Adult Autism Research Priorities and Conceptualization in Computing Research: Invitation to co-Lead with Autistic Adults

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Autism research is primarily targeted toward children and at normalizing autistic traits. We conducted a literature review of computing research on adult autism, focusing on identifying research priorities set by autistic adults and their allies, determining participation levels, identifying how autism is conceptualized, and the types of technologies designed and their purposes. We found: 1) that computing research in adult autism is neither representative of older and non-binary adults nor of autistic adults living outside the USA and Europe; 2) a lack of technologies geared towards the priorities set by autistic adults and their allies, and 3) that computing research primarily views adult autism as a medical deficit and builds design solutions and technologies that follow this marginalizing narrative. We discuss the status quo and provide recommendations for computing researchers to encourage research built on user needs and respectful of autistic adults.

CCS CONCEPTS • human centered computing

Additional Keywords and Phrases: Adult, Autism, Research Priorities, Disability, Double Empathy Problem

1 INTRODUCTION

Throughout this paper we choose to use the term autistic instead of person with autism as the majority of autistic adults in the European region prefer an identity-first language [1-3] as it is felt that person-first language may accentuate stigma [2]. We acknowledge that colleagues in the United States of America and other countries and cultures where person-first language is preferred might find this jarring.

Autism is a lifelong disability[1]. It is estimated that 1% of the global population is autistic [4]. However, this figure is known to be an underestimation because it is specific to high-income countries and because autism diagnosis remains inaccessible to many adults globally [5]. An autistic person experiences the world and interacts with others in differently than most of the human population [6]. In turn, this means that how autistic people interact with technology, especially technology that aids human-to-human interactions, will be different to non-autistic people.

Spiel [7] has recently reviewed the agency of autistic children in technology research. They described how most research is driven by external goals of non-autistic researchers, making autistic children secondary to the direct beneficiaries of such research (who range from teachers to parents or other non-autistic

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[1] "If you say I have special needs, I'll assume you're referring to my need for fresh-picked figs. I'm a Californian & this is non-negotiable. But if you're not referring to figs, then just say the word: #disabled. Euphemisms only fuel ableism. #Disability is not a dirty word." Haben Girma (https://twitter.com/habengirma/status/1433883995104681986?lang=en-GB)

stakeholders) [7]. This review demonstrates the focus of research on the discomfort and challenges faced by non-autistic people (mostly adults), rather than the needs and wants of autistic children. They contributed guidelines to consider children's agency in computing research. This demonstrates that historically researchers have not used a positive autism framing for their research with children. Instead, the predominant narrative continues to focus on correcting, othering and normalizing children [7, 8] and infantilizing autistic adults [9, 10]. Other work that has written further about normalizing technologies applied to autism. Wearable technologies for autism interventions underrepresent sensory and motor integration, executive function, emotion regulation and communication [11]. Furthermore, it is unclear if the priorities of current computing research align with the research priorities agreed by the autistic community and their allies [12, 13].

In contrast, there are a growing number of autistic and non-autistic researchers who have slowly begun to influence and challenge some of the deficit-focused, infantilizing and ableist[2] narratives that surround much of the autism research in computing research and research more generally [7, 15-20]. Their efforts focus on promoting fair, accountable, positive, ethical, inclusive, and relevant computing research in autism. However, despite the progress being made, much still needs to be improved in the way autism is portrayed in research publications and how research priorities are set, particularly in the field of computing. A previous critical review explored common practices and problems in user experience studies involving autistic individuals of any age from 2010 to 2016 [21]. Only 22 out of the 98 reviewed papers involved autistic adults, the other studies focused on non-specified age, preschool, children, and adolescents. The review recommended that future studies should better understand their audience, familiarise all actors with the product and the study, and develop more concrete plans [21]. B. Çorlu, Taşel [21] also noted that better reporting of participants characteristics and learning was needed, after performing research in this topic. It is worth noting that 75% of computing research utilises western participants residing in industrialised rich and democratic countries [22]. It follows that existing autism computing research may also be not representative of autistic people living in low resourced settings.

It is not clear how much positive autism awareness and acceptance has impacted computing research relevant to adults, but we know that publications regarding autistic children and their carers or personal assistants and parents has not improved significantly, as shown by the recent critical reviews [7, 9, 10, 12, 13]. This paper builds on past reviews by focusing on a persistently under explored population: autistic adults older than 20 years old. We also focus on a database that is heavily favoured by most computing research authors (The ACM Guide to Computing Literature), a choice that we find dubious because no rigorous past work has scrutinized how adult autism is conceptualized in such database. We contribute a detailed account of how adult autism research priorities are largely under researched by computing research. Complementing previous work, our literature review focuses on the purpose and topics of researched technologies and their subsequent effectiveness and validity. Finally, we uncover how the conceptualization of autism affects research decisions pertaining to methods, research phases and participation levels of autistic adult participants in computing research. We will begin by explaining adult autism as a disability, the latest

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[2] Ableism is a value system based on functioning, appearance and behaviours that are considered as standard to live a fulfilling life e (Special Rapporteur on the Rights of Persons with Disabilities, 2019). It is also the conception of a perfect body with the implications that disability is the loss of ableness (Campbell, 2019).

knowledge regarding the lived experiences of autistic adults. We will also summarize past work in technology and adult autism. We will then explain the methodological approach and the purposes of the two studies performed in this work. We will engage with the questions of whose research agenda is effectively been sought and whether autistic have agency in such research. We close with recommendations for computing researchers to reflect on what the adult autism research priorities and how their fulfilment -or lack of- situates adult autism computing research against the "nothing about us with us" stance [23, 24].

2 BACKGROUND

2.1 Disability and autism concepts

Disability is a complex experience that indicates an interaction between features of a person's body and features of the society and environment in which they live [25]. Therefore, disability is also an umbrella term that covers impairments, activity limitations and participation restrictions [25]. Where impairment is a disruption in body function or structure, activity limitation is a difficulty encountered when trying to execute a task or action and participation restriction is a challenge experienced when involved in life situations [25]. Approximately 15% of the human population has a disability [25, 26]. In this background section we will unpack disability and neurodiversity paradigms and other concepts which are considered paramount in modern autism research.

2.1.1 Disability paradigms applied to autism

The *medical model* of autism originated from diagnostic tools and guidelines that work from clinical deficit-based models. These models are designed with a discourse that promotes the idea that autistic individuals are collection of deficits and a minority population that needs to be cured, controlled, and prevented (in line with historic eugenic approaches to disability). Psychology has a role in defining, measuring, and supporting autistic people. However there is no psychological theory able to describe all autism traits adequately and thus there is no single universal standard of diagnosis and care in autism [27]. The Diagnostic and Statistical Manual of Mental Disorders is a product of the American Psychiatric Association (APA) in the USA, the latest version is DSM-5, released in 2013 and the past version is DSM-4. The DSM-5 introduced autism spectrum disorder as a single disorder that combines four previously separate disorders in the DSM-4. As a consequence, Asperger's syndrome[3] is not listed separately in the DSM-5. The Autism Diagnostic Observation Schedule (ADOS) is a diagnosis protocol that uses structured and semi-structured social interaction tasks between an examiner and the person being assessed. The first version of ADOS was published in 1989 and designed based on a *sample of children between 6 and 18 years old* [29] and was followed by a second edition released in 2012 (ADOS-2) that is meant to be relevant to individuals from 12 months through adulthood [30].

The *social model* of autism proposes that society's perceptions and judgements exacerbate or ameliorate autistic behavior and cognition, where cognition shapes autism observable features, which in turn influence society's perceptions and judgements of autistic people [27]. While the social model of disability is more

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[3] Historical evidence shows that Hans Asperger, that created the term 'Asperger's syndrome', worked with the Nazi regime and organizations that publicly legitimized race hygiene policies like forced sterilizations and child euthanasia (Czech, H., 2018).

humane to people with disabilities and recognizes the role of society in the topic of disability, it does not fully incorporate contextual features and flexibility required for people with invisible disabilities that also have physical traits, like sensory sensitivity of autistic people. This aligns with the larger criticism of medical vs social dichotomies of disability advanced by more recent byo-psycho-social models [31].

The UN Convention on the Rights of Persons with Disabilities has provided a *human rights model* of disability which states that disability results from human interactions, attitudinal barriers and environmental barriers that hinder the full and effective participation in society on an equal basis with others [32]. The UNCRPD marked a shift in thinking about disability from a social welfare and medical concern to a human rights issue that admitted that barriers and prejudices created by society are themselves disabling [32].

2.1.2 Neurodiversity, neurodivergence and complementary cognition

Judy singer is a sociologist that coined the word neurodiversity in her doctoral work in 1998 [33]. *Neurodiversity* is a term that represents the diversity in neurology in the human species. Neurological refers to the nervous system, which includes our brain and the nerves in all our body. Judy Singer coined the term Neurodiversity as a political term aimed at protecting the undeniable diversity of cognition of the human species and for it to be used as a paradigm for social change [34]. Diversity is a measurement of the level of variability of a specific characteristic in a specific population (for example, flora, fauna, objects, humans) [34]. Hence, diversity is not a measurement that can be applied to a single individual in a population, in other words, saying that an individual is neurodiverse is incorrect. Neurodiversity refers to both strengths and disability. Not recognizing this complexity leads to misinterpretations of the term neurodiversity, which distorts and over-simplified arguments about autism [35, 36]. Approximately a quarter (25%) of the human population is neurologically different or *neurodivergent* compared to most of the human population with typical neurology (75%), also called neurotypical. The most common presentations of neurodivergence have been labelled as disorders following the medical model of disability; these are autism, attention deficit (hyperactive) disorder and dyslexia.

More recently, Taylor, Fernandes and Wraight [37] suggested that the human species has adapted and evolved cognitively to complement each other through cognitive specializations and effective collaboration. That is, we are meant to work together leveraging our different cognitive abilities. Yet, humans have created cultural systems and practices that undermine our complementary cognitive capacity as a species [38], such as neurotypical social impositions and diagnostic labels for learning and neurodevelopmental disorders. In the next section, we explain what autism strengths are and how they complement the strengths of the neurotypical majority.

2.1.3 Autism

Autism is experienced as a constellation of traits and often alongside other neurodivergent traits and mental health problems. Autism is better understood as a multidimensional constellation of traits because traits change throughout the day with fluctuating support needs. Autism does not fit a linear spectrum because autism is experienced dimensionally and heterogeneously [27, 39]. Once one has met one autistic individual, they have met one autistic individual – which is true for other disabilities – because autism varies widely across individuals. Other typically accompanying diagnoses may be attention deficit hyperactive disorder (ADHD), dyslexia, dyspraxia, dysgraphia, alexithymia [40], dyscalculia, interoception impairments,

intellectual disability and more [27]. Accompanying mental health problems could be depression, anxiety, post-traumatic stress disorder and more [27].

Autism characteristics can be disabilities or abilities depending on the situation and context. For example, sensory sensitivity or sensory processing differences in the visual, hearing, tactile, olfactory, gustatory, vestibular, proprioceptive and interoceptive domains can be enjoyable but also overwhelming [41-43]. Social systems in which the autistic person lives, for example, being taken advantage of or manipulated due to their honesty and ingenuousness to neurotypical social rules, can be troublesome for autistic adults. Nevertheless, research has identified autism cognitive strengths or abilities that demonstrate that autistic people have superior creativity [44, 45], focus and memory [44, 45], auditory performance [46, 47], attention to detail [45], increased efficiency [44], open-mindedness [48], love of learning [48], and personal qualities like honesty [44, 45, 48], fairness [48], loyalty [45], dedication [44], effective information transfer [49] and empathy for animals and other autistic people [45].

2.1.4 *The double empathy problem and power imbalance*

Autistic and neurotypical people experience the world differently and when they try to communicate with each other, they face mutual incomprehension. The double empathy problem [15] explains that it is not the autistic individual lacking empathy and that empathy is a two way process that involves the neurotypical experience. The mutual incomprehension leads to misunderstandings, assumptions and every so often the creation of psychological theories and approaches that biased towards seeing failures and deficits in only one side of the communication process. Research has provided a qualitative account of the reduced capacity of practitioners to empathize with autistic, resulting in the absence of relational depth which unfairly shapes pathologizing practices preoccupied with fixing a problem that they assume solely residing in the autistic person [50].

The double empathy problem is a problem of communication that takes two individuals, but it is also compounded with an issue of power. Neurotypical individuals amount for 75% of the population and thus they hold a bigger social power that oppress [51] autistic individuals. Thus, the power imbalance and the miscommunication problems are often made a problem of the autistic instead of our problem (autistic and non-autistic).

2.2 Key dimensions of the lived experiences of autistic adults

Experiences past 20 years old and up to death are poorly researched for autistic people [52-54]. Most of what we know about autistic adults is dire and originates from personal accounts published in blogs, books, communal knowledge within social networks (digitally and nondigitally) and more recently in the peer-reviewed journals of Journal of Autism in Adulthood and Ought: The Journal of Autistic Culture, that provide spaces for live experience narratives and radical research approaches by autistic authors. Production of research on autistic adults has been further hampered by funding that is biased to children and genetics of autism, instead of issues across adult life [55, 56]. What we know is also not globally representative, with most research being performed in high income countries and recruiting predominantly white autistic participants [57]. Structural racism persists in autism research and practice [58-61], people of color remain underrepresented. Research of autistic adults with intellectual disabilities [62] is not within the scope in this paper.

2.2.1 Late diagnosis and identity

Many autistic adults receive their diagnosis later in life, often after battling a system that struggles to recognize them. Diagnosis services are not only difficult to access for adults but are also often inaccessible to women [63, 64], people of color [58-60, 65] and children who then become adults unaware of their disability. Research into adult autism diagnosis is dominated by studies based in high-income countries, which are not representative of adult autism globally. Realizing that one is autistic and receiving a diagnosis as an adult has tremendous life-changing effects on personal identity [66, 67]. After a late diagnosis, a process of acceptance follows: reliving the past, negotiating current relationships and community, changes to wellbeing decisions and views of one-self [68]. For most autistic people, a late diagnosis can positively impact self-awareness contributing to a positive autistic identity [69]. After the acceptance process, the impact of others reaction to autistic adult's diagnosis sees them facing autism stereotypes [68] and the consequent test on their mental health, support networks and disclosure decisions. Post diagnosis support is typically deficient or absent, albeit what we know is mostly from people living in high-income settings [62, 70-72].

