



City Research Online

City St George's, University of London

Citation: Barros Pena, B., Koteyko, N., van Driel, M., Delgado, A. & Vines, J. (2023). "My Perfect Platform Would Be Telepathy" - Reimagining the Design of Social Media with Autistic Adults. In: CHI '23: Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems. (pp. 1-16). ACM. ISBN 9781450394215 doi: 10.1145/3544548.3580673

This is the accepted version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/29923/>

Link to published version: <https://doi.org/10.1145/3544548.3580673>

Copyright and Reuse: Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to [City Research Online policy](#).

"My Perfect Platform Would Be Telepathy" - Reimagining the Design of Social Media with Autistic Adults

BELEN BARROS PENA, Centre for HCI Design, City, University of London, United Kingdom

NELYA KOTEYKO, Queen Mary, University of London, United Kingdom

MARTINE VAN DRIEL, University of Birmingham, United Kingdom

ANDREA DELGADO, autistica, United Kingdom

JOHN VINES, University of Edinburgh, United Kingdom

In this paper, we critically examine the design of mainstream social media platforms from the point of view of autistic experiences and perspectives, drawing inspiration from the neurodiversity movement, the notion of autism as neurodivergence, and the concept of autistic sociality. We conducted 12 participatory design sessions with 20 autistic adult collaborators. Through thematic analysis of qualitative data, we identify seven challenges our participants experienced when using social media, and a set of imagined features that represent their vision of how design could better support their social media use. We discuss how mainstream social media platforms are primarily designed to address neurotypical sensitivities, and fail autistic adults through lack of user control, inadequate mechanisms for expressing tone and intention, and an orientation towards phatic interactions. To close, we outline how autistic sociality can inspire the design of kinder and more considerate social media platforms.

CCS Concepts: • **Human-centered computing** → **Collaborative and social computing**; **Empirical studies in collaborative and social computing**.

Additional Key Words and Phrases: social media, autistic adults, autistic sociality, participatory design

ACM Reference Format:

Belen Barros Pena, Nelya Koteyko, Martine van Driel, Andrea Delgado, and John Vines. 2023. "My Perfect Platform Would Be Telepathy" - Reimagining the Design of Social Media with Autistic Adults. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (CHI '23)*, April 23–28, 2023, Hamburg, Germany. ACM, New York, NY, USA, 26 pages. <https://doi.org/10.1145/3544548.3580673>

1 INTRODUCTION

It is estimated that 1% of the world population are on the autism spectrum [57]. The medical definition of autism portrays it as a neurodevelopmental spectrum disorder "*characterised by difficulties in social communication and interaction, and restricted or repetitive patterns of behaviour or interests*" [30, p. 80]. Autistic people¹ also experience sensitivity to sensory stimuli, and may be either hypersensitive or hyposensitive to, for instance, sound, taste, vision, touch or movement [3, 18]. In addition, autistic people have a higher prevalence of alexithymia, which refers to difficulties in recognising and distinguishing between different emotions, and in expressing those emotions [30].

This research does not take a medical approach to autism however, but considers autism from the neurodiversity perspective. Neurodiversity rejects the deficits-based conception of autism, and presents it instead as an alternative

¹Following autistic adults' own preferences, we use identity-first language in this paper. See [8]

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

© 2023 Copyright held by the owner/author(s). Publication rights licensed to ACM.

Manuscript submitted to ACM

cognitive style [50]. According to Spiel et al., neurodiversity perspectives supersede the dichotomy between the medical and the social models of disability, by celebrating variation without ignoring the embodied experience of autism [50]. While recognising that autism may result in challenges, neurodiversity brings attention to the fact that autistic people have "*valuable traits*" [45, p. 125], although what constitutes those depends on context and societal values [45]. Autistic adults have mentioned as advantageous aspects: exceptional memory, focus, tenacity, perseverance, attention to detail, logic, vivid imagination, compassion, honesty, reliability and integrity [45]. Russell et al. conclude "*that autistic people can make significant contributions to society and flourish in the right social environment*" [45, p. 130].

Today, our social environments comprise mainstream software systems and tools that mediate many aspects of our lives. Little is known about whether those tools and systems are "right" for autistic adults. Our research explores this question for one of such mainstream software systems: social media platforms. It does so from the premise that autistic people's distinct cognitive style entails "*different ways of socializing, communicating and sensing*" [28, p. 23]. The particular style of social coordination enacted by autistic people has been named "autistic sociality" [41]. Our study examines the design of existing social media platforms from the perspective of autistic sociality, asking the following research questions: 1) How suitable are mainstream social media platforms for autistic adults' socialising preferences and needs?; and 2) What can we learn from autistic sociality about the design of mainstream social media platforms?

Through a collaboration with 20 autistic adults across 12 participatory design sessions, we uncovered a set of challenges our participants experienced when engaging with mainstream social media platforms, and a set of imagined features that represent their perspective about how design could better support them when facing those challenges. We conclude that mainstream social media platforms are mostly designed to address neurotypical social sensitivities, and fail autistic adults by limiting control over the user experience, through inadequate ways of expressing tone and intention, and through narrow support for informational intent.

With this paper, we contribute: 1) to our knowledge, the first participatory design study about social media with autistic adults; 2) autistic adults' perspectives on how social media platforms could be redesigned to better support their preferred social practices; and 3) a demonstration of the value of autistic sociality as a lens for design critique.

2 RELATED WORK

2.1 Autism and social media

Although much research on digital systems and autism focuses on children [22, 46], some studies do exist on mainstream social media use by autistic adults², both within HCI [13, 42], and across other disciplines such as socio-technical studies [6], disability studies [23], psychology [37, 56], sociology [52], and linguistics [31]. Within HCI, research has found that new connections can be established through digital channels, particularly through interest groups, however maintaining relationships was found difficult [13]. Additionally, Page et al. found that young autistic adults with complex needs tend to interpret social media affordances literally, thereby enacting affordances differently from neurotypical users [42]. Across other disciplines, Mazurek studied the association between social media use, friendship networks and perceived loneliness [37]; Ward et al. explored the relationship between social media use and happiness [56]; Gillespie-Lynch compared the preferred functions and perceived benefits of computer-mediated communications across autistic and neurotypical populations [23]; and Triantafyllopoulou et al. looked at the associations between social media use, cyber-bullying and well-being [52].

²We have purposefully excluded literature concerning social media and autistic teenagers, since adults are likely to have different needs. See [46]

Our study differs from the above scholarship in both methods and purpose. While existing research on social media and autistic adults has mostly relied on surveys [23, 37, 52, 56], interviews [6, 42], and participant observation [31], our research applied participatory design methods. In terms of purpose and research questions, much of the existing work has focused on evaluating the potential of social media to ameliorate autism's impact on social relationships, and to improve perceived happiness, independence or well-being (e.g. [13, 37, 42, 55]). This line of work generally aims to address reported *"higher levels of loneliness"*, *"more restricted networks of friends"*, and lower satisfaction with interpersonal relationships amongst autistic people [42]. Consequently, studies assess whether the use of social media by autistic people could improve the perceived quality of their social lives, could *"lead to social benefits"* [55], or enhanced well-being [56].

Our research differs from this prior work in that our main object of study are the social media platforms themselves, and not so much the outcomes of their use by autistic people. We subscribe to the view that issues surrounding the social lives of autistic adults are complex. They not only involve the autistic population and their preferred means of communication, but also the cultural context within which they find themselves, as well as the neurotypical population [39]. Without disregarding the benefits and satisfactions that autistic adults may derive from using social media, we do question whether the use of any digital system, in and of itself, could have any real impact on the quality of one's social relationships [56]. Instead, our main concern was deploying the perspectives and experiences of autistic adults as a means to critically assess how mainstream social media platforms are designed. Like Zolyomi and Snyder, we argue that the *"social lives of autistic individuals are rich and nuanced and provide insights that should inform the design of (...) computing systems"* [58, p. 2]. The focus of our study is, therefore, social media platforms' deficits, rather than purported autistic ones, with *"autistic sociality"* [41] acting as a critical lens to support our inquiry. In the next section we introduce the concept of autistic sociality, and how it connects to the neurodiversity movement.

2.2 Autistic sociality

Attributed to the autistic sociologist Judy Singer, neurodiversity moves away from medicalised, deficit-based conceptions of autism [16, 47] towards the idea of difference. From this perspective, autism is a reflection of human's neurological diversity [47]. It is a differing cognitive style [16], another way *"of existing as humans"* [28, p. 21], a different *"form of life"* [17] that entails *"different ways of socializing, communicating and sensing"* [28, p. 23]. Building on this perspective, two key theories were developed that inform our research approach: the *"double empathy problem"* [39], and *"autistic sociality"* [41].

