair in [59]) used. These behaviors may result in irreversible situations leading to session cancellations.

Another problem derived from the inappropriate tools and materials chosen for the studies. Due to poor consideration of physical ergonomics, there were cases where the participant could not perform proper use of materials. For example, in a study conducted with autistic children [16], the 3D shutter glasses the children tried wearing, were designed for adults. Even though this case was independent from the ASD population, we've found it worth mentioning as a reminder for thinking about the physical ergonomics, particularly the unusual head orientations and body postures some autistics have, regardless of their age.

#### *Tasks, Techniques and Instructions*

Tasks, technique and instruction related problems were reported mainly due to the mismatch between users' cognitive and attentive capacities and the expected data to be collected. For example, think-aloud was reported in several studies (e.g. [3, 27]) as an improper mode of expression for individuals with ASD since they usually remained silent whilst using a product despite the instructions given by the researchers on how to think aloud. Similarly, use of personas was left for further consideration in [42] since it created confusing outcomes when applied in a PD session with autistics because some of them did not understand why they were designing something for someone who is not real.

Task simplicity and understandability were reported to impact the data collection as well. Autistic users may tend to take instructions and prompts literally and fail to perform the expected task. For example, in the usability study in [Bahiss2010], the participant was expected to fill in an online form and it resulted in an attempt of looking for a pen and paper once he was asked to *write* his name, instead of *typing* it. Some tasks which seem very simple to a typically developed researcher may actually be complicated for an autistic user [21]. Similarly, tasks that are engaging enough to be completed for a typically developed user, may seem too dull for an autistic user, or users may not be interested in all the aspects of the product under scrutiny. In an exploratory study on a working prototype [47] five of the fifteen users were interested only in a small portion of the functions available. Based on the five users' account, researchers reported that they got bored using the product. However, it was not clear whether the bored group of users was the same group with those who were not interested in all the functions available. Moreover, the researcher did not report what happened when they encountered such a disengagement.

In cases regarding understandability and engagement, commonly reported consequences were as follows: (1) the

researcher simplifies the task according to the user's cognitive capacity by changing its content or order to be able to continue collecting data, or (2) user ends the study session. Or, as in the last example above, it remains unclear what happens when the disengagement occurs.

#### *Data Analysis*

Researchers reported struggle in interpreting the users' experiences. For instance, in a study with LFAs [37], the authors mention the challenges they faced while trying to extract meaning from the data they gathered through a simple questionnaire consisting of faces with different expressions (similar to Smileyometer). However, the children in that study had limited verbal skills and could not express their experiences verbally, so the reason behind why they chose a particular face in the questionnaire remained unknown.

#### **DISCUSSIONS**

Here we discuss what the previous studies involving autistic users in the UX design processes mean to HCI and present suggestions on how to design future studies in the domain. Then we propose a guideline on how to better conduct studies with autistics.

Our findings show that, based on the substudies that specified the degree of autism, *severe autistics'* involvement ( $n=5$ ) in design processes was very limited in comparison to HFA and M/LFAs' involvement. The most probable reason behind this may arguably be the varying levels and types of environment awareness and self-expression capabilities of people with severe autism. In most cases where researchers managed to collect data from individuals with severe autism, interpreting and validating the collected data remained a strong challenge. This may also be a reason why severe autistics were never included in phase R, even through actors. And in phase E, data was mostly collected through interpreting physiological signals or counting on an actor's accounts - 72 substudies, predominantly for phases R and ER were conducted with actors only. This leads us to believe that actors have significant roles in defining and expressing the needs and experiences of autistic users. Thus, researchers either collect UX data quantitatively or largely depending on filtered information mainly structured by an actor. Both ways might prove beneficial in certain research settings, however, future research should focus on valid interpretation measures regarding how autistic people, particularly severe autistics, express their subjective experiences. We think UX researchers should challenge conventional methods to collect less actor-filtered information through a more systematical consideration of multiple sources of quantitative data such as physiological signals from autistics which can support and, to some extent, explain the reasons behind a specific experience.

Autistics involved in UX studies were mostly present during the phases E and RE. This means autistics' experiences were studied predominantly through product

evaluations. Even though there were R and D studies involving autistics that did not incorporate any product evaluation, autistics were predominantly brought into the process once a product was designed based on literature findings. This relative late inclusion of autistics in the research process may be resulting from the challenges in recruiting autistic people and their caregivers for design studies. Alternatively, the needs and questions extracted from the literature may be found sufficient enough to inform the design process without any user input.

In total, 143 substudies were conducted with autistic children and adolescents, whereas adults were involved in 22 substudies. Numerous research shows that early intervention and special education in autism helps improving social interaction, communication, behavior management and independence. Yet, given that autism is a lifelong condition, HCI should not neglect adult autistics and extend its focus to (1) including and (2) assisting autistics from all ages, not only the young. The studies also showed that the products were primarily developed for educational settings aiming at better social communication skills. Even though social skills are one of the core deficit areas in autism [2], it should not be addressed as a problem which only the autistics should learn how to deal with. Rather, taking a neurodiversity-aware perspective and considering approaches that can bidirectionally mediate the social interaction between autistic and neurotypical users would be beneficial for both groups.

Prior to our study, we did not consider including virtual characters and robots as actors in the analysis, but in some cases, they took the human therapist's role as they gave instructions or prompts to the autistic user with therapeutic purposes [6, 59]. Besides, human-robot interaction studies in autism have been proving that robots' presence and guidance can be more efficient than humans' in educational and therapeutic settings [59]. Thus, their involvement in future studies may not only be based on how the users interact with them, but also how robots take roles in UX studies as actors.