Note that not all neurodivergent people identify as disabled [73, 74] and that some neurodivergent individuals may have more AD(H)D traits compared to autistic traits, but still have autistic traits, yet prefer to identify as someone with AD(HD) and not autistic. The reason for these identity choices has not been researched deeply and thus we cannot provide here an explanation for such choices; we can only ask that computing researchers consider this when designing research projects involving neurodivergent people.

2.2.2 Mental health

Mental health problems can be triggered or influenced by social structures lacking the double empathy problem [15] and socially prescribed perfectionism [75], violence [76], stigma [77-80], victimization [81, 82], inaccessible physical environments [83]. Autistic people experience high rate of mental health problems [84-86], have lower life expectancy [87], lower self-compassion [88] and also higher suicide rates compared to neurotypical people [89-91]. Lever and Geurts [92] estimated that 54% of autistic adults have had anxiety. Distinguishing autism from other conditions like schizophrenia and bipolar and personality disorders, is a persistent problem [62]. In addition, there is evidence that suicidal thoughts are experienced differently compared to neurotypical people [83]. This has potential implications for technology designed to prevent and/or manage suicide that has been designed with neurotypical criteria.

Unfortunately, general and mental health services do not support autistic adults appropriately and can cause additional harm [93, 94], like trauma [95], self-injury, and suicidality [96]. A common, known intervention to aid in mental health is talking therapy. However, this is often not accessible to autistic adults. The most common challenges in accessing therapy for autistic adults is the therapists' lack of adult autism knowledge, training, and experience, typically expressed in misconceptions and outdated beliefs of autism that further deter autistic adults from seeking therapy [97, 98]. Given that autism diagnosis remains inaccessible to many adults globally [5] it is likely that mental health support for autistic adults is absent in LMICs.

2.2.3 Gender and sexuality

Damaging studies and theories based on imposed stereotypical binary gender expectations (male or female), just as the theory of Baron-Cohen [99], have contributed to the prevalent autism research gender bias [100, 101] that favors recruitment of male participants and the exclusion of diverse gender experiences of autistic adults. The two most common diagnosis tools (DSM and ADOS) have been designed largely for the male gender, which also perpetuate gender bias in autism research [100, 101]. However, many autistic adults identify with transgender and gender-diverse identities [102-105] and with non-heterosexual sexual orientations [106, 107]. Unfortunately, physical and sexual violence is more prevalent in autistic individuals [108, 109] and autistic homosexual females are more likely to have negative sexual experiences compared to heterosexual females [106]. Further, transgender autistic are more likely to experience depression and anxiety [110].

2.2.4 Menstruation, pregnancy, childbirth, and menopause

It should come as no surprise that some autistic humans have a uterus, menstruate, have the potential to give birth, and experience menopause. In both, LMICs and HICs, menstrual experiences are influenced by the social and cultural context which in turn impact behavioral expectations [111, 112]. Such as the common expectation that individuals who menstruate would be cis-gender women. It was noted that social support can positively or negatively influence the menstruation experiences [111], but most autistic adult have no support network nor access to a health system that is autism aware.

Furthermore, autism sensory sensitivity exacerbates menstruation, pregnancy, childbirth, and menopause experiences or vice versa [113-116]. A preliminary study identified that menstruation exacerbates autistic sensory sensitivity and emotion regulation [117]. Autistic people experience higher menopausal complaints when compared to non-autistic people [114]. Pregnancy, childbirth, and menopause professional services lack awareness of autism and appropriate support is rare [113, 116]. Menopause is viewed as a complex transition by autistic people with negative components grounded in uncertainty and unpredictability and positive components grounded in increasing self-awareness and autism late diagnosis [115].

2.2.5 Adulthood and older age

Accounts of the experiences of autistic adults in older age are rare in the literature [55, 118, 119] because their participation has not been considered central to research [120]. Autistic adults engage in masking or camouflaging autistic traits to appear neurotypical, to fit into neurotypical social structures, and obtain employment [67, 121, 122]. Camouflaging has severe detrimental physical and mental health consequences, such as burnout [83, 123]. Autistic adults experience burnout as chronic exhaustion, loss of skills and diminished tolerance to stimulus [83, 123]. While autistic adults can meet education and employment requirements with the right support, they face inaccessible working environments, inaccessible career, and social systems, which are very likely to contribute to the pervasive underemployment of autistic adults [44, 118, 124, 125]. Further, autistic traits appear to worsen with older age, which exacerbates loneliness [126], anxiety, depression, and suicidality [113, 127]. To make matters worse, autistic adults may also be at a higher risk of drug and alcohol misuse, due to the amelioration of some autistic traits; however, autistic adults are underrepresented in drug and alcohol support services [128, 129].

Parenthood by autistic adults of autistic children is an under researched area [130]. Yet there are reports of autistic adults feeling incompetent and isolated, finding it difficult to communicate with health professionals, and facing detrimental experiences [131].

Older adults may experience intricate physical and mental health comorbidities [118]. Preliminary studies have suggested that dementia and Parkinson's are more prevalent in autistic adults but it is not understood whether these neurodegenerative disorders present earlier or progress more quickly in autistic adults [132]. A multidisciplinary group that included autistic adults identified residential care services that would be needed for older adults, these needs spanned through supporting transitions to residential care, staff training, and supporting physical health [133].

2.3 Past work in technology and adult autism

Over the last two decades, studies looking at current and potential use of technology by autistic adults have proliferated. Consequently, many scholars have begun conducting reviews to synthesize, evaluate and critique the quality of the evidence on the topic. Many of these reviews focus on assessing the potential of technological interventions aimed at teaching or training a specific set of skills which are often valued by neurotypical individuals [134-136]. Unfortunately, most research and technology are catered towards children [21], to finding a cure [138] or to "fix" autistic traits (to normalize). For example, the systematic review by Wainer and Ingersoll [136] focused on studies featuring interventions that leverage computerized technology to improve the development of social and communication skills among autistic individuals. Intervention methods varied from computerized behavioral learning programs, educational ABA[4]-based software such as TeachTown to virtual environments, development of vocabulary skills and functional language to emotion recognition and social understanding [136]. The review does not focus on a particular age group and the 14 studies reviewed included participants between 3 and 52 years old [136]. Another past review focused on specific types of technologies or technological interventions, such as robotics, telehealth, or computer assisted learning [141-146].

In most cases these reviews focus on technology applied for therapeutic purposes such as behavioral analysis, diagnostic assessment, self-management, or functional communication training [142-144, 146]. In contrast, another subset of reviews focused more on measuring the impact of different technologies on more general skills applied to educational or work contexts [147, 148]. For example, technology-mediated interventions examined in the review by Walsh, Holloway [148] focused on practical and specific employment-skills such as sorting mail, cooking, fire safety and clerical skills. On the other hand, other reviews such as the one by Chen [149], examined relevant literature to identify challenges and opportunities for the design of technologies with specific interaction modalities, in this case multitouch tabletop technology, regardless of their purpose of application. More recently, scholars have also started to look at how autistic adults themselves use technology, not for any pre-defined therapeutic or training purpose, but in their everyday lives. An example of this is the recent systematic review by McGhee Hassrick, Graham Holmes [150] which examines how autistic youth and adults leverage ICT for communicating with others.

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[4] ABA stands for Applied Behaviour Analysis, it is a controversial technique used to induce behaviour modification based on rewards and punishments (Leaf et al., 2022). ABA is deemed abusive, ineffective long term and known to cause PTSD in autistic individuals. (Sandoval-Norton, et al., 2021 and Wilkenfeld and McCarthy, 2020).

Results, highlight that patterns of ICT use were influenced by demographic characteristics (such as age, gender or ethnicity), cognitive level, ICT preferences (communication interface, social media use, or other engagement), and the relationship between sexuality and ICT (including online dating, sexual arousal and seeking information about sexuality) [150]. Social interactions through ICT also generated several benefits for autistic people from the development of social skills to the increase of social capital and mental health support [150]. At the same time, these interactions could also lead to negative outcomes such as misinformation, addiction or experiencing cyberbullying [150].

Finally, a handful of literature reviews have focused on a critical examination, rather than a systematic appraisal of the literature [16]. One work critically reviewed 66 studies about games examining the target population for these games, the research methodology, the play scenarios envisioned, and the purpose of play embedded in the games. Results showed that existing literature over-focuses on children, fails to consider non-binary or transgendered, neurodivergent players and relies on disempowering medical classifications. Furthermore, research methods were often established by researchers in a non-participatory way, limiting participant agency and conceptualizing play as an extrinsically motivated activity that overemphasizes therapeutic and educational aims disregarding enjoyment, self-determination, and immersion [16].

In summary, despite the presence of numerous reviews focusing on technology and autistic adults, most of this work often tends to focus on the technology used in a particular context and with specific purposes. Critical examinations of the literature that consider the agency and priorities of autistic adults is rare. So far, have been conducted on selected topics rather than looking at the ACM literature more generally and specifically about autistic adults.

3 METHODOLOGY

Having gone through a late autism diagnosis and having undertaken 2 years of voluntary research of autism literature across all aspects of being human, for self-awareness and self-management, the first author determined that major literature and critical reviews were needed. The first author noted how adult autism research was minimal, frequently ableist and normalizing and a particular lack of multidisciplinary approaches, with most studies not citing important work outside computing research found in the The ACM Guide to Computing Literature. To test this hypothesis, the first author of this paper formulated the idea of performing this work and decided on the research approach, with subsequent advice from the rest of the authors. The first author sought autistic and non-autistic collaborators in non-HCI and HCI fields via email. This work took more than three years, starting in April 2019; it took an extra 2 years for the first author to lead, considering a pandemic, personal extenuating circumstances closely tied to disability, and illness leave. In this section we present our positionality using an intersectional framework followed by the methodology that enabled a literature review of adult autism computing research, a scoping synthesis of broader adult autism research priorities and a critical review adult autism computing research.

3.1 Positionality

We are a group of HCI researchers who live in a HIC. One of us is autistic, was born and lived until their 26 years of age in an LMIC country, and while writing this paper they do not hold an academic tenure because of choosing a 100% research academic trajectory. They have left the institutionalized discrimination in academia to work in the tech industry. Here we draw attention to an autistic older adult, Cos Michael's

words - "a*s more neurodivergent researchers join academia, stasis will be challenged, but those pioneers are forging uncharted paths, battling marginalization and prejudice*" Cos Michael, autistic adult [151]. Most of the papers included in the corpus were unknown to the first author, allowing for the analysis to be developed from the content of the papers rather than the first author's individual familiarity with the broader (not HCI specific) autism research literature. While performing this work, it became impossible for the first author to remain unaffected emotionally from the ableist narratives and approaches that dominate computing research, in the topic of adult autism. The first author developed a method to empty the first reactions and emotions into a digital repository, that then allowed work to continue distanced from emotions.

The second author does not identify as disabled or neurodivergent and, despite having worked as a researcher and clinician in the field of assistive technology has no firsthand experience of disability. Throughout the analysis carried out for this paper they relied on previous experience conducting literature reviews and engaging in critical scholarship, including critical disability studies, in the context of HCI and beyond. To help ground their understanding of autism and neurodivergence, the second author asked the first author to recommend a series of essential reading that they completed before starting the review of included studies.

The last author identifies as neurodivergent. She has recently been diagnosed as having ADHD, traits of autism and dyslexia. During the diagnosis journey, it was suggested that autism traits were most prevalent due to ADHD not being successfully managed. Her neurodivergent traits make systematic reviews very difficult, and the challenges she faces sometimes affect her confidence as an academic. However, she felt it was important to persevere with this review.

3.2 Literature Review

This literature review is intentionally limited to The ACM Guide to Computing Literature because it is the most comprehensive database in existence that focuses on computing. It is our intention to identify the dominant conceptualization of adult autism research in work compiled by The ACM Guide to Computing Literature with the hope that this demonstrates our hypothesis that by looking at this one database, although deemed 'comprehensive', authors will miss the ways autistic adults and allies are challenging research outside computing research and fall into the trap of thinking that current computing research approaches in adult autism are fine, when they are not fine. We followed the systematic review process, which included searching of one database and utilizing the PRISMA 2020 [152]. We chose to utilize the PRISMA 2020 because it is a guideline that recommends principles, some of which we have found useful to follow. These are: describing the inclusion and exclusion criteria, describing the method to tabulate and display results, describing the methods used to synthesize results and describing studies and utilizing the PRISMA flow diagram for new systematic reviews.

3.2.1 Corpus construction

The ACM Guide to Computing Literature was searched on April 2022 for (adult*) AND (autis* OR asperger OR aspie OR ASD) with no time limit and limited to publications in English. The search identified 1,903 references that were then transferred to Rayyan [153]. After duplicates were removed and agreement on the inclusion or exclusion by at least two authors, 464 references were left to screen for eligibility by reading the full text. 44 papers were included that included autistic adults (>20 years old) alone or in combination with

other disabilities, excluding intellectual disability. Studies were excluded when they were not related to adult autism, focused on autistic children with no contribution relevant to autistic adults, did not include autistic adults as participants, did not utilize data originating with or from autistic adults and if the type of publication was not a research article or conference proceeding. The Prisma flow diagram showing the corpus selection process is available in Appendix A. We chose 20 years old because adulthood is the period at which physical and intellectual maturity has been reached and is typically considered to start at 20 years old. Individuals under 20 years old are adolescents [154]. We acknowledge that many countries will have varied legal definitions of when an individual is considered and adult.

3.2.2 Analysis

To visualize the corpus the following analyses were performed: geographical origin of autistic participants, frequency analysis across venue publishing the work, distribution of publications across time, the purpose and topic of the study and type of the technology being studied. The general characteristics of participants (age, gender, occupation, education, living conditions and ICT experience) were extracted alongside specific research methods used and identified research phases in each paper. We also identified reported ethical approval, searched for the presence or lack of acknowledgement to participants in the acknowledgement section, identified the recruitment method and any reported compensation to participants, and determined the participation level of participants in each paper following the participation ladder guide [155].