2.2.1 The double empathy problem and autistic communication. The *"double empathy problem"* is grounded on an understanding of communication as social interaction, and reframes the supposed social communication deficits of autistic people as a mutual and reciprocal matter between autistic and neurotypical interlocutors [39]. From this perspective, unsuccessful communication is not a problem of the autistic person's so-called *"deficits"*, but a breach *"that occurs between people of different dispositional outlooks and personal conceptual understandings"* [39]. Essentially both parties, neurotypical and autistic, are responsible for the difficulties in understanding or relating to each other. Rather than placing the full responsibility for a failed interaction with the autistic participant and their lack of neurotypical understanding, Milton demonstrates that neurotypical participants conversely have a lack of understanding of autistic preferences [39].

Subsequent research supports this idea. For instance, Crompton et al. compared the effectiveness of verbal information sharing within groups of autistic people, groups of neurotypical people, and mixed groups including autistic and

neurotypical participants [15]. They found no differences in communication quality between the autistic-only and neurotypical-only groups, with both exhibiting the same information sharing abilities. Mixed groups, however, performed significantly worse, and reported poorer interactional rapport with their peers. The fact that autistic adults communicate with each other as effectively as neurotypical adults questions the traditional deficit narrative of autism [15]. Similarly, Heasman and Gillespie studied interactions between autistic people during collaborative video gaming sessions [27]. They found "*a generous assumption of common ground*" [27, p. 915] that leads to rapid rapport; and a low demand for coordination that helped autistic people recover quickly from small misunderstandings. These features make autistic interactions extremely flexible and tolerant of other characteristics of autistic speech, such as topic shifts. They also allow autistic interlocutors to experiment with ways of relating to each other with minimal detrimental consequences [27]. These features all contribute to the conception of an "autistic sociality".

2.2.2 Autistic sociality. The notion of "autistic sociality" rests on an understanding of human sociality as "*a range of possibilities for social coordination with others*" [41, p. 69], with autistic sociality being "*one of these possible coordinations*" [41, p. 70]. Autistic sociality can be enhanced through social conditions including: short sequences of conversational actions, rather than extended discourse; topics related to objective knowledge, rather than subjective or affective ones; interactions mediated through artefacts, rather than face-to-face interactions; restrained affect in speech; and moderate to rapid speaking tempo [41].

Additionally, Bertilsdotter Rosqvist distinguishes between two different forms of sociality: interest-based sociality and socially based sociality [5]. Interest-based sociality is built around the importance of common interests as a "*central motivator for social interaction*" [5, p. 173]. Socially based sociality is mostly concerned with social positioning, reproducing a social group, "*the accumulation of social capital*" and "*social identity building*" [5, p. 174]. Interest-based sociality is most relevant to autistic contexts, while socially based sociality applies to neurotypical ones. Bertilsdotter Rosqvist's autistic participants described socially based sociality as tiring and demanding, requiring a lot of effort and guesswork to decipher, and introducing uncertainty with regards to interpretation [5]. Addressing this uncertainty, Belek highlights autistic speakers' "*candor and directness*", a process he termed "explicitation" [4, p. 176]. While autistic sociality is still a matter under study, based on existing research we can highlight as prominent features the importance of common interests for social interaction purposes [5], a need for routine and familiarity [2], and a preference for explicit interactions [4].

The double empathy problem and autistic sociality raise the question of how neurotypical researchers can actually engage in meaningful autism research [40]. Milton argues that autism research should involve autistic scholars, and deploy participatory methods [40]. In the spirit of seeing neurodiversity "*as a spectrum of intellectual riches*" [16], and in appreciation of autistic people's strengths, abilities and gifts [47], we ask what can be learnt from autistic sociality about the design of social media platforms. To answer that question, and following Milton's guidance [40], our team includes an autistic scholar, and we engaged autistic adults as collaborators through participatory design methods.

2.3 Participatory design with autistic adults

Existing participatory design work in technology has prioritised autistic children, adolescents and students [22, 44]. Much of this research has attempted to develop assistive technologies (e.g. [20, 35, 51]), which aim to alleviate the perceived difficulties or deficits accompanying the autism spectrum [50]. There is significantly less participatory design work with autistic adults [36], and many of the studies that do exist also focus on assistive technologies. For example, Kim et al. designed a gamified mobile application to promote physical activity [29]. Aslam et al. developed an assistive

robot co-creation toolkit [1]. Grond et al. worked on an affective technology for emotional expression through music [25]. Rapp et al. explored how crowdsourced maps could assist autistic adults in identifying urban locations that matched their sensory preferences [44]. Simm et al. developed an anxiety management tool that integrated peer support [46]. Stepping outside the domain of assistive technologies, the ASCmeI.T. project sought to extend participatory design to the ideation stages, by providing a mobile application that collected autistic adults' ideas on what technologies they would like to see developed [24, 43].

As can be appreciated from the above examples, participatory design research with autistic adults has been mostly concerned with the development of new technologies. What this research has yet to explore is the suitability and appropriateness for autistic adults of existing, mainstream software systems. Our study attempts to do precisely that for social media platforms. To our knowledge, ours is the first participatory design project about social media with autistic adults.

3 METHODS

Our research team included five researchers, four of whom are neurotypical and one who is autistic (Author3). Authors are white European from different parts of the continent (West, East South) and Latin American. The research was designed with autistic voices in mind, and both participants and Author3 were taken as more authoritative voices on autism than the neurotypical team members.

Participant recruitment was done in collaboration with *autistica*, a UK autism charity. We recruited 20 autistic adults with no history of intellectual difficulties: 6 who identified as non-binary or agender; 9 who identified as female; and 4 who identified as male. One participant did not disclose their gender. Ages ranged between 20 and 60 years old. All participants had a diagnosis of autism, and had experience with different social media platforms (e.g. Facebook, Twitter, Instagram, LinkedIn, Discord, reddit). Although participants' needs varied, none of them reported complex needs. Their participation was compensated at the public involvement rate recommended by the NIHR Centre for Engagement and Dissemination [21].

We organised 4 participatory design workshops broken down into 3 sessions. The 20 participants were split into 4 groups of 5 people which, as far as possible, remained unchanged across all 3 sessions. Overall, we ran a total of 12 2-hour sessions with participants (3 sessions per group). Due to cancellations and schedule changes, each session had between 3 and 6 attendees. Participant information, the group they belonged to, and the sessions they attended, as well as their unique identifier in this paper, are provided in Table 1.

Our sessions were carried out remotely over a video conference platform (Zoom) and with the support of a web-based digital whiteboard (Miro). They were done remotely not because of public health constraints related to the Covid-19 pandemic, but because this was the participants' preferred mode of interaction. Autistic people can experience anxiety and sensory discomfort in social situations and unfamiliar physical environments [44]. Doing research remotely allowed participants to engage in the activities from the safety and comfort of a familiar location.

The researchers developed custom materials for each of the sessions with both a digital and a physical instantiation. The digital version of the materials was displayed on the digital whiteboard. The physical version of the materials was printed on cardboard and posted to participants ahead of each session. Participants could opt-out from receiving the physical materials, but only one of them (P8) decided to do so. Participants were invited to use whichever instantiation of the materials (physical or digital) worked best for them. They were also encouraged to display the posted physical materials within their own space, and to keep them until the end of the third session.

Table 1. Participants' IDs, gender, age, group and attended sessions

ID	Gender	Age	Group	Attended sessions
P1	Female	20	1	1 and 3
P2	Female	52	1	1 and 2
P3	Female	22	1	1 and 2
P4	Female	48	1	1, 2 and 3
P5	Female	31	1	1, 2 and 3
P6	Male	59	2	1, 2 and 3
P7	Non-binary	22	2	1, 2 and 3
P8	Female	37	2	1, 2 and 3
P9	Male	51	2	1, 2 and 3
P10	Agender	58	2	1, 2 and 3
P11	Male	28	3	1 and 2
P12	Female	60	3	1, 2 and 3
P13	Non-binary	24	3	1, 2 and 3
P14	Male	52	3	2 and 3
P15	Non-binary	28	3	1 and 2
P16	Non-binary	49	4	1, 2 and 3
P17	Female	42	4	1, 2 and 3
P18	Non-binary	29	4	2 and 3
P19	Not disclosed	29	4	1 and 3
P20	Female	35	4	1, 2 and 3