#### **Guidelines for UX Studies with Autistic Users**

Given that people with autism have perceptual and cognitive sensitivities, failing to prepare the appropriate study settings and materials may lead to two undesirable consequences: (1) irritated, uncomfortable users, and (2) measurement error and data loss. Even though existing guidelines for clinical research with autistics [e.g 34] would help preventing these problems, UX studies require guidelines considering the interdisciplinary, reciprocal and multi-acted nature of UX. So, here we present a set of guidelines on how to conduct UX studies for autistic users informed by the recommendations proposed in the papers together with the autism literature. We gathered the guidelines under 4 categories, which also correspond to the steps that should be taken while conducting a user study:

**Know your Users:** *Understand your users' individual perceptual, cognitive and physical capacities by collaborating with their caregivers or directly interacting with them prior to conducting the study.* Beside their strengths and interests which were highlighted as cores for eliciting better design contributions in PD studies [23], learn what kind of environmental stimuli (e.g. certain sounds, textures) they cannot tolerate. Learn if they regularly use or are acquainted with any product similar to what you are working on. Get to know the users with the help of small interactions in their own settings without interfering with their routines. When it is not possible to be involved in their daily activities physically, use online platforms such as e-mail, instant messaging to remotely communicate. Getting to know each user individually may prevent most of the major problems we mentioned in the previous section.

**Train the Actors:** *Present the product to the actors prior to the study especially when they are to collect data.* Let them understand to what extent the product can be used, what kind of problems can emerge and how to handle the emergent issues during the study. If the study has multiple sessions, remind them the product features prior to each session. If data collection is via a device which the actors allow the autistics to use (e.g. when autistic kids use an app on their parents' tablet), let the actors know what kind of data they should set available to share with researchers. So, the data type obtained from different users can be balanced.

**Familiarize your Users:** *Let your users get to know you and the study environments.* If the study should be conducted in an unfamiliar setting, familiarize them with the setting, materials, tools and devices that will be used in the study. Let them ask you questions about what they are expected to use. Give them enough time to feel comfortable while e.g. wearing sensors or sitting on a chair. If familiarization is not appropriate due to the nature of the study, let them at least know the duration of the session and the steps to be followed. For longitudinal studies where the users and further actors actively take part (e.g. PD sessions), set meeting dates early enough – e.g. before the whole study starts.

**Have a Plan B:** *Think about cases where the data collection might fail, and come up with back-up plans accordingly.* Even if you take precautions regarding the users and actors, there can be situations you may not avert, e.g. you may have used a technique you think should have worked, but haven't. For example, using the think-aloud technique just because the users are verbal enough may not be efficient after thoroughly reconsidering the whole study concept. Having secondary data collection techniques and tools in mind prior to study may prevent measurement errors. Similar recommendations were proposed in different PD models as 'being flexible' [9] or providing 'creative freedoms' [38]. However, being flexible may not be precise enough where neat data collection is required. Instead of losing data completely or causing measurement errors by momentary decisions, preplanned techniques can be applied when needed.

Note that, this guideline set is not a PD model which forms a basis for capturing different participants' design contributions. Rather, it is a set of suggestions for researchers who conduct UX studies with autistics to design their research in better accordance with study participants.

### Suggestions for Reporting UX Studies with Autistics

In numerous papers, participant and study details were not enough to have a clear idea about the setting, the users' characteristics and the way the actors participated in the study. So, we find it worth mentioning how to better report the study details, even though it's beyond this paper's primary focus.

Beside the common details such as age, sex and autism diagnosis (e.g. ASD, HFA), users' individual characteristics should be presented. Each individual's communication modes, motor capacities, prior experiences and interests regarding the product under scrutiny should be briefly described. Other than participant characteristics, facilitation details (when facilitation was needed, who facilitated what and how the facilitation was carried out), and if present, the familiarization process should be provided since they can directly affect the outcomes of the study. Moreover, researchers should report the problems they encountered during each task in detail in order to inform future studies to establish and develop suitable methods and techniques.

### CONCLUSION

Through a qualitative and quantitative analysis of UX studies conducted between 2010-2017 that include autistic study participants, we identified frequent problems and commonly practiced solution approaches. Different than previous works of review research with similar research questions, we contribute to the field by examining the studies conducted with and primarily for autistic users of all ages. Additionally, we do not exclude any research based on the prototyped, developed and/or tested product's underlying technology. Deriving from the problems researchers encountered within the 98 reviewed papers, we propose guidelines on how to better conduct and report on UX studies including individuals with autism. We believe that these guidelines will help HCI researchers and reviewers. Also, researchers from related fields such as psychology and special education should benefit from our findings as well. Above all, we profoundly hope that, be it directly or indirectly, autistics will benefit from these guidelines the most.

### Future Work

We will now work on evaluating and refining our guideline set through organizing empirical studies involving autistics. Other than that, we will continue analyzing the here reviewed paper set in order to generate design implications for future products developed for autistic individuals.

### Limitations

Our study has several shortcomings. First, due to the page limit, we could not have mentioned all the papers we reviewed. Second, we have chosen the papers focusing on autistics as primary users and including design considerations at different levels. Meaning we ignored the papers focusing at topics other than design even if autistics were involved (e.g. psychological experiments). Our analysis is based on the authors' explicit accounts in the

papers we reviewed. So, throughout our analysis we used names of techniques and diagnosis the way they reported. Lastly, we retrieved papers only from 3 databases and between the years 2010 and 2016.

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