3.3 Review and scoping synthesis of research priorities

The first author determined that it was necessary to create a synthesis of research priorities relevant only to autism in adulthood, for the purpose of determining how and if computing research trends have been fulfilling the research priorities set by autistic adults and their allies, in line with "nothing about us without us" [23, 24]. Autism research priorities set by autistic adults and their allies have been published but are scattered in the literature and often hidden among the literature that focuses on autistic children and their parents. One past effort in synthesizing research priorities of the autism community exists; however, it is not focused on adult autism as it combines priorities for children and by stakeholders that are not explicitly identified as autistic adults [156]. Therefore, a scoping review to obtain only adult relevant research priorities was necessary adapting the aim to the specific goal of identifying research priorities rather than gaps.

3.3.1 Corpus construction

Google scholar and the Autism in Adulthood Journal were used to identify key documents that mentioned "autism AND research AND priorities". This database has access to relevant papers in general autism journals and was complemented with the past work on research priorities that the first author had already collected by engaging with the autistic community and autism-related stakeholders.

3.3.2 Analysis

We adopted a deductive content analysis method [157] that consisted in selecting a corpus, coding according to an inclusion and exclusion criteria, gathering content, grouping content, merging duplicates, and categorizing. It is adapted in that we did not have an already developed structured analysis matrix but rather an exclusion and inclusion criteria. Deductive content analysis is a flexible method that is useful when

wanting to determine categories and then use them in comparison studies. All the reports, guidelines and research papers found were deductively analyzed for content that was recommendations for future research or explicit statements of research gaps relevant to autistic adulthood. This deductive content analysis saw us coding the research gaps that fit our inclusion criteria. Any autism research priority that was explicitly relevant to infants, children, adolescents younger than 20 years old and their parents and educators, or they were purely relevant to genetics, neurology, neuroimaging, and clinical trials of medications and/or sought to cure autism, were excluded, and thus not coded. The coded autism research priorities were then grouped by generic topics. Repeated research priorities were merged and counted as one. For example, if various references recommended adult autism research of sensory sensitivity, the resulting autism research priority was one and the references recommending such priority cited along that one research question. The resulting identified adult autism research priorities were grouped into themes and then into categories. The first author (autistic) and another author (not autistic) of this paper then discussed the categories and together agreed on categories.

3.4 Review of autism conceptualization

We used the same corpus used for the literature review. We focused on extracting information from the corpus related to the conceptualization of autism and to the level of participation of autistic adults in the research studies of the corpus. For us, the conceptualization of autism is framed by theories (double empathy problem), definitions (disability paradigms, autism classifications) and practices (participation level, ethics, funding, recruitment methods) followed by research studies that involve autistic adults and the narratives that emerge from the framing chosen by computing research authors.

3.4.1 Analysis

To visualize the corpus the following analyses were performed: identified the autism classification tool used or not used, identified the presence of consideration or lack of consideration of the double empathy problem in any part of each paper (excluding the abstract, references, appendices, keywords, and acknowledgements), searched for phrases that convey assumed interpretations about autism and phrases that convey attitudes towards autistic adults. Then we classified such interpretations and attitudes to form a picture of interpretations and attitudes regarding autism and specifically autistic adults in the computing literature. Specifically, we searched for paragraphs in the papers where definitions of autism and description of autistic adults were given. Then when reading the texts, we asked these questions: Which words and what specific attitudes are these words conveying? What community is this text including or excluding or representing? Is the text revealing biases or assumptions about the topic of autism or about autistic people specifically?

4 LITERATURE REVIEW RESULTS

4.1 Global representation, venues, and open access

Most studies recruited autistic adults from high income countries in the global north, 21 times from the USA [158-177] in the Region of the Americas (AMR) and 21 from the European Region (EUR), where participants were recruited from the UK 14 times [172, 178-190]. Four studies recruited autistic adults in Italy [191-194] and one time in Sweden [195], Spain [178], Netherlands [196], Denmark [197], and Bulgaria

[178]. Only one study recruited autistic adults from Brazil [198] and another one from Australia [199]. No study represented autistic adults in the Eastern Mediterranean Region (EMR), South-East Asia Region (SEAR), African Region (AFR), nor in central America. One study recruited autistic adults from three countries (UK, Spain and Bulgaria) [178] but still within Europe and one other from two countries in different WHO regions (USA, UK) [172]. It was not possible to determine the geographical location of autistic adults recruited by two studies because it was not reported [200, 201]. Two papers did not explicitly report the country of recruitment thus, we estimated these [182, 190] to be based in the UK. This regional distribution of autistic participants represents mostly autistic people living in high-income countries that speak English.
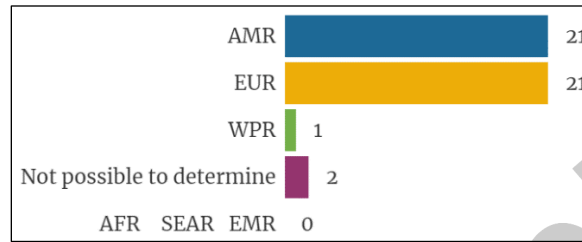

Figure 1 Number of papers that have recruited adult autistic participants computing research for each WHO regions. WPR: western pacific region.

Overall, the accepted corpus had contributions published across 14 different conferences and 7 different journals. The most common conference was CHI (6 papers), followed by 4 papers published at the International Conference on User Modeling, Adaptation and Personalization (UMAP), International Web for All Conference (W4A) and the International Conference on Computers and Accessibility (ASSETS) each. Only 3 papers were published in the Conference on Computer-Supported Cooperative Work and Social Computing (CSCW) and 2 papers in the International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and the International Conference on Mobile Human-Computer Interaction (MobileHCI) each. One paper was published at the International Symposium on Pervasive Displays (PerDis), the Pervasive Technologies Related to Assistive Environments Conference (PETRA), the Conference on Designing Interactive Systems (DIS), the International Conference on Virtual-Reality Continuum and its Applications in Industry (VRCAI), the International Conference on Multimodal Interaction (ICMI), the Automotive User Interfaces and Interactive Vehicular Applications (AutomotiveUI) and the Annual Computer Security Applications Conference (ACSAC) each. Regarding journals, the most published was Computers in Human Behaviour Journal with 3 papers. Only one paper was published at each of the following journals: Computers & Education Journal, International Journal of Cyber Ethics in Education, Computer Vision and Image Understanding Journal, Psychological Science Journal, Expert Systems with Applications Journal and the ACM Transactions on Accessible Computing (TACCESS). In addition, the majority (90%, 37 papers) of the literature was not open access.

4.2 Technologies, purposes, and themes

We looked at the temporal study of technologies in studies in our corpus (Figure 2). Papers span from 2007 tol 2022, from 2007 to 2012 there was only 1 paper published per year (excluding 2011) that recruited

autistic adults. The most popular research technology is online interactions with 17 papers being continuously researched from 2007 to 2021, followed by interaction interfaces with 8 papers but researched only from 2015 to 2021. Notably, 2015 and 2019 are the only two years in which 8 studies were published that included autistic adults, and they studied a varied range of research technologies. In 2015 three papers researched online interaction, 2 papers researched gaming, while augmented reality (AR), interaction interfaces, and no specific technologies were studied once.
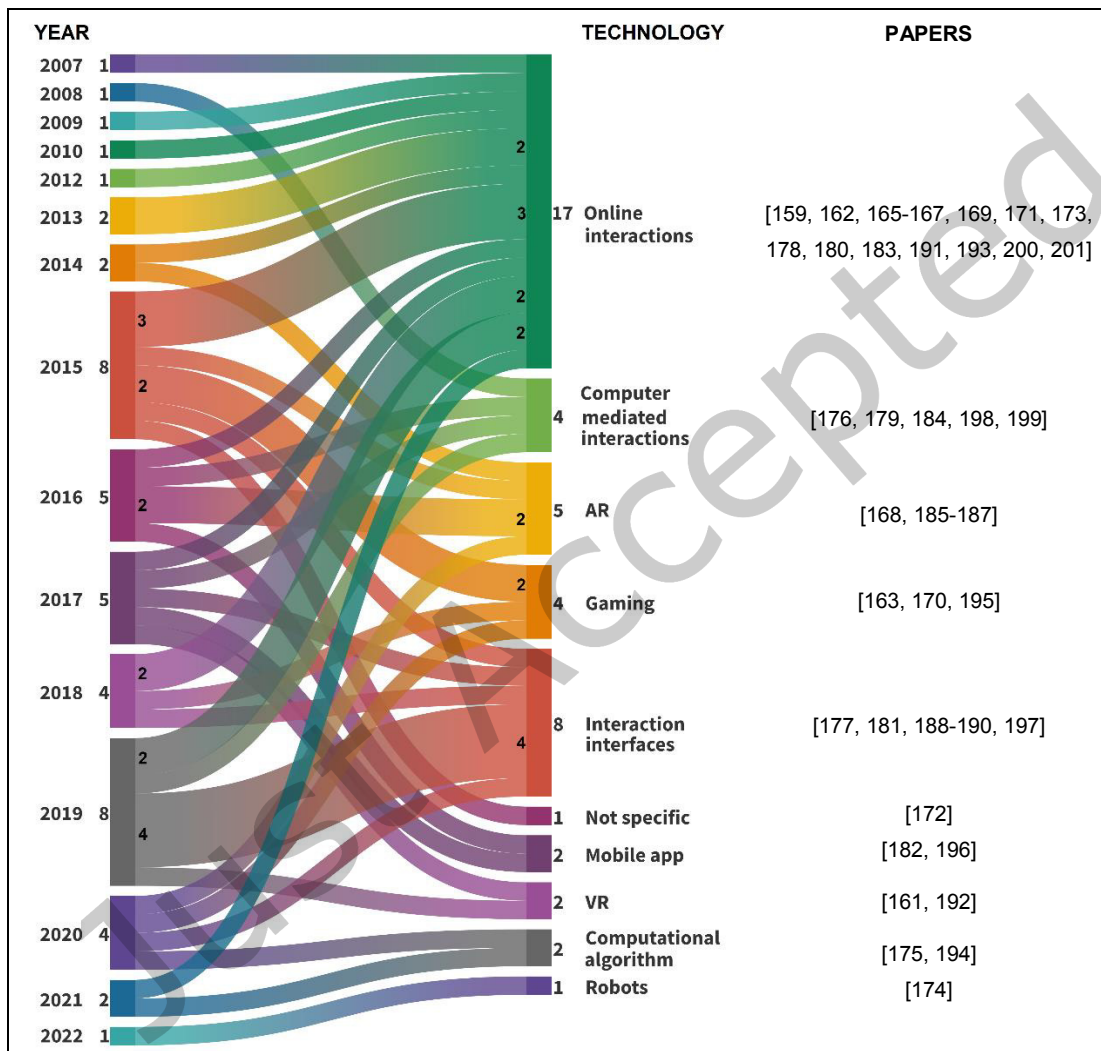

Figure 2 Alluvial plot of the number of publications per year (left side) and the 10 respective specific technology identified (right side).

Taking each technology in turn, the first paper looking at AR, which recruited autistic adults as participants, was published in 2014, followed by 2015, 2016, and then a long gap until 2020. Only one paper has investigated robots while recruiting autistic adults in 2022. Computational algorithms are markedly researched recently with two papers in 2020 and 2021. Only two papers have research mobile applications in 2016 and 2017. Only two papers have studied VR while recruiting autistic adults in 2017 and 2019.

Having looked at the temporal distribution of technologies researched, we wanted to further understand the purpose with which such technologies were studied and to which topic those technologies and their purposes were studied. We identified 8 purposes of the technologies researched in our corpus, and 19 topics covered such purposes. The purposes identified are understanding user's experience [162, 169, 172, 176, 180, 187, 190, 195, 200], assisting [160, 164-166, 177, 182, 185-187, 196, 198, 201], affect detection [167, 183], behaviour analysis [163, 173, 183, 188, 194, 198], education [158, 159, 161, 171, 178-180, 197, 199], inclusion of autism trait [191, 193, 194], change behaviour [168, 184, 192] and diagnosis [175, 181, 189]. The 19 topics identified are: anxiety [187], employment [172], online search [180], social skills [158, 160, 162, 164, 166-169, 176, 179, 183, 192, 195, 197, 201], affective responses [163, 170], information processing [188, 190], anxiety management [182, 186, 187], driving a car [185], independence and caregiving [165], communication skills [159, 174, 184, 192, 198, 200], basic daily living skills [171, 196], ICT security skills [173], online learning [199], reading comprehension [178], programming [159], teamwork [159], vocational skills [161], sensory sensitivity [191, 193, 194] and diagnosis [175, 181, 189].

Figure 3 depicts the flow of technologies researched, their purposes and topics of research, considering when papers researched various combinations of these. The number of times flows were identified in the corpus are represented by the width of the chord joining technology to purpose and topic to purpose. For instance, for the purpose of diagnosis (which is also a topic), interaction interfaces have been researched twice and computation algorithms only once; only these two technologies have been investigated for the purpose of diagnosing adult autism. The purpose of including autism traits has been identified only as relevant to sensory sensitivity and leveraging a computational algorithm once and online interactions twice. Research with the purpose of changing behaviour has focused on communication and social skills while utilizing three types of technologies, once each: AR, VR, and computer mediated interactions. Interaction interfaces (once) and online interactions (twice) have been researched for the purpose of affect detection but only applied to social skills.