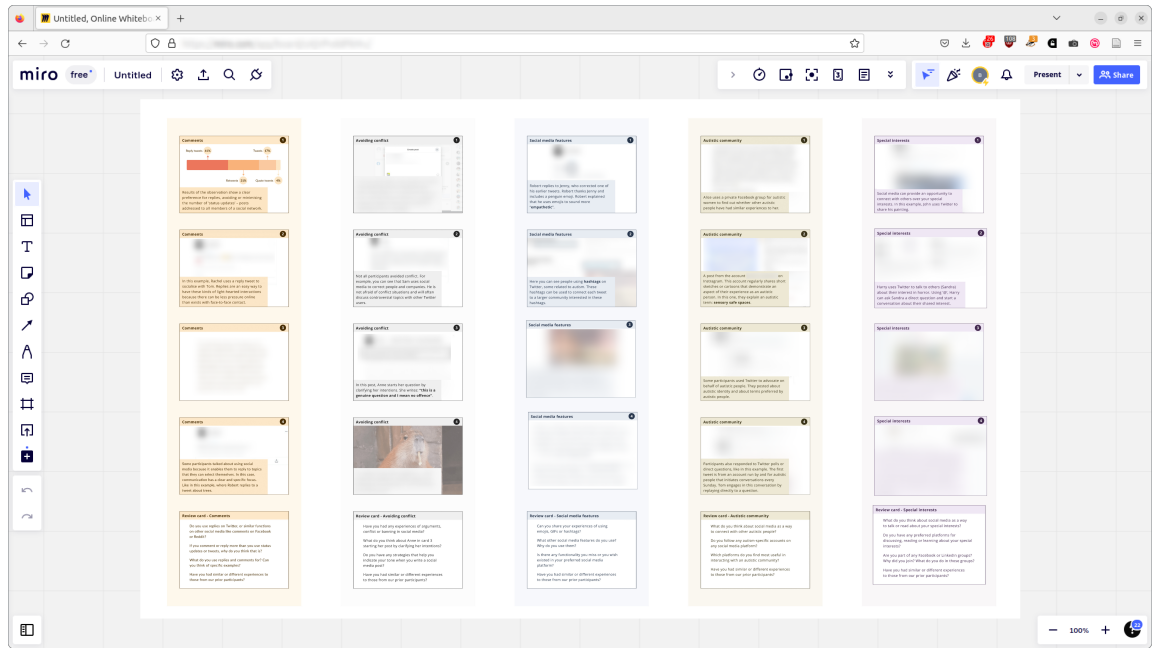


Fig. 1. The digital version of the materials for session 1. Each column represents a data theme. Some content has been blurred to protect participants' anonymity. All names are pseudonyms.

3.1 The workshops and sessions

The workshops followed a process that moved participants from a descriptive mindset (session 1), into a reflective one (session 2), and finally into a creative phase (session 3). Session 1 encouraged participants to describe their personal social media experiences through a data immersion activity. This descriptive effort aimed to set the foundation for the reflective exercise in session 2. Our data immersion activity was inspired by the "evidence safari", a group activity for engaging, interrogating and discussing curated research data [19] popular in policy design circles within UK government institutions [49]. The researchers selected a subset of data about autistic adults' social media use from a prior phase of the Autistic Adults Online research project. Starting from the existing analysis of this data, the research team adapted and developed 5 themes, and selected 4 representative examples per theme from the data corpus. These data examples were developed into evidence cards consisting of an image and a brief explanatory statement. Each theme included 4 evidence cards, followed by a questions card with 4 questions to guide the theme review. To accommodate session time constraints, we assigned 2 of the 5 themes to each group for review, making sure that each theme was reviewed by at least one group.

Session 2 invited participants to reflect on their social media practices. It did so through a set of "questionable concepts", provocative design proposals purposefully assembled to motivate creative critique [54]. The research team brainstormed ideas for questionable concepts, drawing inspiration from prior literature on autistic adults and social media, and on the discussions and conversations from session 1. The team came up with a list of 18 potential concepts, from which 6 were selected, iterated and developed for use during session 2. Each questionable concept was made of 2 components: an explanatory card, and an interactive prototype developed with a design tool (Figma). Explanatory cards included: 1) the concept name (e.g. The Small Talkifier); 2) a brief description; 3) a link to the interactive prototype (e.g. <https://tinyurl.com/smalltalkifier>); 4) a QR code participants could scan to access the prototype from their smartphones; and 5) an image showing the main concept screen (see figure 2 for an example). All 6 explanatory cards are available in a public Git repository³.

Ahead of session 2, participants were asked to choose a personal anecdote about their own social media use; then review the "questionable concepts", and consider whether any of them addressed the circumstances of their anecdote. Some participants identified a connection between their anecdotes and the questionable concepts (e.g. P6, P20). Others linked their chosen concept to recurrent frustrations in their social media use (e.g. P16), and yet others provided a thoughtful critique of all 6 questionable concepts (e.g. P14). During the session, each participant narrated their personal anecdote, identified their selected questionable concept and explained the rationale behind their choice. Each participant's contribution was followed by questions and a brief discussion.

Session 3 moved from a reflective into a creative mindset, by inviting participants to imagine features for a brand new social media platform. We set this task in order to divert focus from any individual platform (e.g. Facebook or Twitter), since our subject of interest was social media as a category of digital system, rather than specific instantiations of it. The task succeeded in getting participants to address elements that are common across most platforms, such as infinite streams of algorithmically-structured content, user-generated content, and networks of contacts. During the third session, we used a design card-based activity [32] to support the creative process. We chose design cards because they have been successfully used in the past for participatory design purposes with autistic adults [1, 22]. The design cards were loosely based on the inspiration cards workshop [26]. They included 3 colour-coded types of cards: action cards (blue), entity cards (orange) and blank cards (white). Action cards represented things users can do on social media

³https://github.com/autisticadultsonline/autisticadultsonline/tree/main/workshop2_questionable_concepts

(e.g. send or delete). Entity cards represented objects users can manipulate on social media (e.g. posts, friends). There were 17 action cards and 17 entity cards. The list of actions and entities was a combination of existing items from social media platforms (e.g. send, search, emojis, hashtags), and items that surfaced during prior sessions (e.g. preview, read aloud, rudeness, different views). We also provided blank cards that allowed participants to add their own actions and entities. The design cards are available in a public Git repository⁴.

During session 3, participants engaged in 3 rounds of feature-making. Rounds started with 10 minutes of individual work, during which participants envisioned and composed their features using the design cards. After the 10 minutes, each participant introduced their feature, and answered questions from the group. Each round of feature-making was followed by a short break. Of the 16 participants who attended session 3, all but 2 (P9 and P10) used the design cards as expected by the researchers. P9 and P10 did create features as well, albeit more abstract and less formed than the features developed by the other participants. These differences were substantial enough to consider them outliers, so the researchers decided to exclude them from analysis. Overall, 14 participants designed a total of 38 social media features.

4 DATA ANALYSIS

All 12 sessions were audio recorded and transcribed, and all comments left on the digital whiteboards were extracted. The data corpus was complemented with the chat logs from all sessions. We carried out reflexive thematic analysis [9–11] on this material. The first author engaged in a first round of coding and discussed the outcome with all authors. We generated two initial themes at that early stage: one about challenges participants had to contend with while using social media; and a second one about coping strategies participants deployed in order to tackle those challenges. Using those initial themes as a guide, the first author carried out a second round of coding. During that second round, the first author aimed to identify a more exhaustive and granular list of challenges and coping strategies. The second round of coding also paid particular attention to: how existing features in social media platforms interacted with challenges and coping strategies; how challenges and coping strategies connected to each other; and how the participants' features created during session 3 related to those challenges and coping strategies. The outcome of the second round of coding was once more discussed and reviewed by all authors.

The second round of coding resulted in a set of 7 challenges: 1) Underserved interest-led sociality; 2) Expressing emotional intent; 3) Irrelevant and harmful content; 4) Sensory overload; 5) Audience uncertainty; 6) Compulsion to use; and 7) Conveying and interpreting meaning. These challenges relate to the question of how suitable are mainstream social media platforms for autistic adults' socialising preferences and needs (RQ1). In addition, we identified connections between 35 of the imagined features and these challenges, with each feature addressing one or more of them. Features and their associations with challenges relate to the question of what can be learnt from autistic sociality about the design of mainstream social media platforms (RQ2). We describe the 7 challenges and how they connect to the imagined features in the next section.

5 FINDINGS

In this section, we refer to participants through a unique identifier (see Table 1). For each participant quote, we also indicate the source material: 'Chat' for the chat logs, 'DW' for the digital whiteboard, and no source for the session transcripts; the session number (S1, S2 or S3); and the participant group (G1, G2, G3 or G4). For instance, a quote from participant P17 taken from the chat log corresponding to group 4's session 1 will appear as "P17, Chat, S1-G4".

⁴https://github.com/autisticadultsonline/autisticadultsonline/tree/main/workshop3_design_cards



Fig. 2. The explanatory card accompanying one of our questionable concepts. Use the URI or scan the QR code to access the interactive prototype.

Participants were not required to identify themselves when adding comments to the digital whiteboards, although some of them did so voluntarily. We have respected participants' preferences, therefore some whiteboard quotes do not include a participant ID.

5.1 Challenges using social media

5.1.1 Underserved interest-led sociality. Autistic sociality seemed poorly served by mainstream social media platforms such as Facebook, Instagram and Twitter. These platforms favour phatic interactions, a communicative practice where content and meaning are subordinate to the goal of maintaining networks [38, 53] of pre-existing and adjacent connections (i.e. friends of friends). By contrast, our participants' use of social media was characterised by interest-based sociality [5]: driven by the desire to interact on topics of interest rather than phatic and 'convivial' interactions [53]. The difference between phatic and interest-based social media use was summarised by P2 as *"two distinct styles of comm[unication] (...) psych[ology] vs interests"* (Chat, S1-G1).