The most researched purposes are to understand user experiences (11), assisting (12) and education (11). Six types of technologies have been researched with the purpose of education and related to 8 topics. Online interactions (5), gaming (1), computer mediated interactions (2), interaction interfaces (1), VR (1) and robots (1) were researched with the purpose of education in relation to social (2) and communication skills (2), basic daily living skills (1), online learning (1), reading comprehension (1), programming (1), teamwork (1) and vocational skills (1). Five types of technologies were researched to understand users' experiences and related to 7 topics. Online interactions (4), AR (1), gaming (2), computer-mediated interactions (1) and interaction interfaces (2) were researched with the purpose of understanding users' experiences in relation to anxiety (1), employment (1), online search (1), social (4) and communication skills (1), affective responses (1) and information processing (1). Five types of technologies have been researched to assist and relate to 6 topics. Online interactions (4), AR (4), mobile apps (2), computer mediated interactions (1) and interaction

interfaces (1) were researched with the purpose of assisting in relation to social (5) and communication skills (1), anxiety management (3), driving a car (1), independence and caregiving (1) and basic daily living skills (1). Note that not all technologies and purposes have been researched on all the topics mentioned.
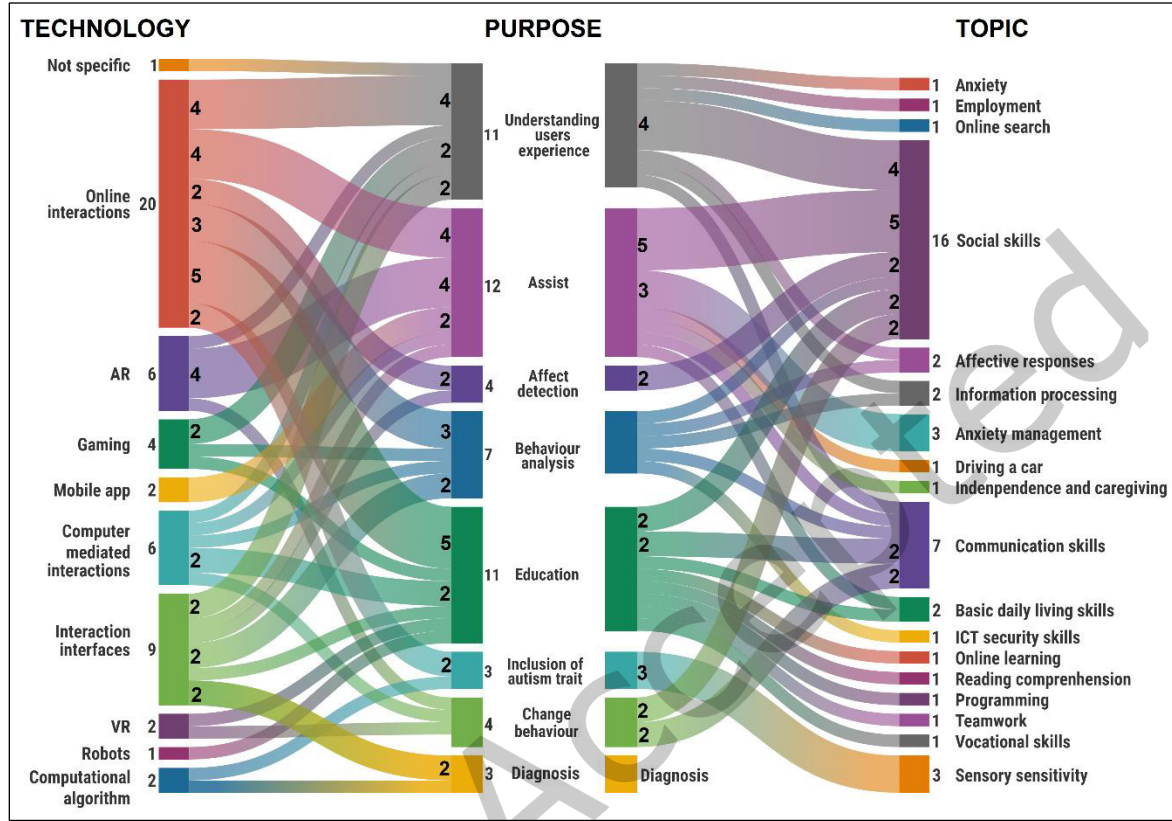

Figure 3 Alluvial plot of the technology researched (10), the identified purpose (8) and the topic of research (19).

Some papers had more than one combination of technology and purpose and topics. We classified each combination separately. Begel, Dominic [159] researched programming, communication and teamwork for the purpose of education utilizing only online interactions. Tarantino, Gasperis [192] researched communication and social skills for changing behaviour utilizing only VR. Matthews, Eraslan [183] researched social skills for two purposes (affect detection and behaviour analysis) utilizing two technologies (online interaction and interaction interfaces). Passerino and Santarosa [198] researched communication skills for two purposes (behaviour analysis and to assist) utilizing only computer-based interactions. Simm, Ferrario [187] researched anxiety management for two purposes (understanding users' experience and assisting) utilizing AR. Downing [199] utilized computer based interaction and online interactions for the purpose of education in the topic of online learning. Eraslan, Yaneva [180] utilized online interactions and interaction interfaces for the purpose of understanding users experience in the topic of online search.

4.3 Age and gender

Most papers (28) recruited autistic adults between the age of 20 to 30 years. Followed by 18 papers in the 30 to 40 years old, 8 papers in the 40 to 50 years old and 3 papers in the 50 to 60 years old range. No paper has reported explicitly to have recruited autistic adults who were over 60 years old. For three papers it was not possible to discern the age of autistic adult participants, the age of autistic participants age could not be separated from the rest of a sample that was not autistic [165, 172]. Additionally, nine papers did not report participants' age at all [159, 168, 175, 178, 182, 186, 193, 200, 201].

From 2007 to June 2020, the computing research literature recruited 702 autistic adults identifying them as male, 289 as female and one undisclosed. We say "identifying them" because studies do not disclose the way they have determined the gender. Thus, it is unclear if researchers have provided a binary choice only (male or female) or more inclusive options. Seven papers did not report gender in a measurable way or reported it incompletely. Thus some of their autistic adults with unidentified genders have not been included in the participants' gender description of the corpus [164, 165, 172, 174, 186, 193, 202]. In addition, seven papers did not report the gender of participants [161, 168, 175, 182, 183, 200, 201].

4.4 Occupation, education, living conditions and ICT experience

There is an overwhelming lack of agreement in the way participants' occupation, education, ICT experience and living conditions are measured and reported in the literature. Nevertheless, we analysed the number of participants for whom a measurable and specific employment, education, ICT experience and living condition was documented (Figure 4).

From 15 papers, we know that most of the autistic adults recruited have been employed (308 participants), while 144 have been students, and 84 unemployed at the time of their participation in research. From 9 papers, we know that 66 autistic adults lived with their family, 23 lived independently alone, 16 lived independently in shared accommodation, and 20 lived in a residential school.

From 12 papers, we know that most of the autistic adults who have taken part in computing research have been educated to pre-university and university levels. Yaneva, Ha [188] reported that participants had 16±3.3 years of formal education, unfortunately the meaning of "formal education" was not defined by the authors and its units could not be matched to the way education is documented in the rest of the literature.

From 22 papers, we know that the largest number of autistic adults have been involved in videogames research (131 adults), followed by autistic adults with skills in using social media (108 adults), web access (103 adults) and basic computer skills (25 adults). One study reported recruiting two autistic adults that used feature phones [166]. Three papers reported that 25 participants used smartphones [166, 191, 196]. Bozgeyikli, Bozgeyikli [161] only reported that participants had no VR experience. Zolyomi, Begel [176] reported that participants made video calls in a variety of devices but did not explicitly state if all participants were able to do video calls on all the devices mentioned. Although the participants recruited by Morris, Begel and Wiedermann [172] were software engineers, we could not make assumptions about peoples' ICT experience or separate those relevant to the recruited autistic adults. We were not able to classify "engagement with e-learning platform" among the other ICT skills observed in the corpus because this statement is too vague in the paper of Downing [199]. Burke, Kraut and Williams [162] reported various percentages of participants that had specific ICT skills but did not indicate if these were mutually exclusive, thus we were not able to document number of participants for whom general ICT skills were reported; for

instance, we were not able to determine from the reported data if a participant was included in the percentage of participants who knew how to use email (13.8%) were also amongst those who knew how to use discussion forums (9.5%). This analysis excludes papers that did not report data on education (32 papers) [158, 160-164, 167-169, 171, 172, 174-177, 179-182, 184-187, 190, 191, 193-197, 200, 201], occupation (29 papers) [160, 163, 165, 167, 168, 171, 175, 177-191, 193-196, 198, 200, 201], living conditions (35 papers) [159-161, 163, 164, 167-169, 171-182, 184-187, 189-197, 200, 201] and ICT experience (22 papers) [158, 160, 163-165, 167, 168, 171, 174, 175, 177-179, 182, 185, 186, 190, 192-194, 200, 201].
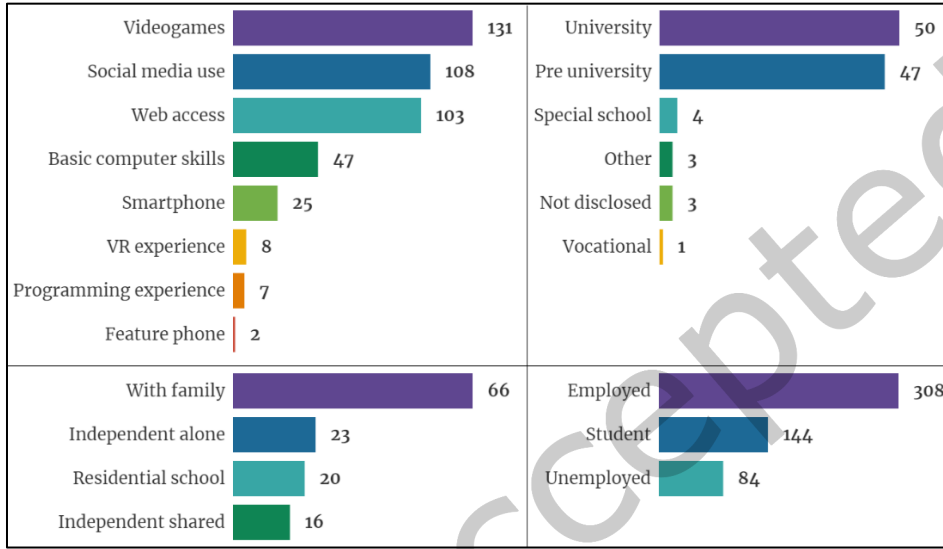

Figure 4 Matrix of bar charts of the number of participants recruited for whom ICT experience (top left), level of education (top right), living conditions (down left) and occupation (down right) were documented.

4.5 Research methods

We identified the research phases used in the overall corpus and present here the number of papers that used each research phase (Figure 5). No single paper was expected to follow all the identified research phases. The most common phase identified was user tests (present in 19 papers). Despite all featuring autistic adults as study participants, only 15 out of 44 included papers performed studies focused on identifying and understanding their experiences as users of technology. Notably, only one study presented a research phase that involved community engagement aimed at transferring knowledge and making a sustainable intervention by and with the community [187]. We classified six papers as having a core of data collection (like social media) or purposeful creation of data (like eye tracking). 17 papers had dedicated sections focusing on the analysis of existing or created data in their studies [164-166, 169, 172, 173, 176, 177, 190, 195, 198, 200, 201]. Some papers designed or built solutions that were then tested through user tests that do not capture user experiences, for example by measuring time to complete a task rather than asking participants about their experience when completing a task (19 papers) or tested through targeted user experience methods (6 papers).

Figure 5 Number of papers for which a research phase was identified. Twelve research phases were identified in the corpus: identify users experiences, design, pilot test, redesign, data collection, build solution, performance evaluation, user tests, user experience, evaluation, analysis, community engagement.

We present a synthesis of the methods and the number of papers that have used them Figure 6. Most papers used a combination of these methods; thus, we present only the number of papers and not percentages of the corpus. The most used methods were surveys (24 papers) [158-161, 163, 166, 169, 172-174, 178, 182-185, 187-190, 192, 194-197] and semi-structured interviews (20 papers) [162, 165, 166, 172, 174, 176, 177, 184, 187, 191-194, 196, 198, 199], followed by 10 papers that used observation [159, 160, 162, 165, 171, 184, 191, 192, 197, 198] and another 10 papers that used video recording [159-161, 167, 171, 177, 188, 192, 196, 198]. Nine papers used computer-based experiments or tests [163, 173, 178, 179, 181, 183, 185, 191, 196]. Six papers used audio recording [159, 160, 162, 171, 176, 184] and another six used field notes [160, 176, 191, 192, 197, 198]. Five papers used data mining [164, 166, 187, 200, 201] whereas five other papers used group discussions or meetings [159, 165, 182, 187, 198]. Four papers each, used eye tracking [183, 188-190], prototyping [159, 165, 186, 187], and brainstorming [159, 176, 186, 187]. Similarly, three papers each used focus groups [165, 171, 187], workshops [177, 186, 187], usability tests [168, 171, 196], structured interviews [160, 168, 170] and think aloud method [177, 191, 192]. Affinity mapping [177, 196], sketching [160, 191] and in the wild tests or evaluations [186, 187] were used in two papers. 28 other methods were matched to one paper each once: online feedback form [182], group induction [182], narrative elicitation [182], group feedback [182], peer evaluation [182], activity log [199], online experiment [179], questions via email [162], motion tracking [161], speed dating exercise [160], informal chat [158], follow up questions [171], iterative crafting [160], highlight report [176], play partner and observer [184], show and tell [187], individual user's feedback [178], project pitch [187], knowledge sharing training session [187], hand-on exploration [177], exit interview, guided conversation [167], mirroring game [167], thumbs up/down game [167], yes and… game [167], ball game [167], electroencephalography [175] collection and action telephone game [167]. An interactive visualization of a temporal analysis of the methods used is available at https://zuleimamorgado.wixsite.com/beautiful-data/adult-autism-research-priorities.
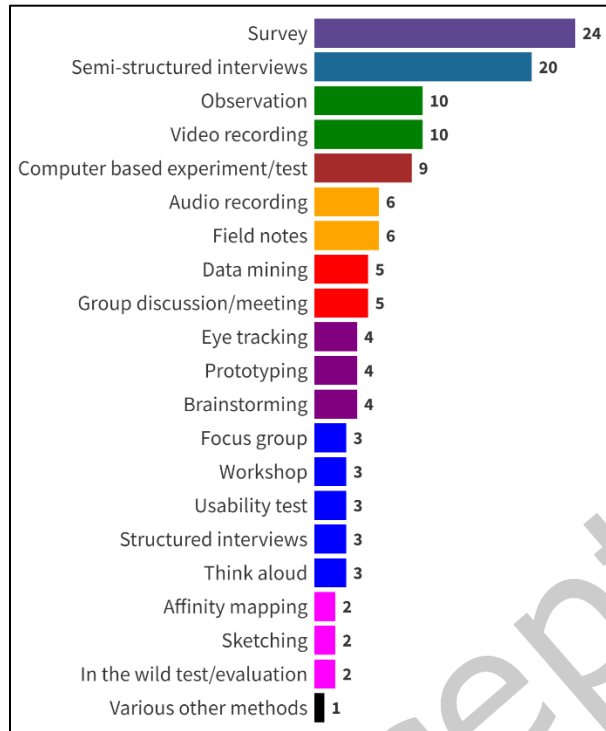
Figure 6 Number of papers that used specific research methods identified in the corpus.