Although participants used social media to stay in touch, particularly with family and friends they knew offline, most other engagements gravitated around specific subjects. For instance, for P5 the value of social media resided in how *"You can meet people from all over the world with shared interests"* (P5, S1-G1). P20 only really commented or replied

"if it's a shared interest (...), because it feels like a safe structured conversation." (P20, S1-G4). As this last quote illustrates, participants had a preference for well-structured, purposeful and informational social media engagements.

Facebook groups have been pinpointed as key in serving this type of interest-based, content-centred sociality [42], and several of our participants did run or belong to such thematic groups, for example about painting (P12), cars (P6), robotics (P9), literature (P7) and autistic parenting (P17). In addition, participants identified tagging and hashtags as supportive of autistic sociality. They searched hashtags to locate content they were interested in, even if they rarely used hashtags themselves; and used tagging to bring content to someone else's attention: *"I do tag friends on posts related to shared special interests on Facebook"* (P7, DW-G2).

In spite of these useful features, participants also described how Facebook, Instagram and Twitter were not ideally suited to their preferred style of sociality. For instance, P6 described Twitter as *"a morass of people"* where *"things aren't grouped necessarily by subject matter"* and *"it's sometimes very difficult (...) to get them all sort of grouped together in my head"* (P6, S2-G2). For P7, Twitter was *"so, so diverse and so much different content goes on Twitter"* that it became *"hard to know how or what to share"* (P7, S1-G2). Facebook, in spite of their useful groups, was perceived as being *"interspersed with personal things (...) which, to be honest, you have to be polite about, but not that you are interested in"* (P6, S2-G2). For P9, Facebook groups felt like *"camera"* groups (P9, S1-G2), used mostly for *"showing off"* (P9, S3-G2). Participants identified other social media platforms that they found better geared to their interest-based sociality, such as Quora and reddit:

I find reddit quite good because it's organised into subreddit[s] and you know exactly what each subreddit is for. It's clearly labelled and all the posts kind of have a similar nature, so it's quite easy to engage in and you kind of know what you're doing on there. (P7, S1-G2)

5.1.2 Expressing emotional intent. Participants also reported challenges when using some of the features deployed by social media platforms to enhance communication and express emotional intent. These included emojis, animated GIFs and hashtags. Although pretty much all participants used a limited set of emojis to some degree for clarifying their intention and tone, they also voiced their dissatisfaction with them. Emojis emphasis on representing emotion caused problems to some participants, something that resonates with the higher prevalence of alexithymia between people on the autism spectrum [30]. For instance, P10 found their own emotions hard to identify. That made it practically impossible to map them to a visual representation: *"is totally confusing, emojis. I don't know how I'm feeling. How do I know which one to use?"* (P10, S1-G2). For P12, who had difficulties interpreting facial expressions, it was the fact that emojis rely on a stylised version of such expressions as a representational strategy, what P20 called *"the little yellow circle"* (P20, S2-G4): *"I just don't get people's faces at all (...) if you can't read people's expressions, and know what they are meaning, then how could you do it with a picture of a circle with dots and lines on it?"* (P12, S3-G3).

Others struggled with the fact that the meaning of emojis is situated. The same emoji can mean different things depending on the content it accompanies, and the nature of the thread within which it is embedded: *"they can have different meanings (...) And then you're left trying to interpret inference again. And that can mean that some things on the emoji chart feel off-limits to me, because I'm scared of using them for the same reasons that I'm scared of saying the wrong word"* (P8, S1-G2). Some participants shied away from actively using GIFs and hashtags for similar reasons. These issues with ambiguous and fluid meaning connect to difficulties experienced by autistic people when interpreting non-literal speech such as jokes and sarcasm [4].

While reflecting on these matters, P3 pointed out that features such as emojis and GIFs encourage a certain type of communication that felt alienating to her:

it (...) raises interesting discussions about how neurotypicals communicate, and how social media apps are always very enabling. There's like GIFs and emojis and videos etc, and there's never much room for definitive, non-flourished language (...) there's an influx of memes and reaction photos, and people (...) copying and pasting each others' tweets and then changing them, and it is very confusing and I'm not in the loop most of the time. (P3, S2-G1)

What P3 describes is a 'phatic' [53] style of interaction that our participants perceived as characteristic of neurotypicals, and that clashed against their more direct and literal approach.

5.1.3 Irrelevant and harmful content. Participants berated the quality of the content they encountered on social media. Much of what came through their feeds felt irrelevant:

pictures of cute kittens, children, their food, their holidays, etc., (...) the clutter that comes through on social media. (...) I don't want to read about people's political views. (...) I don't want to hear what they've had for dinner. I don't necessarily want to know about their children. (P6, S3-G2)

Similarly, P20 was *"not interested in retweets or things popping up on my timeline from somebody who knows somebody that I know sort of thing"* (P20, S2-G4). Participants also shared concerns about fraudulent approaches and spam, found themselves *"bombarded with fake friend requests"* (P9, S1-G2), and reported receiving messages from complete strangers. In addition, social media platforms were awash with posts that were too *"combative"* (DW, G1), too *"extreme"* (P19, Chat, S1-G3), *"harmful"* (P3, S2-G1) or downright toxic. Non-autistic social media users must of course confront these very same issues. What was different about our autistic participants was the degree of discomfort and distress caused by the exposure to this type of content: *"if people say really hateful things sometimes it can affect me quite badly. I can sometimes find it quite difficult to move on from nastiness"* (P16, S2-G4). P8 found *"it all overwhelming and exhausting. Especially the conflict and negativity"* (P8, DW-G2). The ability to block and mute brought no relief: *"of course we can mute and we can block and do all these things, but we've seen it. We've seen it and even if we don't see it we're still aware of it"* (P2, S2-G1). Overall, there was a distinct sense that a lot of the content present on social media was not worth consuming, and that some of it was actually harmful.

5.1.4 Sensory overload. In addition to the quality of the content, participants took issue with its quantity, which was *"too much"* for P8, made P9 feel *"lost"* (S1-G2), and felt overwhelming to P5: *"sometimes I feel a little bit overwhelmed by [Facebook]. There's always something interesting popping up to read from one of the pages I follow, which can take up a lot of time"* (P5, S2-G1). P7 connected these feelings to having limited capacity to deal with social media content: *"sometimes I don't have the mental health space to deal with the entire content (...) and I only have the headspace to kind of process what my friends are up to"* (P7, S3-G2).

Sensory overload was not only connected to the amount of content, but also to overbearing stimuli. P4 described social media platforms as *"visually too busy"* (P4, S1-G1). Movement, as in animated GIFs, was found to be *"very distracting"* (P20, S2-G4) and *"disturbing"* (P5, S1-G1). P5 and P1 disliked audio, in particular when autoplayed while scrolling or when coming up *"unexpectedly through headphones"* (P1, S3-G1). Some participants also described particular sensory issues that affected them while using social media. For example, the colour yellow made P1 *"physically sick"* (P1, S3-G1), and P8 experienced nausea when encountering pictures of food. From the above testimonies, it appears that autistic people's characteristic sensitivities to sensory stimuli [3, 18] also affect their interactions with online spaces.

5.1.5 Audience uncertainty. Participants expressed concerns about the lack of transparency and general uncertainty around who could see what content: *"I am a bit paranoid about social media, not because what I hear that there are bad*

people and all that stuff. It's rather because it's all public, and I never know who sees my comments" (P17, S1-G4). Equally, P16 was "wary of F[ace]B[ook], as I don't understand who can see" (P16, Chat, S1-G4). Audience uncertainty interacted with participants' privacy concerns, and with worries about the permanent availability of online content. For example, P8 spoke about "a fear" of permanent online records, and "the ways that people's comments (...) come back [to] haunt them" (P8, S1-G2).

Some participants attempted to assert control over their audiences through the privacy settings provided by the different platforms, but were dissatisfied with them. For instance, P17 managed to create separate Facebook user groups for each of the two languages she used when posting, but remarked on how complex it was: "It was quite complicated to set up (...) it's possible, but it's really, really not simple (...) switching between the two [groups] is hard as well" (P17, S1-G4). For P2, the privacy settings available were not fit for purpose: "the filters now that you can have, you know, that friends of friends can't see, that's not sufficient, that's not good enough" (P2, S2-G1). Autistic people's preference for routine and structure [18], their "heightened need for control" [48, p. 21], and their avoidance of unknowns may make them less tolerant of audience uncertainty on social media.