4.6 Participation level, acknowledgement, and compensation

48% of the corpus engaged in non-participatory studies and 45% of the corpus in tokenistic participation styles. Non-participation was observed in 17 papers (39%) which manipulated participants [159, 163, 164, 167, 171, 173, 175, 178, 179, 181, 183, 184, 190, 192, 198, 200, 201] and in 4 papers (9%) which sought normalization of autistic people towards neurotypical behaviours [160, 165, 174, 176]. Token participation was identified in 18 papers (41%) that offered an informing participation [158, 161, 162, 166, 169, 170, 177, 180, 182, 185, 188, 189, 193-197, 199], 1 paper (2%) offered consulting participation [168] and 1 paper (2%) offered placating participation [172]. Three papers (7%) offered authentic participation in the form of partnership [186, 187, 191]. No paper in the corpus offered participation in the form of delegation nor full control to autistic adults.

Only 34% of the corpus (15 papers) thank participants for their participation in the acknowledgement section [160, 162, 163, 165-167, 169, 170, 172, 176, 177, 186, 190, 192, 199], while other 34% (15 papers) did not acknowledge participants but acknowledged funders, colleagues, organizations, and individuals [159, 161, 164, 168, 171, 173, 174, 178, 179, 184, 187, 191, 193, 194, 200]. And 32% (14 papers) of the corpus did not thank anyone [158, 175, 180-183, 188, 189, 195-198, 201].

Only 18% (8 papers) of the corpus explicitly stated that they compensated autistic adults for their participation in computing research, with an average payment of 30.8±21.1 USD and with some studies offering such compensation in cash and others through gift cards [162, 163, 166, 169, 172, 173, 176, 185]. Only one paper reimbursed expenses [187]. Most of the corpus (77%, 34 papers) did not report having

compensated autistic adults for their participation in research. Compensation for participation was not possible to calculate specifically for autistic adults in the study of Hong, Gilbert [164].

4.7 Funding, ethical approval and recruitment method

Half of the corpus (22 papers) did not report funding. Nine papers reported funding from a university [160, 163, 168-171, 177, 179, 184] and 10 papers reported funding from a national government [160-162, 167, 171, 174, 178, 179, 186, 187]. Both universities and national governments were largely from UK and USA. Only four papers reported funding from private companies [164, 166, 168, 176] and three papers reported funding from a civic association [191, 193, 194]. Two papers reported funding from the European Union [178, 179]. Funding from a consortium [167], a charity [179], and individuals [160] were reported once each by different papers. Six papers reported a combination of the funding sources mentioned [160, 167, 168, 171, 178, 179].

Only 16% (7 papers) of the corpus reported having ethical approval to perform their studies with human participants [163, 173, 175, 183, 189, 194, 195], all from universities located in the USA, UK, Italy and Hungary; 14% (6 papers) of the corpus did not report having ethical approval explicitly but mentioned information sheets and consent forms [160, 162, 176, 177, 181, 197]. One paper from a USA company review board was not explicitly presented as an ethics review board [177]. Sadly, most of the corpus (70%, 31 papers) did not report ethical approval nor gave any indication of having asked participants for their consent to participate in the research [158, 159, 161, 164-172, 174, 178-180, 182, 184-188, 190-193, 196, 198-201].

29.5% of the corpus (13 papers) did not report how they recruited autistic adults [161, 168, 174, 175, 178, 180, 185-187, 191, 193, 194, 196]. Seven papers reported their recruitment of autistic adults via social media [162, 164, 176, 195, 200, 201] or via a charity [171, 181, 183, 184, 188-190] or via colleges or schools [158, 162, 165, 167, 176, 197, 198]. Five papers recruited participants via a university [159, 173, 183, 188, 192]. Similarly, four papers used local contacts, local support leaders, local support groups or local associations [160, 162, 176, 195]. Three papers used a recruitment database [169, 173, 179] to contact autistic adults and three other papers did so via an autism centre [163, 176, 177]. Eight other approaches of recruitment were mentioned only once by one paper each: advertisements [189], private company [172], medical center [170], public events [166], MTurk [164], supported living residence [182], direct contact with an autistic adult [199] and employment program [160].

4.8 Summary

Overall, computing research in autism is representing mostly autistic adults that live in the USA and in the UK, mostly male and between 20 and 40 years old. Older autistic adults and non-binary autistic adults are grossly underrepresented. While we only specifically included papers that recruited autistic adults, they are rarely involved in research in a self-determined and truly participatory way. Most of what is being researched tends to focus on communication and social skills. The most researched technologies are online interactions, interaction interfaces and computer mediated interactions. The most researched technologies purposes are determining user experiences, assisting and education. There is an overwhelming lack of information about autistic adults so far recruited in computing research since 2007. We know very little about them in relation to their occupation, education, ICT experience and living conditions. We could not identify papers utilizing

modified methods to include autistic adults in research. Most computing research utilizes mostly surveys, semi-structured interviews, and observation. Most studies do not start with determining users' experiences, and only one paper included a research phase that involved community engagement. There is an overwhelming sense of lack of appreciation of autistic participants, with almost half of the corpus employing non-participatory methods, 77% of the corpus not compensating their participants, 66% of the corpus not acknowledging the participation of autistic adults in the acknowledgements section and 29.5% of the corpus not reporting how they recruited their participants. This is worsened by the finding that half of the corpus has not reported their funding, and 70% of the corpus not reporting ethical approval.

5 REVIEW AND SCOPING SYNTHESIS OF RESEARCH PRIORITIES

5.1 Scoping synthesis of research priorities

This corpus was constructed through a scoping review to obtain only adult-relevant research priorities (section 3.3.1). We describe the corpus in chronological order and focus on the methods, stakeholders involved and their geographical location when determining research priorities. A 2012 research effort gathered the views of autistic adults on sexuality and intimate relationships through group meetings. It determined 10 research priorities that focus on supporting autistic sexual health and relationship satisfaction [203]. We excluded one of these priorities because it was relevant to autistic adults with intellectual disabilities, which is not within the scope of this article. Through focus groups and interviews that included 14 autistic adults in the UK and through online surveys that included 398 autistic adults in the USA, two studies determined 5 similar research priorities relevant to issues of immediate practical concern and relevant to autistic adults [204, 205]. Followed by a similar study that identified five similar research priorities. In May 2015, a survey was released in the United Kingdom to ask what autistic individuals and autism stakeholders thought the top ten autism research priorities were [206]. Stakeholders included autistic individuals, parents, professionals, extended family, and NGOs [206]. In April 2016, the survey results were narrowed to 25 priorities relevant for children and adults, with no specific differentiation between both. However, some priorities were drafted specifically for autistic children. Thus they have been excluded from the selected research priorities, along with priorities relevant to investigating cures and causes of autism, which we deemed out of the scope of computing research and HCI. A study over 2 years recruited 297 autistic adults from the USA, and through stakeholders meetings, focus groups and an online survey, determined five mental health related research priorities, but these were aggregated. Thus we separated them into 7 priorities [207]. A panel that included representatives from Argentina, Kenya, Pakistan, Bangladesh and India, two of which were autistic adults, explored the concerns in the topic of autism in low- and middle-income countries in 2019. They chose 19 research priorities relevant to autistic adults, but we chose only six research priorities after applying our exclusion criteria [12]. The Autism Research Editorial Board and Associate Editors ahead of the INSAR Conference of 2019, wrote what they thought were research gaps [208]. Notably, 17 of these Editors were based at the USA, three in the UK, two in Australia and one editor representing each of the following countries: Canada, Argentina, Belgium, Bangladesh, Japan, South Africa and Spain. None of these editors declared themselves to be autistic adults. The statements of 13 editors were excluded as they were not relevant to adults, or purely relevant to genetics, neurology, neuroimaging, and clinical trials of medications and/or sought to cure autism. After exclusion, 59 overlapping research priorities

relevant to autistic adults were identified. Included research priorities are represented by 10 editors from the USA and one editor from each of the following countries: Canada, Australia, Argentina, Bangladesh, Japan, and South Africa.

The resulting list of 117 identified adult autism research priorities were grouped into 24 themes and then five categories: 1) activities and participation, 2) services and systems, 3) interpersonal interactions and relationships, 4) communication, and 5) life experiences (Figure 7). The research priority questions were synthesized in Figure 7 but are available in full in Appendix A.2.

Figure 7 Priority adult autism research priorities identified and classified into 5 categories, 24 themes and 117 priorities. To interact with this visualization via a computer go to this link (interaction via a mobile is not recommended): https://zuleimamorgado.wixsite.com/beautiful-data/adult-autism-research-priorities.

5.2 Review of autistic adult research priorities in computing research

More than half of the literature (24 papers, 54%) did not perform research that fulfills any autism research priority. Three papers researched adult autism priorities for each of the following: communication and

language skills, diagnosis, lived experience and education. Four papers researched mental health priorities, two researched parents and extended family and services delivery, and one researched employment. We found that the literature related to autistic adults did not research 66.6% of the adult autism research priorities, that is, the following 16 out of 24 adult autism research priorities themes: sensory preferences, social skills, fostering and supporting activism and advocacy, distress and burnout, power of language, awareness, understanding and tolerance, parenthood, sociocultural, linguistic and economical diversity, ageing, relationships, sexuality and intimacy, drug and alcohol use, training for autism researchers, the criminal justice system, non-verbal and minimally verbal individuals, identity and social care.
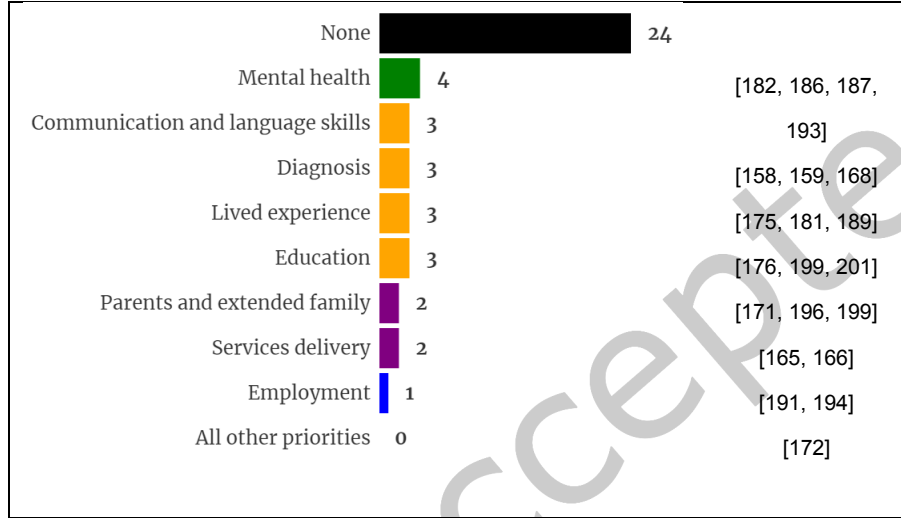

Figure 8 Horizontal histogram of adult autism research priorities researched by the computing literature. Only 8 out of 24 themes of adult autism research priorities were studied and no theme was researched by 24 papers.

5.2.1 Mental Health

Four papers researched interventions to reduce anxiety and stress in autistic adults [182, 186, 187, 193], we considered that studying technology to help autistic adults self-manage anxiety was closely related to reducing anxiety. However, two papers did not report the participants' sample size and ages. Thus we include them in the corpus based on the assumption that they included autistic adults over 20 years old.

5.2.2 Communication and language skills

Although some papers [158, 159, 168] investigated technology within the communication and language skills theme, we considered their approaches inadequate. In contrast, other papers did not fulfil any research priority within this theme [160, 162, 184, 200]. The approaches of two studies [158, 184] are patronizing and prescriptive, lacking understanding of the double empathy problem and promoting the idea that autistic adults need to improve their communication skills to better match neurotypical expectations. Specifically, the study of McGowan, Leplâtre and McGregor [184] seeks to fulfil the priorities of parents and other stakeholders (not those of autistic adults) while infantilizing autistic adults. The work of Begel, Dominic [159] is only relevant to autistic-autistic interactions, which are intrinsically easier for autistic adults

compared to autistic-neurotypical interactions (recall the double empathy problem). Lin, Huang [168]'s augmented reality study promotes "appropriate" empathetic responses that appear normalising and exclude the possibility of an autistic doctor facing a neurotypical patient, focusing most of the time on the idea that doctors are neurotypical facing neurotypical and autistic patients. Boyd, Rangel [160] designed a wearable device to detect atypical prosody. Their approach is normalizing (trying to make autistic speak like neurotypical), thus not fulfilling any autism research priority.

5.2.3 Education

A case study exploring the experience of an autistic student of a vocational course [199] is relevant to the identified research priorities within the education and lived experience themes. Thus, classified once under each theme. In contrast, the work of Barbu, Martín-Valdivia [178] could have implications in education. Still, the research community has chosen more pressing priorities that do not include technology for text simplification. Although the work of Morales-Villaverde, Caro [171] focused on supporting the learning of basic skills (recognition of shapes, numbers, colour, currency) through technology, it has non-transferable contributions since it was tested only with two autistic adults and the system was designed with exclusively non-autistic stakeholders. And, Shahid, Voort [196] focused on the interface design of a mobile app aimed at helping autistic adult students with organization and planning.

5.2.4 Social skills

No paper studied interventions to improve social skills specifically, while other papers did work related to social skills broadly but not relevant to the identified research priority [169, 179, 195, 198]. The paper of Mazurek [169] and Sundberg [195] do not research a specific intervention to improve social skills. They provide empirical evidence that could be utilized to test technology as an intervention, social media, and online gaming. The approach of Cassidy, Stenger [179] tested a realistic avatar presenting neurotypical facial expressions without consideration of the double empathy problem. While the prominent infantilization of autistic adults in the work of Passerino and Santarosa [198] only interpretations of researchers that focus on seeking self-control on autistic adults and social interactions judged without autistic voices, thus lacking knowledge of the double empathy problem and the human rights model of disability. Lastly, investigating if violent content in games increases the risk of aggressiveness in autistic adults is not a research priority and it is unfortunate that research funding is dedicated to challenging socially constructed misunderstandings led by neurotypical people, namely the implicit suggestion that aggression is a problem within the autistic community [163].