5.1.6 Compulsion to use. Participants reported feeling compelled to engage and spend time on social media. Some participants, like P3 and P5, described it as a "fear of missing out on something" (P5, S2-G1). Other participants connected their drive to engage with aspects of their autistic personality. For instance, P5 and P16 described their difficulties extricating themselves from "aggressive" (P5, S2-G1) comments and disagreements:

Once I kind of started to get into an argument with someone I find it very difficult to disengage (...) if someone says something really outrageous (...) I need to tell them I don't agree, I need to tell them. But (...) I think that's the part which does no good for me at all, and isn't helpful. (P16, S1-G4)

P19 spoke about "an urge to start fact-checking whether this person is expressing just an opinion or if they're saying things [that] are factual, but that urge (...) is problematic for me" (P19, S1-G3). Others felt subjected to peer "pressure (...) to react" (P6, S2-G2), a need to comply with others' social expectations: "I feel like if I don't go onto F[ace]B[ook] for a day and miss a post by a friend and don't like it, they might judge me for it, so I can get embroiled and a bit stressed in feeling I have to like things" (DW, G1). Not complying with those social expectations could have negative consequences. P7 spoke about "frustrating people" (P7, S1-G4) for taking too long to reply, and P8 about upsetting others for not checking with them on social media with the conventional frequency: "I upset people all the time, because I get distracted with life, focused on work (...) and I don't check in with people, and they take it really personally. They think it's because I don't think about them or I don't care about them and it's not that at all" (P8, S3-G2). Yet for others, this compulsion to engage derived from a sense of responsibility and obligation towards their own user-generated content and those who interacted with it:

if I post something like a status update, I put myself out there. You guys comment on it, reply (...) do something with it, and (...) I have to engage in that communication (...) I can't just pull out and say: oh, actually, I'm not interested anymore. Because I posted it. I put it out there (...) I have to own it, and I have to be there. (P17, S1-G4)

P12 felt similarly responsible towards those posting in the painting Facebook group she created and administered, and she liked "to put a comment (...) to encourage people and keep people belonging to the group (...) But the only thing is: it does take a lot of time because you get posts every single day and you feel like you've got to keep writing replies" (P12, S1-G3). P12 introduces here the main problem derived from this compulsion to engage: participants were concerned

about investing unwholesome amounts of time and effort, and about losing control over their social media use. P8, P18 and P4 hinted at episodes of *"doom scrolling"* (P4, S3-G1), *"getting addicted"* (P8, S2-G2), and overuse at times of poor mental health. Social media platforms provided participants with little or no support for self-managing their time and use.

5.1.7 Conveying and interpreting meaning. The final challenge added to worries regarding time and energy spent on social media: participants laboured to make themselves understood, and to understand others. Participants placed responsibility for these communicative difficulties firmly on themselves, and did not appear to consider how platform design could be contributing to them. For instance, P9 found it *"really hard to read a situation"* (P9, S2-G3); P20 believed that she misunderstood *"other people's meaning quite frequently"* (P20, S1-G4); and P12 explained how, on her Facebook group, *"I won't understand if they're having a joke with me, and also I won't understand some of the long words"* (P12, S2-G3).

Participants reported having trouble not only interpreting meaning, but also expressing what they wanted to say. One participant had *"experienced other people being very critical and not appreciating my meaning"* (DW-G4). Both P6 and P9 spoke about being too *"direct"* (P9, S1-G2; P6, S2-G2), coming across as *"rude"* (P6, S2-G2) and getting *"into trouble"* (P9, S1-G2) as a result. P1 explained that *"people can be quite harsh against people online who are autistic (...) because of the way that we phrase things (...), or we take too long to say a point or write a point, or it comes across as being too direct"* (P1, S1-G1). These difficulties interpreting and conveying meaning resulted in frequent misunderstandings. For instance, P20 was wrongly accused of being inconsiderate during a Twitter public conversation, and summarily blocked when attempting to clarify the matter. In a second example, what P6 had intended as a factual and informative reply to someone else's post in a Facebook group was met with a rude and abusive response.

Concerns about misunderstandings translated into inordinate amounts of effort when composing posts and replies. Participants described reading, re-reading and proof-reading their user-generated content over and over again, in an attempt to get across what they wanted to say: *"I always have to go through everything like 10 times. And am I saying everything correctly? Does it make sense? Will people understand? Is my message clear?"* (P17, S2-G4). P4, who was also the mother of an autistic teenager, explained how *"even the smallest, most (...) innocent kind of sentences are dissected in my house"* (P4, S1-G3). Adapting their personal style of communication to neurotypical standards was found to be a most straining task: *"trying to work out how you're meant to react. Are your emotions appropriate? How do you say that? How do you have to fluff it out to make it palatable to other people? Just exhausting, totally exhausting"* (P8, S2-G2). The constant labouring to convey and interpret meaning, to make oneself understood, prompted P16 to wish for telepathy:

I think my perfect platform would be telepathy. I've always wished that telepathy existed. (...) before I got a diagnosis, I went (...) to the GP, and I said: 'Wouldn't it be great if telepathy was a thing? And then I could explain to you how I feel' (...) he just thought I'd lost the plot. (P16, S2-G4)

Compounded with other circumstances, such as dyslexia, this constant battle to convey and interpret meaning resulted in effortful and tiresome social media interactions.

5.2 Addressing challenges through imagined features

While sessions 1 and 2 encouraged participants to describe and reflect on their social media practices, session 3 was envisioned as a creative activity. Participants were invited to imagine features for a new social media platform designed by autistic adults. Participants came up with a total of 38 features, 35 of which clearly addressed the challenges described in section 5.1. An overview of the features developed by participants, and challenges related to each, is provided as

supplementary material, where each feature is identified by the letter F followed by a unique number. In this section, we provide some examples of how the features envisioned by our participants addressed their challenges.

5.2.1 Addressing underserved interest-led sociality. In section 5.1.1 we described how mainstream social media platforms do not necessarily take into account autistic sociality, which is characterised by a desire to interact with others on the basis of common subjects of interest. During session 3, participants envisioned 4 features that enhanced and supported this interest-led sociality: F19, F21, F26 and F34. These features proposed interest-based connection recommendations (F19 by P12), interest-based people search (F26 by P16), the serendipitous spotlighting of interest-based threads (F34 by P19), and the establishment of connections through an interest on accessibility matters (F21 by P13).

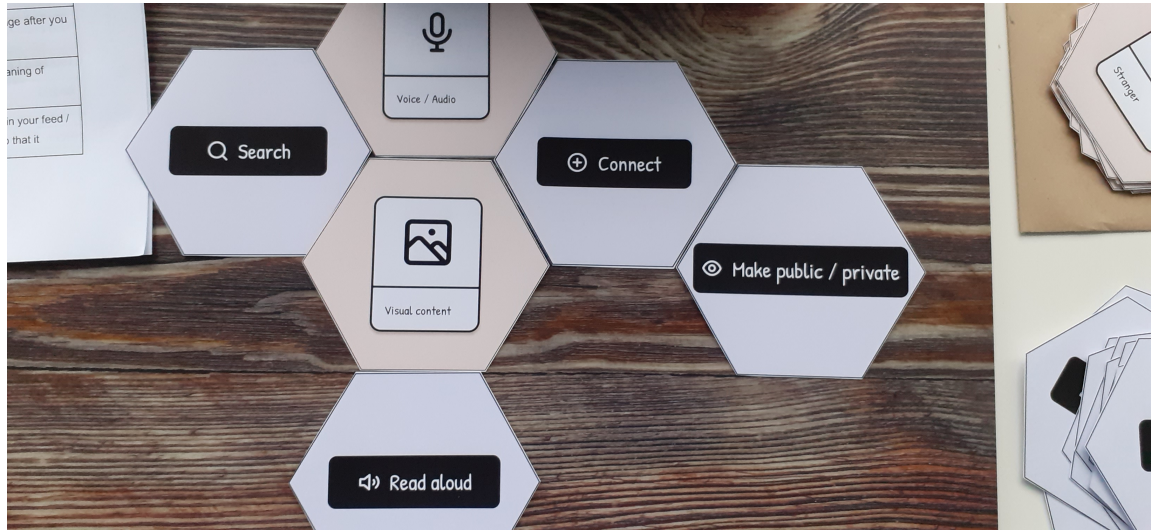


Fig. 3. Feature F19 as composed with the cardboard design cards by P12.

Through their features F19 and F26, P12 and P16 expressed a desire to find new connections based on common interests. In F19, P12 emphasised automated interest-based connection recommendations within existing groups:

if you're in a group, it'd be quite nice (...) for it to tell you who else is also interested in the same thing as you without you having to ask around (...) so that you'd automatically be connected with friends that you perhaps didn't know yourself had that interest. (P12, S3-G3)

In F26, P16 suggested the ability to search for new connections by subjects of interest:

maybe I want to talk to more people who are interested in autistic parenting, or I want to talk to people who are interested in washing machines (...) I'm thinking: oh, I'm really interested in this, I'd love to meet more people who like those things. So I'd like to be able to search that way. Find some people and then decide whether to connect with them or not. (P16, S3-G4)

For F34, P19 drew inspiration from reddit live⁵ to create a version of it that would spotlight threads based on subject searches:

⁵<https://www.reddit.com/r/live/wiki/index/>

When you go on reddit sometimes you scroll down and you see somebody is live and they're doing something. But it's usually something random. And it popping up is also kind of random. So this is (...) a little bit less random, because you'd be searching for a particular subject. (...) The only random thing would be which post is being put into the spotlight. (P19, S3-G4)

The participant named this feature *"Ramlight: The random spotlight"*. The ultimate purpose of Ramlight, as with the 2 other features described in this section, was to establish interest-based new connections: *"it'd sort of be a cool way for people's posts to (...) create engagement and maybe you can make some new friends (...) connect with more people"* (P19, S3-G4).

These imagined features clearly demonstrate these autistic adults' desire to grow and develop their social graph in ways that align with their preferred style of sociality. They also provide social media designers with examples of how connection recommendations, search results and promoted content could be enhanced to take into account certain interests.

5.2.2 Addressing the expression of emotional intent. Participants identified emojis as a particularly problematic social media feature. This may be connected to their paradoxical relationship with them. On the one hand, most participants relied on emojis to clarify and qualify their tone and intention, since this was the main tool platforms put at their disposal. On the other hand, they struggled to interpret them due to their focus on emotions, their representational approaches, and their indeterminate and highly contextual meanings. As a result, most participants constrained their use to a narrow subset of emojis that were widely used by others and felt obvious, such as smiley faces and hearts.

Reflecting these concerns, 5 imagined features focused on supporting emoji use: F12, F14, F18, F22 and F36. 3 of these features (F12, F14 and F36) aimed to assist with emoji interpretation. For instance, F12 by P7 was called *"What will this mean?"*. It was a preview utility for one's posts, clarifying their meaning before making them public: *"I would like to be able to preview what I'm posting or commenting will mean, particularly with emojis, as they're not always the clearest things"* (P7, S2-G2). The feature intended to support experimentation when using emojis:

it should be in the context of whatever you're posting, because I know the meaning of them can change. So if you could sort of preview whatever you're posting with an emoji, and get an explanation telling you what that post would (...) mean with that emoji attached, and then you could try a few different ones to get the meaning right before you actually post it. (P7, S2-G2)

Three of the features (F18, F22 and F36) included a customisation element. For instance, F18 by P12 was called *"Emoji alternatives (use pretty pictures instead)"*. It was a function to replace a certain emoji with a personalised, alternative image that better portrayed the meaning of the emoji for a particular user:

maybe use something else visual instead to mean happy or sad or whatever (...) maybe like the sun I would see as being happy and cheerful (...) dark clouds I'd see as being sad. I do better in a more artistic way. I could see the picture rather than seeing faces. I just don't get people's faces at all. (P12, S3-G3)

These features represent how emojis as a communicative instrument currently fail autistic adults. They also hint at how personalisation options and standardisation of meaning could address some of their shortcomings.

5.2.3 Addressing irrelevant and harmful content. Our participants' definition of poor quality content included things that were uninteresting, fraudulent, hateful, harmful, rude or too argumentative. The 7 imagined features tackling this challenge (F8, F9, F10, F25, F28, F35 and F38) expressed a desire to remove such content, mostly through filtering and the ability to customise one's content feed.

For instance, P6 wished to block *"rudeness"* from people he did not know (F8). The feature was grounded on his experience with a Facebook group he ended up withdrawing from, after a member reacted abusively to one of his comments. P6 defined rudeness as *"inappropriate language, or inappropriate images"*, and constrained the filtering to content *"specifically from strangers"* (P6, S3-G2). This is because P6 acknowledged that *"you might be sort of playfully rude between friends"* (P6, S3-G2), but such an attitude was unacceptable to him coming from people he did not know.

P14 created a feature he named *"Personalised feed"* (F25), where he expressed his desire to override the Facebook algorithm and decide for himself what content to see. This personalised feed would be *"sorted in order of relevance rather than (...) randomly"* (P14, S3-G3). In addition, it would be a finite content stream, rather than an infinite one: *"What would be really nice is that (...) it might just give you 5 items and then it says: (...) there's nothing more that would be of interest to you after this point"* (P14, S3-G3). Therefore, this function also seems to address the sensory overload challenge.

These sample features demonstrate participants' desire for a high degree of control over the content fed to them by platform algorithms. This desire seems justified, given the participants' strong reactions to poor quality content, and its detrimental effects on participants' well-being.

5.2.4 Addressing sensory overload. Participants described how the amount, speed and nature of social media content could make them feel overwhelmed or anxious. They also explained how they did not always have the energy, or were in the right frame of mind, to interact with their full social media feeds. Participants conceived 7 features to address this sensory overload challenge: F3, F11, F13, F20, F24, F25 and F33. The features rely mostly on 3 strategies: restricting content, setting up reminders and to-do lists, and automating posts.

As described above, the *"Personalised feed"* (F25) by P14 tackled sensory overload by suggesting a finite feed that would reduce the amount of content served. Two other features, F3 and F13, relied on content restrictions as well, although based not on the amount, but on the nature of the content. F3 by P14 was called *"Activate stillness"*, and suggested a feed display mode that would remove all sound and movement, leaving only static images and text. *"Activate stillness"* intended to provide a calmer, less strident viewing experience. F13 by P7 provided the ability to temporarily filter out user-specified types of content. These included *"different views"*, *"particular hashtags"*, *"argumental"* content or *"everything from strangers"* (P7, S2-G2). The feature was aimed at better matching social media content to one's personal capacity to handle it at any given point in time.

Two additional features (F20 and F24) relied on the ability to set reminders and create to-do lists. F20 by P13 was named *"Controlled connectivity"*. Among other things, it proposed a prompt to remind oneself about content unread or awaiting reply. F24 by P14 was titled *"Remind me: my to-do list"*, and suggested that reminders could be turned into a to-do list to be tackled whenever one had time and energy to do so.

Finally, F20 by P13 and F33 by P19 recommended the automation of posting. F20 included a utility to schedule posts and direct messages, so that you could compose them in advance but send them at a later time. F33 envisioned a *"reservoir"* of content to be posted automatically at certain intervals. The goal was to minimise the effort involved in posting regularly and often. These features illustrate autistic adults' need to manage the sensory demands of social media, and propose specific strategies for doing so, such as powerful content filtering, custom notifications and automation.

5.2.5 Addressing audience uncertainty. Participants expressed unease about being unable to identify who their audience was on social media, and who had access to their user-generated content. These worries combined with concerns about privacy and the permanence of social media content. A total of 7 features were created that addressed the challenge of audience uncertainty: F1, F5, F7, F23, F27, F28 and F30. They can be split into 2 groups: one focused on the nature and

identity of social media connections (F7, F23, F28 and F30); the other on the visibility and permanence of user-generated content (F1, F5 and F27).

In the first group, participants P14 (F23), P16 (F28) and P17 (F30) expressed a desire for more information about potential new connections. For instance, F23 by P14 was titled *"Find out about people before accepting them as a new connection"*. P14 explained it as follows: *"I get a lot of friend requests, often from people I don't know, and something that would make it (...) easy to find out about them before I say 'yes' it's helpful (...) sort of explain who they are"* (P14, S3-G3). P14 suggested each user should be able to determine *"a matrix of things you want to know"* (P14, S3-G3). For him, it would include perspectives on certain subjects, political views, past content not publicly available, geographic location and mutual connections. He believed Facebook could put the personal and behavioural data currently used for advertising purposes to the service of such a feature: *"Clearly Facebook knows what I'm interested in, because I get bombarded with advertising of things which I might have searched for recently, so I'd like to see what other people have been buying or searching or are interested in"* (P14, S3-G3). Also in the first group about social media connections, a fourth participant - P5 - wished for an automated way to weed out spurious followers (F7), which P5 described as piggybacking on popular profiles for questionable purposes.

The second group of features dealt with the visibility and permanence of user-generated content, and it included 3 features: F1 and F27 about content visibility, and F5 about content permanence. F27 by P16 was called *"I want to choose who sees what I post easily"*. It represented a critique to existing content visibility controls on Facebook, and a call for increased flexibility on Twitter:

I want to choose who sees what I post easily and I know that Facebook does that, but I can't work it. It's just too confusing and I can never work out the settings, so I'd like something simple. (...) On Twitter (...) you can have a private account, but I don't want to have a private account all the time. I just want [to] be able to be more flexible, but for it to be really easy. (P16, S3-G4)

Through feature F5, P5 requested a way to configure a time interval after which all her user-generated content would be automatically deleted:

a time-limited way of having things on there would be quite good, so that you could set up an interval, say two weeks or something, so your reaction, post or reply would stay up long enough for people to see it, and then be deleted after a set amount of time. (P5, S3-G1)

The feature was a way of handling the anxiety provoked by permanent content: *"this was a (...) feature to just make it easier to manage that feeling that I've basically got years and years of social media history all over the internet"* (P5, S3-G1). These features illustrate the frustrations and anxieties derived from uncertainty with regards to what happens to one's social media content. Enhanced connections functionality, improved content visibility settings and more control over the availability of one's content could contribute to ameliorate such worries.