5.2.5 Parents and extended family

Only two papers were relevant to this theme and both employed social networks. Hong, Kim [165] developed an online social network restricted to autistic adults and a "trusted" network of family, friends, and professionals, which was used to provide advice and enable autistic to practice life skills. Hong, Yarosh [166] explored the impact of a social network that enabled autistic adults to connect with extended family members who then were able to communicate with them and provide them advice with everyday life questions.

5.2.6 *Diagnosis*

Diagnosis of autism utilizing eye tracking was explored in a similar way by 2 studies [181, 189] and only one utilized EEG [175]. Yaneva, Ha [189] proposed that the correlation between searching for information in webpages and autism could be used as a diagnosis test, however causation is not the same as correlation and thus even when this paper fits within the diagnosis theme, its classifier achieved a maximum accuracy of 0.75. All these three studies offer only a preliminary exploration of a technology-based solution to the overall global problem of scarce access to autism diagnosis. Although Salekin and Russo [175]'s model achieved 85% accuracy, it is limited to a sample of 105 individuals that is not representative globally.

5.2.7 *Service delivery*

Two studies leveraged technology and awareness of sensory differences in autism to study two interventions, one to design crowdsourced maps of sensory inclusive places [191] and the second to support sensory differences and individual preferences in a recommender system [194]. We considered these two papers relevant to service delivery because digital maps and recommender systems are technologies used to deliver services in multiple industries. The aim of the study by Hong, Gilbert [164] of crowdsourcing a service that provides advice to autistic adults, is aligned in theory but not in practice with the identified priorities. They purposefully excluded advice by individuals that disclosed being autistic, only accepted advice from neurotypical people and the authors determined the usefulness and "appropriateness" of neurotypical answers to questions posted in the online community by autistic adults.

5.2.8 *Lived experience*

Studies that explored perceptions, feelings, needs, expectations, and experiences of autistic adults in any aspect of living with autism were accepted for meeting the lived experience theme. Zolyomi, Begel [176] explored the experiences of autistic adults using video calling and the strategies they have built around their sensory and communication needs. Whereas Hong, Abowd and Arriaga [201] explored experiences of autistic adults seeking advice on everyday life challenges in online forums. Managing warnings while driving a car [185] may be a priority for a minority of highly independent autistic adults living in high income settings and being privileged enough to own a car. However, this is not a priority shared by the broader community as there are more pressing needs to research.

5.2.9 *Employment*

A study focused on researching how employers could be more inclusive towards autistic adults and maximize their potential when employed in Software Engineering [172]. Bozgeyikli, Bozgeyikli [161] designed a virtual reality system that is focused on improving the experiences of vocational trainers, this is not an autism research priority and the "rehabilitation" approach taken by the authors incorrectly assumed that autism is something that humans can, or indeed should, recover from. In contrast, a concerning approach by Ramnauth, Adeniran [174], sought to teach normalizing responses to meaningless and meaningful at work interruptions alike to autistic adults through a robot, which is not a research priority and could perpetrate harmful consequences by encouraging masking as appropriate. Research that is focused on fixing the individual only and not the environment in which the individual is employed does not meet adult autism employment research priorities.

5.2.10 Noteworthy work outside research priorities

Even though the work of Burke, Kraut and Williams [162] does not fulfil any adult autism research priority, it is noted that understanding how autistic adults use computer-mediated communication may be important for designing interventions. However, this study did not involve autistic adults throughout the study from design to data analysis, thus designing technology and reached conclusions that lack consideration of the double empathy problem. Another study focused on studying the usability, effectiveness, and enjoyment of touch based and touchless interactions for autistic adults [197], which could have valuable implications in how interaction interfaces are designed for this specific population. Yaneva, Ha [188] make a valid point that inclusive web design relies on guidelines that often do not include the needs of neurodivergent people, thus even when their work does not fit any adult autism research priority, it could have implications in how information is presented online for accessing information, for instance, booking an appointment with a doctor online. A similar point is made by Yaneva, Temnikova and Mitkov [190] with documents that combine text and images and by Eraslan, Yaneva [180] that explored the barriers when seeking information on the web. We can identify value in research exploring the adoption of technology by autistic adults is useful, as in the work by Tarantino, Gasperis [192] that researched the adoption potential of VR technology by autistic adults. However, it is not useful to replicate approaches that deny the voices of autistic adults, Tarantino, Gasperis [192] did not once seek to communicate with autistic adults and instead relied on observations and perceptions of non-autistic stakeholders. We appreciate that this might have been due to restrictions such as insufficient ethics approval, but we would advocate for improvements in engagement for future research. Finally, although not fulfilling any research priority chosen by the autistic community, we want to recognize that entertainment is important for wellbeing and that the work by Zolyomi, Gotfrid and Shinohara [177] and Mazurek, Engelhardt and Clark [170] could have implications in multiple areas of the autistic lived experience that are worth investigating through smart textiles and video games.

5.2.11 Research that is unsubstantiated and not user-centred

Although some studies made great efforts in recruiting autistic adults and attempted to link autism to their topic of research in computing, they did not meet any autism research priority theme, utilized non-user-centred approaches or did not offer any contribution which aligned with to computing research priorities set by the adult autistic community. Neupane, Satvat [173] established the hypothesis that autistic adults are vulnerable and susceptible to deception according to psychological theories, and therefore, they are more susceptible to online phishing. However, whilst deception is observed in in-person interactions, there is not a proven link to online interactions, thus, it is incorrect to assume the same for online remote interactions. In addition, the authors would have benefited greatly from performing interviews with autistic adults in advance of establishing such a hypothesis. Meanwhile, Matthews, Eraslan [183] expected autistic adults to show greater arousal associated with stress while accessing the web. Still, autistic arousal is interest dependent [209, 210] and varies greatly within autistic adults (recall the constellation model of autism). In lay terms, showing websites with content outside the interest of each autistic adult was set to show low arousal, thus invalidating the hypothesis. And Kaliouby and Teeters [167] set to improve real-time facial processing systems while posing that communication difficulties reside only in the autistic adult, thus this fails to acknowledge the double empathy problem this research set to solve a problem that is not articulated correctly.

6 REVIEW OF AUTISM CONCEPTUALIZATION

6.1 Autism classification and disability paradigms

Most of the corpus did not acknowledge nor report any autism guide or paradigm used to define or frame autism in their introductions and background sections (40%, 18 papers), 17 papers (38%) used an autism definition from the DSM5 [159, 163, 172-175, 179, 181, 185, 190-197], 3 papers (7%) cited the now outdated DSM4 [166, 169, 200], 2 papers (4%) referred to the ADOS version *applicable only to children* [170, 180], only 1 paper (2%) cited the ADOS-2 applicable to adulthood [175], only 1 paper (2%) referred to the social model of disability and the spoon theory [176] and 3 papers (7%, [164, 198, 199]) cited other not widely used or outdated criteria: an outdated book [211], the Virginia Department of Education in USA without any reference, and two guides that refer to Asperger's [212, 213]. Only one paper mentioned two guides (DSM5 and ADOS2), this paper was counted once in each category [175]. A problematic paradigm found in 14 papers was the use of unsubstantiated mentions of high-functioning and low-functioning, which incorrectly assume that autism is a linear spectrum and often promotes the idea of neurotypical functioning as optimal [158, 161-163, 165, 166, 179, 180, 186, 188, 191, 194, 196, 201].

Most of the corpus (77%, 34 papers) utilized a medical or deficit model to frame autism, only 1 paper (3%) utilized a social model of disability [171] and 8 papers (18%) used a combination of the medical and social paradigms [164, 166, 168, 172, 173, 179, 200, 201] and only 1 paper (2%) of the corpus referred to the neurodiversity paradigm [176]. Similarly, most of the literature (79%, 34 papers) utilized person first language (people with autism) while 4 papers (9%) used autistic or 'ASD people' [168, 177, 192, 201], and 5 papers (12%) alternated between autistic and with autism [159, 176, 191, 193, 194]. No paper in the corpus mentioned any autism conceptualization similar to the theory of complementary cognition [37] or at least did not cite it directly.

6.2 Double empathy problem

Although no paper within the corpus explicitly mentioned or cited the double empathy problem [15], we identified that 16% (7 papers) had instances where they indirectly considered the double empathy [162, 170, 172, 177, 186, 187, 191]. In contrast, the majority of papers (59%, 26 papers) did not consider the double empathy problem, not even accidentally. In addition, 11% (5 papers) presented statements and approaches that both considered and did not consider the double empathy problem [165, 168, 176, 193, 199]. We neither found instances of consideration nor inconsideration of the double empathy problem in 6 papers (14%) because the double empathy problem is relevant only when a study researched a topic that is relevant to or affects communication between two humans [163, 175, 181, 182, 185, 188]. We compared papers that presented instances of not considering the double empathy problem (31 papers) against identified papers that utilized the medical paradigm of autism alone (34). In combination with any other paradigm (8), we identified 31 matches. In general, this means that papers that utilized the medical model, which is fixated on deficits, were more likely to ignore the non-autistic side of the autistic-non-autistic human interaction and thus failed to consider the double empathy problem.

Six papers are noteworthy because they succeeded in considering the double empathy problem in parts of their narrative while utilizing the medical paradigm of autism [162, 170, 172, 177, 186, 191]. Throughout their study, two papers [162, 191] took steps to listen to the needs of their participants while volunteering for

research. Mazurek, Engelhardt and Clark [170] made a statement through which they acknowledge that researchers mostly speculate the motivations of autistic people and that no research had solicited autistic themselves for their perspectives. Morris, Begel and Wiedermann [172] state in their discussion that educating all employees about neurodivergent presentations is beneficial for all. This statement considers that empathy is paramount for neurotypical employees and employees still unaware of their neurodivergence. Zolyomi, Gotfrid and Shinohara [177] demonstrated how it is possible to avoid the imposition of neurotypical ways of communication in research.

In contrast, 31 papers show a lack of awareness of the double empathy problem in their justification of the problem, their aim, their methods and their analysis. 21 papers <u>justified</u> their research with a one-sided view of communication, that is, attributing a communication deficit on the autistic adult and denying the same neurotypical deficit [158-161, 167, 171, 173, 174, 179, 180, 184, 190, 193-200]. Three papers set to achieve <u>aims</u> that were preoccupied with fixing the communication of autistic adults teaching them neurotypical ways of communication, denying that neurotypical people also have a deficit in communication (based on a medical model) [160, 173, 178]. Eight papers utilized <u>methods</u> that denied a voice to autistic adults and elevated that of other stakeholders, usually neurotypical, or leveraged methods gave no opportunity to autistic adults to have a voice. Thus all data captured was limited to neurotypical observations and understanding [166, 168, 171, 173, 183, 190, 192, 194]. Eight papers developed <u>analyses or recommendations</u> that attribute results to the communication deficits of autistic adults but miss out on acknowledging neurotypical stakeholders' experiences (or deficits based on the medical model) [165, 168, 169, 173, 176, 183, 189, 201].

6.3 The abnormal, the improper, and their deficits

We found that autistic adults are often described as a collection of deficits [158, 164, 167, 169, 173, 174, 185, 192, 193, 195, 196, 200], hindered by mental conditions [158], with hindered mental growth [158], with atypical prosody [160], with abnormal vocalics [158], abnormal proxemics [158], abnormal chronemics [158], abnormal haptics [158], being overly literal [158], with abnormal reactions [191] a burden to a caregiver [166], a societal issue [172], mysterious [200], peculiar [193, 214], "a person whom we cannot connect with" [198] and as "people suffering from autism" [173].

Some papers communicated an ableist position claiming that if a human cannot integrate visual cues with vocal information simultaneously, then they do not have the abilities necessary to interpret emotional responses [158, 179]. This is a troublesome ableist position that then assumes that also people with visual impairments, dead/Deaf and deafblind would be equally described as unable to interpret emotional responses because they would also lack the ability to interpret visual and vocal cues simultaneously. These ableist discourses "other" disabled communities with visual, hearing, and cognitive impairments. Further, it is a discourse that is designed to favour non-disabled and neurotypical communication styles. We caution that research studies grounded on these types of discourses are set to fail autistic adults from the start and to exacerbate the power held by most non-disabled computing researchers. Other papers list difficulties such as making eye contact in a way that assumes that it is a behaviour universally expected and that such expectation is acceptable [172, 174, 200]. One paper went further into arguing that autistic adults are difficult to contact and that it is challenging to ask them questions about themselves, in an attempt to justify the tokenistic informing participatory method used [194]. Whereas one other paper assumed that autistic people

could not be relied upon in reflecting and self-reporting their own behaviours and emotion [192], in another attempt to justify the method used in the study that denied autistic adults a voice and humanity. Yaneva, Temnikova and Mitkov [190] cite a limitation in their study referring to it as an *"imposition"* due to the difficulty of autistic participants in concentrating for long periods of time. This is a troublesome framing in that it places the blame on the autistic participants instead of computing researchers acknowledging that they failed to design inclusive methods.

Additional culturally influenced discourses refer to what is "proper" [174, 178, 179, 194, 195] or "not performing well" [167] or refer to autistic adults as in need of changing [160] as if it was universal across societies and cultures, and by doing so perpetuating an ableist and exclusionary narrative that favours the majority non-disabled computing researchers that are predominantly from USA, UK, Spain, Bulgaria, Italy and Sweden.

7 DISCUSSION

Computing research in adult autism is not globally representative as it is skewed towards recruiting participants mostly from USA and Europe (mostly from the UK). No study represented autistic adults in the Eastern Mediterranean Region (EMR), South-East Asia Region (SEAR), African Region (AFR) or the central America region. No literature review has looked at the global representation of autistic people in computing research before this work.

Overall, there is a predominant focus of computing researchers on communication and social skills. However, their efforts are largely focused on deficits and lack consideration of the double empathy problem. We also identified the exclusion of older autistic adults, autistic adults that do not fit the binary gender sociocultural expectation. Computing research in adult autism is skewed towards recruiting individuals identified as male, with papers following a predominant tendency to report binary genders and do not report how such genders were determined. This gender bias and lack of acknowledgement of non-binary gender identities are also predominant in research with autistic children [7]. Autistic advocates and clinicians have collaborated and agreed on three recommendations for researchers that include autistic people: (1) sex and gender should be acknowledged and measured as separate constructs that should also include nonbinary experiences; including considerations of sociocultural gender norms, (2) work with the autistic community to understand their gender terms and their lived experiences while avoiding stereotypes and (3) research should focus on how autistic traits overlap with gender diversity and advance gender understanding, while respecting autistic people undergoing gender exploration [215].

As noted before by Çorlu, Taşel [21], computing research in autism is in urgent need of better reporting practices or participant characteristics. Our findings concur with this statement, and in addition, we highlight how participants' ethnicity is gravely underreported. We believe that this is important because people of color are often excluded from diagnostic services and their voices are pervasively missing from autism literature [58-60, 65]. The systemic disparities in recruitment (skewed towards young white male autistic individuals) observed in the corpus are in agreement with the systemic disparities and methodological concerns that contribute to the absence of black autistic experiences in autism research [216].

Although our review found several issues with existing HCI and computing related research involving autistic adults in the ACM Digital Library up to April 2022, progress has been made by both autistic researchers and their allies. However, much key work spearheading change in the conceptualization of

autism and examining the implications for technology is not necessarily available on the ACM Digital Library, such as the Ought Journal of Autistic Culture or the Autism in Adulthood Journal, and in many cases is featured in grey literature or blogs and websites of neurodivergent activists. We recommend that computing researchers that engage in adult autism research broaden their background research beyond The ACM Guide to Computing Literature and beyond searching databases dedicated to academic publications alone. This will allow computing researchers to do research that matters to autistic adults and their allies. We strongly encourage researchers to consider adult autism research priorities set by autistic adults and their allies, consider the double empathy problem, consider the International Classification of Functioning Disability and Health, consider the human rights model of disability. Researchers should include autistic adults as partners in research, consider reporting ethical approval, funding, participants characteristics and keep up to date with autistic identity and culture across cultures and geographical regions. We encourage researchers to stop using as a reference past work that is misinformed, biased, dehumanizing and ableist towards autistic adults.

7.1 Accessible, ethical, and participatory research

In answer to the hope expressed by Spiel, Frauenberger [7] in their limitations section, the notion of othering is also prevalent in adult autism computing research. While some employment and self-sufficiency related technologies are researched, these are not geared towards the actual needs of autistic adults but are dominated by a tokenistic and othering conceptualization of autistic adults, comparable to the state of computing research with autistic children.

Autistic adults have outlined that communication difficulties are influenced by the environment and other people, proving that autistic adults have a voice when given a chance to speak [217]. Some autistic adults benefit from communication skills interventions but focusing only on autistic adults and not on the environment and other human interactions is both inappropriate and ableist.

Autistic participants have an overwhelmingly positive experience when research is truly participatory [218]. This is a crucial experience that is missing in computing research. Autistic adults are autism experts and should be involved as partners in any research related to adult autism [219]. We invite computing researchers to strive to utilize participatory research principles and if systems are not designed for participatory research, then let's speak up to change the systems together. There are multiple guidelines and papers with recommendations that are useful to study as researchers thinking of doing computing research in adult autism. A practice-based guideline for the inclusion of autistic adults has been suggested as a starting point for a research team [220]. Other guidelines are dedicated to making the research methods empathetic and accessible for autistic individuals [221], participatory and ethical [222]. A recent guideline helps researchers to acknowledge their own identity and how it affects the research [223], a skill that we believe is sorely needed in computing research in autism. Various papers provide a detailed list of the type of sensory differences to which autistic adults are hyperreactive, hyporeactive or which they seek, which we consider paramount for computing researchers to know in advance of working on the topic of adult autism [42, 43, 224].

An example of how involving older autistic adults has helped to identify technology that they consider useful and thus is worth exploring and improving is in the work by Zheng, Foley [225]. Older autistic adults prefer AT that supports and blends into their daily life with a scaffolded effect [225]. We invite computing

researchers to: embed truly participatory methods, study autism paradigms, perform long-term community-based and interdisciplinary research (rather than the current yearly sprint to submit to inequitable venues [22]) and maximize reaching autistic adults in the global south with research methods that give control to autistic adults or delegates part of the control or is a partnership.

7.2 Attending to research priorities that matter to autistic adults

We encourage computing researchers to work in under-researched adult autism research priorities in the themes of sensory preferences, social skills, fostering and supporting activism and advocacy, distress and burnout, power of language, awareness, understanding and tolerance, parenthood, sociocultural, linguistic and economical diversity, ageing, relationships, sexuality and intimacy, drug and alcohol use, training for autism researchers, the criminal justice system, non-verbal and minimally verbal individuals, identity and social care. Although the themes of mental health, communication and language skills, diagnosis, lived experience, education, parents and extended family services delivery, and employment had one to four dedicated papers each, such research is still only representative of autistic adults, mostly in the USA and Europe, not globally representative. Thus, we consider that greater efforts (starting from funding bodies) need to be given to planning research that seeks to represent autistic adults in the global south, from disadvantaged communities, and that speak languages other than English. Further, more research is needed that focuses on what is relevant instead of what is valid or reliable. In this literature review we showed how studies might provide contributions that are technically valid. However, they fall short of being useful in that they do not follow the adult autism research priorities and utilize non-participatory methods. Furthermore, it is concerning that we identified computing research work that is unsubstantiated, not representative of the global autistic community, and alarmingly, many lack ethical approval. Our recommendations are in agreement with Jones [226] that recommended research to be relevant and useful for autistic people to ensure policies and practices meet the lived experiences of autistic people.

Notably, the lived experience of autistic adults is often bleak, and the scoping synthesis shows how this has impacted the choices of research priorities into themes that represent access to basic needs, inclusion in communities and employment. This has likely shadowed other not-so-paramount aspects of life, such as entertainment, recreational travel, fashion, and art. Autistic adults will focus on choosing autism research priorities that are relevant to practical things. It is up to us, the computing community (disabled and non-disabled together), to determine how to compartmentalize the more specific research questions that will lead us to fulfil adult autism research priorities. For example, we suggest research that explores the design of interactive interfaces that are inclusive to autistic sensory sensitivity is a worthwhile and important topic of research that could have a positive implication on how technology for practical as well as recreational aspects of living is designed.

It is important for future research to be aware of and work towards solving the autism research priorities before engaging in autism related research, before applying for funding and before planning research. Ask autistic adults what is meaningful research for us [227]. This paper has contributed a synthesis of such research priorities, set by autistic and their allies.

The Global Autistic Task Force on Autism Research has provided perspectives on the gaps in research that the future of clinical autism research is not likely to consider in the next five years [228], thus, it is up to

us in computing research to help through technology research to support these themes: advocacy ad scholarship of autistic people, challenge stigmatizing terms such as "profound autism", embrace participatory research, research autism research priorities set by autistic people and their allies (not by eugenicists), challenge harmful research and treatments, support only behavioral concepts and interventions that consider the double empathy problem.

7.3 Conceptualizing autism

This literature review on adult autism has shown that computing research compiled in The ACM Guide to Computing Literature is broadly ignoring adult autistic culture and engaging in the dehumanisation, objectification, and stigmatisation of autistic adults. Dehumanising, objectifying, and stigmatizing research is against the UNCRPD convention. Admittedly, not all countries have ratified the UNCRPD (Eritrea, Holy See, Niue, South Sudan, Timor-Leste); nevertheless all the computing corpus included in this work was authored by people with affiliations to countries that have ratified the UNCRPD. The use of medicalized narratives in autism research suggests an increased likelihood of ableism compared to using other disability paradigms [229]. Computing researchers that utilize medicalized models of autism will likely end up designing dehumanising, objectifying, and stigmatizing technology. Sadly, we have demonstrated that in most cases, this is applicable to computing research in adult autism that has recruited autistic adults over 20 years old and up to April 2022. Furthermore, computing research is exacerbating autism stereotypes (for example, the assumption that autism is a linear spectrum) and engaging in narratives that place communication difficulties solely on autistic adults, thus dismissing the landmark double empathy problem theory.

The framework of the International Classification of Functioning Disability and Health (ICF) enables the integration of the biological, psychosocial and environmental aspects of disability [230], yet, no article from our corpus used this framework and thus missed the opportunity to holistically research technology for autistic adults. Bölte, Lawson [231] speculated how the medical and neurodiversity paradigms are complemented in the ICF framework [230]. Autism researchers are already adopting radical changes in the way they do their research [232-234], computing research in adult autism is lagging by utilizing outdated and stigmatizing autism concepts and approaches. In 2018, an opinion piece by Fletcher-Watson, De Jaegher [235] suggested that future diversity computing could focus on developing technology to support neurotypical people accepting autistic characteristics instead of seeking the normalization of neurodivergent behavior. Four years later, we saw no evidence of any impact of that think piece on computing research in adult autism.

It is unfair that the work on mitigating the harms of autism research performed without consideration of the potential risks and harms of damaging narratives continues to fall onto the neurodivergent community and their allies. Instead, we encourage a research process that analyzes the justifications, the aims and the autism conceptualizations use and their potential risks and harms from the start.

Autistic adults have reclaimed the autism term and incorporated it into an identity and culture that follows UNCRP, the double empathy problem, neurodiversity, and complementary cognition concepts. As autistic and ally researchers, we echo this community and hereby invite computing research researchers to value the UNCRPD, neurodiversity, and complementary cognition concepts as first steps to acknowledging and

accepting autistic adults with both a disability and abilities and as human beings. We believe that adult autism computing research requires a fundamental shift in the way autism is conceptualized toward adopting an ethical position of acceptance of neurodiversity and complementary cognition. Various research studies have provided recommendations on how to avoid ableist language in autism research [35], how to Incorporate neurodiversity approaches to research in adult autism [236] and subgrouping participants instead of subtyping in order to prevent stereotypes through research [237]. The autism definition given in this paper tends to a positive to neutral way of preventing "othering". It moves away from a deficit-based and ableist discourse from influencing computing research in autism. We encourage computing researchers to check their privileges and their biases, specifically asking, am I treating autistic adults as I would treat my neurotypical peers?

7.4 Reading autism research considering author's positionality

For this section we each switch to our own personal voices and experiences and reflect on the impact that analyzing this research had on each of us.

7.4.1 First author

My analysis comes with limitations shaped by my positionality. My review is more easily achieved than those white privileged neurotypical researchers that govern their work by unwritten and unspoken social rules and academic politics that hamper intellectual exploration and radical and timely investigations into the norms and assumptions in adult autism computing research. Every description that I read in 44 papers could have been about me, oriented on deficits, ignoring my voice, misunderstanding me, dismissing my communication skills, and bombarding me with narratives of how I should talk and interact with others. This has been emotionally and cognitively difficult and physically painful [238]. I do not claim that my reading experience of autism research holds for all autistic adults. I belong to a community that is violently attacked and marginalized by research. I refuse to leave my passion for fairness and abandon my community into a complicit silence facing the lack of rigor in autism research. I wish I had better news, but the data presented here speaks the truth loudly. Non-autistic computing researchers need to start building partnerships with autistic researchers, we are here and we "want to cut our own keys" [239].

7.4.2 Second author

Having worked as an accessibility and assistive technology researcher, and as a rehabilitation professional before that for about 15 years I was familiar with ableism. As reflected on by others before me [240], I am also painfully aware that my own work has at times failed to be truly inclusive, has helped to promote negative stereotypes, or has pushed for "well intentioned" normalizing technologies that silence disabled people. What is worse is that I know that there are many instances in which I fail to recognize this as a result of my own privilege. As I read through many of these 44 papers and had the opportunity to engage in critical discussions with my co-authors, I felt often disappointed and outraged at how as HCI and computing researchers we often fail the communities we want to support. Many of the participant descriptions felt dehumanizing, stemming from the idea that as neurotypical researchers we know what is best for others. As a non-disabled researcher working in accessibility, I believe that lived experience of disability is not a pre-requisite for good research on the topic, but acknowledging that we lack this epistemological expertise is a

requisite. We must do better as a community, and to do so we need to start by admitting where we are currently failing and ask our disabled colleagues and participants to call us out on our shortcomings.

7.4.3 Third author

I have always been fascinated by what constitutes disability. This interest has been present from an early age. Working and living in my parents' nursing home, I would question why some people were there at all. I was also fascinated by people's reactions to having a disability or seeing loved ones with a disability. People's lived realities of having a disability were often not those projected onto them by others. I was re-remined of these early days of disability exploration when reading the papers reviewed. Being a person with ADHD I find systematically extracting data quite a challenge and therefore whilst I didn't take part in that part of the paper formally, I did take time to read the papers in my own way – jumping between them and between sections. They were challenging to read for many reasons. First, they were incorrect – plain wrong, my experience of working with autistic people and interacting with their family members was not in any way represented in most of the neurotypical presentations of research. Second, I could feel the pain these representations must be causing the first author of this paper. Third, I felt sad (I don't go to outrage often like the second author) instead I often reflect on the interconnectivity of us all and how misrepresenting people in this way is deeply saddening for us as a profession. I also know that I am guilt of ableist norms within my work practices. They are what we grow up with and so we can quickly default to them especially when we are feeling stretched and tired. There is no excuse for ableism and like others have reflected [240] – I too have failed to live up to what I believe should be best practice, and during the writing process I spent considerable time thinking of how we can produce a more inclusive culture within HCI research and academia more generally.

In contrast to the wide range of challenges, I also found hope. The bar is in all honestly quite low. We can do a lot better very quickly. However, tempering this hope was the ableist norms which persist in Academia – this are baked into core services on occasion. For example ethical review boards believing that people with Autism are vulnerable, making it more difficult to co-design especially for short term projects like Masters' dissertations or capstone projects.

8 CONCLUSION

Most computing research in adult autism has focused on recruiting male, English speaking adults between 20 and 30 years old living in the USA and Europe. About 50% of computing research in adult autism lacks contributions that focus on autism research priorities set by autistic adults and their allies, thus further marginalizing this minority community. Outdated, and sometimes unsubstantiated and medicalized deficit-based autism paradigms are predominantly used in adult autism computing research, compounded with misinformed, dehumanizing, and ableist sociocultural norms (which are not acknowledged by authors) and lacking acknowledgement of autistic adult participants.