5.2.6 Addressing compulsion to use. Participants described feeling compelled to consume social media content and to engage in social media interactions through a combination of personal responsibility, peer pressure and perceived social expectations. This in turn resulted in concerns about the amount of time and energy spent on social media.

Participants created 3 features to tackle this compulsion to use: F4, F29 and F31. The first feature, F4 by P4, was titled *"Mental health protector / self-care timer"*. This utility would enquire about your state of mind and well-being after a certain time, particularly *"if you were looking at lots of negative stuff"* (P4, S3-G1):

sometimes (...) if you're in a bad way, you can end up (...) doom scrolling. Maybe might be good to sort of have a 'set your own time' and say: you've been on this platform now for like an hour and a half. Are you okay? [Laugh] Do you want to go for a walk, or go and bake a cake? (P4, S3-G1)

This feature would turn social media algorithms on their head. If detecting that the user is looking at *"negative"* content, *"instead of giving you more negative stuff, (...) maybe giving you some bunny rabbits (...) To kind of counteract"* (P4, S3-G1). In her feature, P4 advocated for a *"mental health first"* (P4, S3-G1) attitude by social media platforms, their algorithms and their data use.

In the second feature (F29), P17 proposed an *"out of office"* message for social media. The purpose was to engage on social media interactions whenever one felt ready to do so:

it's like an out of office feature (...) I'll post something or I respond to somebody, and I'm not in the right mental frame straight off to receive all the replies. Then it would be quite nice to put a delay on it. Let's say, okay, I'll go away and meditate for half an hour and maybe I'd be better off and I can deal with it all [when I] come back. (P17, S3-G4)

For P17, who felt a sense of responsibility towards those who engaged with her content, it was important to provide visibility of this temporary withdrawal: *"I would like other people to see that I actually can't see the response at the moment ... Sort of like this: 'I am not available at the moment but I will reply on my return'. Or something like that"* (P17, S3-G4). The feature was also a way to control the urgency to constantly check for comments and replies: *"otherwise (...) it keeps nagging me: oh, has somebody replied? Shall I check? If I know I've got a two-hour window [when] I'm definitely not going to see anything, then I can walk away probably calmer"* (P17, S3-G4).

In the third feature (F31), P18 suggested the definition of personal goals in relation to social media use, to be *"reminded of them at specific points"* (P18, S3-G4). The idea was inspired by P18's objective of being in social media *"as little as possible"* (P18, S3-G4). They used blocking after a time period as an example: *"You decide you want it to (...) have a time limit. It'll block you at the end of that period and block you properly"* (P18, S3-G4).

With social media platforms financially invested in maximising users' time and attention, there is currently little incentive to support self-management tools. However, our participants' features suggest there is demand for them between autistic adults.

5.2.7 Addressing conveying and interpreting meaning. Participants struggled with expressing what they wanted to say, and with interpreting what others meant on social media. The intense labour involved in making oneself understood and understanding others resulted in effortful and tiresome social media interactions.

Participants developed 8 features that addressed this communicative challenge: F2, F12, F14, F16, F17, F20, F36 and F37. These features can be split into the task of expressing meaning (5 features: F2, F12, F16, F20 and F36), and the task of interpreting meaning (1 feature: F37), with 2 features covering both tasks (F14 and F17). Most of these features proposed some kind of interpreter that would clarify the meaning of one's or other people's posts. While many relied on machines being capable of interpreting the nuances of natural language to a degree that is probably unattainable today, F2 by P1 and F17 by P12 were remarkably simple and technically trivial. In F2, P1 suggested an audio preview for one's posts, to ensure they sounded as intended before publishing them:

a reading aloud feature (...) a feature that reads back your own posts to you (...) so that you can actually hear how it sounds when it's spoken. (...) sometimes we're trying to communicate one thing, but that's

not quite how it sounds when it's said aloud, and sometimes just having it said aloud to you may change your mind about what you want to post. (P1, S2-G1)

P1 believed that such a feature could help autistic people get "*less negative reactions*" from others (P1, S2-G1). It would also promote reflection and responsibility over one's own content, as well as mitigating people's anxiety about how a post may be interpreted: "*if you hear it and then it sounds fine then you know. You know you're all good, and you can post confidently without worrying that you're not communicating what you want to communicate*" (P1, S2-G1).

In F17, P12 proposed a crowdsourced interpreter that would allow users to share one's drafts or somebody else's posts with trusted others, to get their views about their actual meaning. The main driver was to avoid "*upsetting somebody else*" (P12, S3-G3), or becoming upset oneself due to misinterpretations. While computers remain incapable of comprehending the nuances of human speech, features such as the audio preview and the crowdsourced interpreter could support autistic adults in their efforts to convey and interpret meaning.

6 DISCUSSION

Our findings highlight a set of challenges our autistic participants must contend with when using social media, and a set of imagined features that illustrate how they envisioned design helping them tackle those challenges. Our findings complement those of Burke et al. [13] and Page et al. [42], who also identified a series of challenges experienced by autistic adults when engaging with mainstream social media platforms. Burke et al. named 3 factors that contributed to participants' struggles with maintaining online relationships over time: knowing whom to trust, knowing how much to disclose, and understanding social norms [13]. More recently, Page et al. provided a list of 16 challenges, organised by the social media affordance they related to [42]. Some of them resonate with our findings. Like Page et al.'s participants, our autistic adults engaged in "*interest-based immersion*" [42], they reacted strongly to harmful content, struggled to interpret emotion and intention, felt compelled to engage, and experienced social anxiety.

The above studies stopped their involvement with autistic adults at this point of identifying challenges. The authors proceeded, as expert designers, by suggesting "*opportunities for interventions*" [13, p. 432] and inclusive design recommendations [42]. In committing to a participatory design approach, our research took a different course. Our participatory methods helped us uncover how these autistic adults envision design assisting them with those challenges. The participants' imagined features speak to what design aspects of social media are most urgent to address, and suggest possible design directions.

In our findings section, we highlighted the connections between challenges and imagined features. For instance, participants suggested enhanced connection recommendations, search results and promoted content in order to accommodate their interest-based socialising preferences. They conceived sophisticated filters to remove upsetting, impolite and confrontational content. They critiqued the limited visibility and availability controls currently provided for their user-generated content. They suggested individualised and collaborative tools for conveying tone, intention and meaning. And they bolstered their time management options through personal goal-setting, automated posting, custom notifications, to-do lists, and "out-of-office" messages. Participants' elaborate and powerful features contrast sharply with most social media platforms' design choices, which offer connection recommendations mostly based on existing relationships [14], rigid algorithmic feeds that seem to promote negative and polemic content, binary notification (on / off) and content visibility (public / private) settings, and overly simplistic time management tools based on toothless time limits and time counters.

Beyond the links between challenges and imagined features, an additional thread could be clearly seen across most of the features designed by our participants: a craving for control over one's social media experience. We discuss this further in the following section, followed by a discussion of the research questions that underpinned our studies on reflection of our findings. To close, we provide some design recommendations for more inclusive social media spaces.

6.1 Craving control

Based on their research with autistic adults with complex needs, Page et al. recommended that social media platforms should *"provide realtime social guidance"* and *"design with safety in mind"* [42]. They proposed the implementation of highly structured interactions, the break-down of complex decisions into well-defined steps, and the inclusion of warnings and prompts to promote self-regulation. Our collaboration with autistic adults suggested something different. Our participants did not require further structure or safety measures. Instead, what they craved was control over their own social media experience.

As can be appreciated through their imagined features, the scope and meaning of this control varied across participants, and covered different aspects of social media platforms. For instance, P1 named one of her features (F1): *"Having full control over what is public and private on your social media"*. Through her design, P1 claimed more control not only over the visibility and availability of her user-generated content, but also over other constituent components of her social media presence, such as specific items of information in her profile. For this participant, control was a path to online safety: *"we can hide what we want to hide, and still interact with the communities and still be online, but in a safe way so that strangers and random people can't just see everything you post if you have a public profile"* (P1, S3-G1). This desire for safety speaks to feelings of vulnerability online. Although evidence about higher prevalence of online harms amongst autistic adults seems inconclusive [3, 52], a strong correlation between cyberbullying victimisation and self-esteem has been found [52], suggesting that autistic adults' well-being may be affected by negative online experiences. For autistic adults, tight control over their social media audiences, and over the visibility and availability of their content, is not just a question of privacy and security, but also of self-care.

Participants also wanted control over the content that was presented to them via algorithmic feeds. Content control encompassed several facets: the source of the content (e.g. from friends vs. from strangers); the organisation of content within the feed (e.g. algorithmic vs. structured by interests); the amount of content served (i.e. infinite scrolling vs. finite feeds); the subject and tone (e.g. rude or confrontational content, no food or personal photographs); the content format (e.g. excluding moving images and sound, eliminating certain emojis); and even the presentation (e.g. remove colour yellow from the interface). Many of these content controls were grounded on sensory issues, and seem associated with the sensitivity to sensory stimuli that is currently recognised as one of the main characteristics of autism [3].