Computing researchers need to carefully reflect on their biases, privileges and sociocultural norms when working in the field of autism. We have provided a series of recommendations to seek partnerships with autistic researchers and to perform autism research that is respectful, relevant, and inclusive to autistic people.

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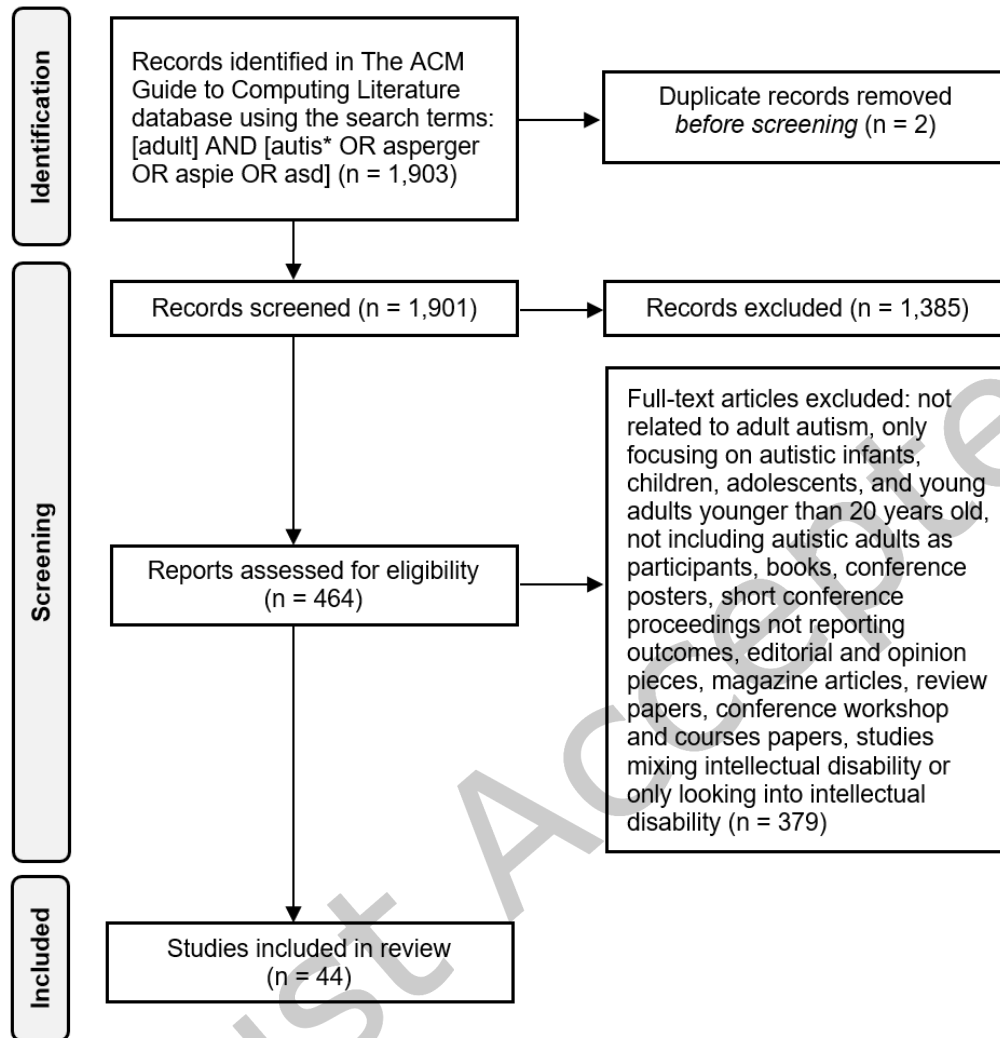Literature Review. Sensors (Basel, Switzerland), 2019. **19**(20): p. 4485.

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A.1 PRISMA-STYLE FLOW CHART FO CORPUS SELECTION

Records identified in The ACM Guide to Computing Literature database using the search terms: [adult] AND [autis* OR asperger OR aspie OR asd] (n = 1,903)

→ Duplicate records removed *before screening* (n = 2)

Records screened (n = 1,901)

→ Records excluded (n = 1,385)

Reports assessed for eligibility (n = 464)

→ Full-text articles excluded: not related to adult autism, only focusing on autistic infants, children, adolescents, and young adults younger than 20 years old, not including autistic adults as participants, books, conference posters, short conference proceedings not reporting outcomes, editorial and opinion pieces, magazine articles, review papers, conference workshop and courses papers, studies mixing intellectual disability or only looking into intellectual disability (n = 379)

Studies included in review (n = 44)

Identification

Screening

Included

A.2 FULL TABLE OF ADULT AUTISM RESEARCH PRIORITIES

Theme	Priority research questions
1. Mental Health [12, 204-208]	1. Which interventions improve mental health or reduce mental health problems in people with autism?
	2. How should mental health interventions be adapted for the needs of people with autism?
	3. What mental health problems are common in autism?
	4. Does Applied Behaviour Analysis improve wellbeing/developmental progress in autistic people?
	5. Which behavioural interventions are most effective for autistic people?
	6. Which interventions reduce anxiety in autistic people?
	7. How can we provide counselling to autistic adults in settings where such services are not currently available?
	8. How can we stop stigmatizing "restrictive and repetitive behaviours" that soothe anxiety, yet being able to identify them and intervene to reduce anxiety?
	9. What is the impact of trauma on mental health outcomes?
	10. What approaches can be used to effectively address trauma among autistic adults (e.g. trauma-informed care)?
	11. What are the best indicators or measures of PTSD, trauma, and adverse childhood experiences in autistic individuals?
	12. What is the impact of social isolation, stigma, discrimination, and other forms of marginalization on mental health and well-being in autistic individuals?
	13. What is the impact of radical inclusion, such as being part of a social movement, on mental health and well-being?
	14. What is the effect of employing community-available approaches and techniques such as exercise/physical activity, yoga, mindfulness and meditation, tai-chi, animal-assisted therapy, art and music-based approaches to well-being?
	15. How can we develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults?
2. Communication and language skills [206]	16. Which interventions are effective in the development of communication/language skills in autism?
	17. What is the clinical and cost-effectiveness of augmentative communication devices for autistic adults?
3. Social care [206]	18. What are the most effective ways to support/provide social care for autistic adults?
	19. How can training for health and social care professionals be improved so that they are more able to recognize symptoms of autism/treat autistic people appropriately?

Theme	Priority research questions
4. Education *[206, 208]*	20. Which environments/supports are most appropriate and effective in terms of achieving the best education outcomes in autistic people? 21. What are the best ways to support autistic adults in higher education to achieve optimal outcomes? 22. What assessment tool can identify individual strengths, challenges and needs at the point of entry into higher education?
5. Parents and extended family *[206]*	23. How can parents and family members be supported/educated to care for and better understand an autistic relative? 24. What parent training approaches benefit autistic adults but also reduce parental stress? 25. How can we increase the reach of interventions?
6. Diagnosis *[12, 206, 208]*	26. How can autism diagnostic criteria be made more relevant for the adult population? 27. How do we ensure that autistic adults are appropriately diagnosed? 28. How can we help train clinicians, so they no longer feel unqualified to diagnose autism in adults? 29. How can we help reach geographical regions that lack adult autism diagnosis services? 30. How can we focus on characterization rather than categorization? 31. How can we expand the diagnosis approach to be cross diagnostic beyond ASD? 32. Can the local community play a role in adult autism diagnosis and support? 33. Is the Neurodiversity App useful for autistic adults in parallel or instead of an autism clinical diagnosis, and how? 34. What is the difference not between autistic and neurotypical groups, but between autistic individuals? 35. How can we better understand the variability of autistic individuals and how can we put this knowledge to good use?
7. Employment *[12, 204, 206, 208]*	36. How can we encourage employers to apply person-centred interventions and support to help autistic people maximize their potential and performance in the workplace? 37. How can autistic adults be supported to find job opportunities, vocational training, and job placements? 38. How can we increase autism awareness of employers and provide networking support between autistic adults and potential employers? 39. Which of the multiple barriers to employment for autistic adults, should be prioritized? 40. Does the way forward lie in giving autistic adults pre-employment skills training or is incentivizing employers also required? 41. When individuals are employed, should employers be responsible of maximizing their skills or is external autism expertise or advocacy also required? 42. What are the enablers of employment of autistic adults? 43. What alternatives for recruitment are inclusive for autistic adults? 44. Is currently available vocational training truly understanding autism and matching autistic adults with appropriate jobs?

Theme	Priority research questions
8. Sensory preferences *[204, 206]*	45. How can sensory processing in autism be better understood? 46. How can sensory processing be better self-managed? 47. Which interventions improve sensory processing in autistic people? 48. How do sensory features impact sexuality and relationships?
9. Services delivery *[13, 204-206, 208]*	49. How should service delivery for autistic people be improved and adapted to meet their needs? 50. Are online autism services effective and accepted by autistic adults and their stakeholders? If not, which other technological delivery or approach would be? 51. What changes do service delivery systems and pathways need to be inclusive for autistic adults? 52. What changes do diagnosis and mental health services need to be equitable for autistic adults? 53. What are the underlying obstacles to service access? 54. How can service delivery reach non-urban areas in low resource settings? 55. Does service provision need to change to be appropriate for older autistic adults? 56. Could service delivery move away from "diagnosis treatment" to "symptom-based treatment" and implemented by local communities?
10. Distress and burnout *[206]*	57. Which interventions are effective in the treatment/management of distress in autism? 58. How can we help autistic adults and their families when facing distress? 59. How can we help autistic adults and their families when facing burnout?
11. Social skills *[205, 206]*	60. Which interventions improve social skills in autistic people?
12. Lived experience *[13, 206, 208]*	61. What is the experience of living with autism? 62. How can non-autistic people better understand what it's like to be autistic? 63. How can autistic people better understand themselves? 64. What are the needs of autistic adults? 65. How does autism impact the lives of adults? 66. What are the enablers of autistic adults living independently? 67. How can we help in establishing and validating an autism appropriate quality of life measurement tool? 68. How can we better understand which factors influence well-being of autistic adults?

Theme	Priority research questions
13. Awareness, understanding and tolerance [12, 204-206]	69. How can public understanding and tolerance of autism be improved? 70. And what is the impact of any improvement in awareness on the wellbeing of autistic people? 71. How to help the general population to understand that autistic adults are different and have abilities that can benefit society? 72. How can media (social media, film industry, TV, and radio) help to build positive and effective awareness, understanding and tolerance of adult autism in the general population? 73. How can we dismantle unverified theories about autism? 74. How can we dismantle unverified therapies that use autistic individual for money making? 75. How can the benefits of autism/abilities of autistic people be recognized and used more widely?
14. Socio-cultural, linguistic, and economical diversity [12, 208]	76. How can we reach unrepresented populations, identify their needs and support them by amplifying their voice? 77. Will investigating autism in multiple cultures clarify the diversity of adult autism? 78. In what culturally sensitive ways can we inform strength-based models of autism without ignoring challenges? 79. What are the needs of culturally, linguistically and socio-economical diverse autism communities, systems, and stakeholders?
15. Fostering and supporting activism and advocacy [12, 208]	80. How can we help autistic adults to be heard further and louder? 81. How can we help autistic adults to utilize social media effectively (and other platforms)? 82. How can advocacy for autism research be supported?
16. Power of language [208]	83. How is the term of autism used, applied, and defined? And how it can mislead?
17. Relationships, sexuality, and intimacy [203, 208]	84. What number and quality of extra familial relationships are sufficient for good health and high quality of life of autistic adults? 85. How can we help autistic adults to develop relationships that are healthy, enjoyable, and sustainable? 86. How can we help autistic adults to enhance or enable safe and satisfactory sexual engagement, considering their sensory preferences? 87. How to prevent sexual victimization and sexual offending? 88. How to involve parents, partners, and professionals to support the sexual well-being and relationship satisfaction of autistic people? 89. How do autistic adults experience and navigate sexuality across the lifespan? 90. How does sexual and gender identity develop in autism? 91. What is unique about autistic sexuality and intimacy? 92. What works for whom in relationships? 93. What are the experiences and needs of LGBT+ identifying autistic individuals?

Theme	Priority research questions
18. Parenthood [208]	94. Is pregnancy experienced differently by autistic mothers? 95. And if so, how should pregnancy care change to be appropriate? 96. How to parent being an autistic adult? 97. How can we help autistic adults to achieve positive parenting to experiences? 98. How can be harness autistic strengths towards positive experiences of parenting?
19. Ageing [13, 208] [13, 208]	99. How do older adults experience autism? How does autism affect vulnerability in ageing? 100. What are the experiences of autistic adults in residential facilities? 101. What lifestyles after retirement doe autistic adults pursue and are these satisfactory or challenging? 102. What are the experiences of autistic adults regarding death (loss of loved ones and terminal diseases)? 103. How aware are gerontologists of the needs of autistic older adults? 104. Are changes in cognitive processes due to age in autistic older adults different to neurotypicals?
20. Drug use [208]	105. How can we support autistic adults in preventing episodes of heavy alcohol drinking? 106. What type of support do autistic adults having episodes of heavy alcohol drinking need? 107. Some autistic adults report using internet searching for support when having heavy episodic drinking, is this efficient and successful?
21. Training for autism researchers [208]	108. How can we increase capacity building of local autistic and non-autistic autism researchers in low resource settings? 109. How can we increase research co-produced with autistic researchers? 110. How can we train autistic researchers to contribute best to autism research efforts?
22. Criminal justice system [208]	111. How can court staff and legal professionals understand, accept, and respect the needs of autistic adult litigants? 112. What ways of communication are efficient between legal professionals and autistic adults?
23. Non-verbal and minimally verbal adults [208]	113. How can research include non-verbal and minimally verbal autistic adults in all stages of research?
24. Identity [208]	114. How can computing research be more inclusive of diverse gender identities of autistic adults? 115. How can computing research help autistic adults through their sexual and gender identity definition? 116. How can we support autistic adults to feel free from the pressure to conform to gender binaries? 117. A late autism diagnosis is a life changing event, how can we support adults in developing their identity after this?