The imagined features also revealed a desire for control over one's time and degree of engagement with social media. There was certainly demand from these participants for tools and utilities to help them scope and self-regulate their social media use. Software in this digital wellbeing space is currently provided by third party applications and the operating systems (e.g. iOS Screen Time, Android Digital Wellbeing), rather than social media platforms themselves. Little is known about the use of such software tools by autistic adults, revealing a significant gap in knowledge and a requirement for further research.

Finally, participants' features also expressed a yearning for control over the meaning and intention of their own content. For instance, when explaining her audio preview feature (F2), P1 justified it as *"a good way to feel more in control of what you're posting"* (P1, S3-G1). The high number of imagined features (7) addressing the 'conveying meaning' challenge reflects the importance that these participants assigned to difficulties making themselves understood, and the

impact these had on their social media practices. Supporting autistic users in their efforts to express themselves on social media appears a key way to make these platforms more inclusive of this population.

Simm et al. identified "*the variety and idiosyncrasy*" [46, p. 352] of autistic adults' needs as the most important lesson when designing for this group, and called for digital systems that allow fine-grained customisation. This insight is reflected in the varied meanings of control and related requirements expressed by our participants. These requirements were rooted in autism-related circumstances such as potential online harms connected to the stigma surrounding their diagnosis, sensory differences, self-care demands, and difficulties expressing meaning as per neurotypical norms. The mismatch between our participants' need for control and the lack of customisation capabilities in mainstream social media raises the question of how well-suited are these platforms to the social interaction preferences and needs of autistic adults.

6.2 RQ1: The suitability of social media platforms for autistic adults

Prior research, and the experiences shared by our participants, indicate that certain elements of the design of social media platforms do work for autistic adults. These include structures that enable subject-based organisation such as Facebook groups and 'subreddits', which facilitate "*interest-based immersion*" [42]. Hashtags, which catalogue content and make it searchable, support subject-based content discovery. Tagging other users, reaction features such as 'likes', and the ability to share others' content (e.g. retweets) provide efficient, low-effort ways of signalling social engagement [31].

However, our study also reveals areas in existing social media platforms that seem unsuitable for the social interaction needs and preferences of this population. As outlined in the previous section, platforms currently provide users with little control over constituent aspects of the social media experience, including served content, audience, and individual attention and engagement. The configuration options for the visibility and availability of profile information and user-generated content were described as limited or inadequate by our participants, who also requested more extensive control over algorithmic content feeds, and expressed a desire for tools supporting self-regulation in use. These requests were grounded in particularities associated with autism.

Participants also struggled with the provided means to express tone and intention, particularly emojis. These became difficult due to their ambiguous and highly contextual meaning, which contrasts with the autistic preference for explicit interactions [4] and literal communication [18]. In addition, emojis reliance on stylised facial expressions as a representation strategy becomes an issue when considering the higher prevalence of alexithymia between autistic people [30]. Mainstream social media platforms also seem to host inordinate amounts of 'phatic' interactions, where meaning and content are subordinated to the expression of membership to loose collectives [53]. This clashes with the interest-based sociality characteristic of autistic ways of social coordination, where the sharing of information about subjects of interest scaffolds interaction [5].

Our drive to recognise and value autistic difference should not distract us from the fact that many of their frustrations and requests regarding social media have much in common with those from non-autistic people, particularly those from other underrepresented groups (e.g. [12]). More control and customisation capabilities seem a common demand across the board, for instance of the Facebook news feed [34], of personal profiles and of user-generated content visibility [12]. The hundreds of apps and browser extensions that provide self-control functionality [33] speak to widespread experiences of compulsion to use. It is also necessary to acknowledge that some of the challenges our autistic participants experienced may be more related to platforms' business models and attached design biases [14] than to their embodiment of neurotypical normativity, and may affect all users independently of their neurological

differences. To what extent autistic and non-autistic people are similar or different in terms of social media use, and how design that helps autistic adults could also support non-autistic people, remain to be explored.

However, and overall, mainstream social media platforms would seem to mostly *"embody normative expectations of a neurotypical society"* [50, p. 1]. They imply that neurotypical forms of communication and interaction are the desired standard, and include no provision to facilitate mutual understanding between autistic and neurotypical populations [50]. In order to adjust this imbalance, mainstream social media platforms should increase peoples' control over their social media experience, explore new mechanisms for expressing tone and intention, and promote communication with informational intent [38].

6.3 RQ2: Lessons from autistic sociality

One of the most recognisable characteristics of autistic sociality is that it is interest-based. Such sociality privileges interactions driven by mutuality of interests, rather than by the social obligations and concerns about politeness that often motivate social media use. Digital anthropologist Daniel Miller suggests that, in England, the primary purpose of using social media is the maintenance of connections according to normative ideas of social appropriateness [7]. This style of sociality seems very different to the interest-based kind. With mutuality of interests comes an emphasis on information dissemination, knowledge sharing, and content-full exchanges. This contrasts with the content-less, phatic acts that currently pervade mainstream social media feeds, whose purpose is the enacting and reproduction of social connections [38, 53]. By comparison, what takes primacy from an autistic sociality perspective is the quality of discussion about a topic of common interest. Without denying the meaning and importance of phatic content on social media [38, 53], particularly for neurotypicals, autistic sociality can remind us of the value of knowledge-based, curiosity-driven informational exchanges, and of the need to enable them through the design of social media platforms.

The focus on content in autistic sociality may be associated with the lower demands for social coordination in inter-autistic interactions [27]. When interacting with each other, autistic people generously assume common ground and give little importance to misunderstandings, quickly recovering from them and resuming communication. There is a lesson about tolerance in these autistic exchanges that seems particularly relevant given the confrontational and hostile character of many social media interactions. Social media platforms should encourage the forgiving attitude that characterises inter-autistic communication, concentrating interlocutors' attention on the subject matter as in autistic sociality. Doing so may contribute towards a kinder and more considerate social media experience for us all.

6.4 Design recommendations

The findings of our study highlight a range of tensions and associated design opportunities for social media platform designers to consider in order to create online spaces that are more inclusive for autistic adults. We bring these insights together here as a series of design recommendations - for possible new social media systems, or for consideration as part of ongoing designs in existing platforms. As already noted, while we offer these recommendations to strengthen the inclusion and enhance the experiences of social media spaces for autistic adults and autistic forms of sociality, many of these suggestions would likely also be of value to other populations that are typically marginalised by design decisions, and in some cases will be of value to most users. Our design recommendations are as follows:

- (1) **Create more powerful tools to engage in interest-based sociality and to establish connections based upon mutual interests**, rather than social, organisational or geographic ties. Our participants' features hinted

at how connection recommendations within and across groups, search results and promoted content could be enhanced to accommodate interest-based ties.

- (2) **Create more sophisticated filters to remove upsetting, impolite, negative and confrontational content.** Our participants appreciated existing features such as blocking individual users, and hiding comments and replies. Additional functionality, such as keyword blocking, could be enhanced and expanded. Our participants also suggested content removal controls based on time and connection depth.
- (3) **Create more explicit and conspicuous tools for setting the visibility and availability of profile information and user-generated content, and provide more granular control over who can view and respond to that content.** Participants described existing controls as too coarse or too convoluted, and resented the inability to decide how long their content should remain available. In addition, they asked for more support with choosing new connections, and with weeding out spurious followers.
- (4) **Enable further configuration and customisation options for algorithmic content feeds.** Participants expressed frustration with what they perceived as irrelevant and never-ending feeds, and craved more control over the content served to them. Requested capabilities included selecting and sorting content according to personal relevance, advertising-free options, removal of certain content formats (e.g. video, sound), configuration of different feed "modes", and finite content feeds.
- (5) **Create multi-modal tools that support autistic adults with understanding tone and meaning in content created by other users, and tools which support exploratory self-understanding of the tone of their own content prior to sharing within a network.** Our participants' suggestions included customisable emoji collections and reaction sets, read-aloud functionality, and collaborative meaning-making. Participants also hinted at the potential of artificial intelligence and language models in this area.
- (6) **Create tools that support autistic adults to manage their time on social media, and avoid over engagement.** In addition to goal-setting and time limits, participants discussed the potential of reminders, to-do lists, automated posting, custom notifications, "out-of-office" messages and temporary withdrawal.

6.5 Limitations and future work

This research is qualitative in nature. Our participants are not representative of all autistic adults, and caution must be exercised with regards to generalising findings. The intent of this study was not to draw generalisable conclusions about the autistic population, but about the design of social media platforms. We opened this paper noting that little is known about whether mainstream digital tools and systems are suitable for autistic people. Much work remains to be done in this area, and across software categories beyond social media.

7 CONCLUSION

In this paper, we have looked at the design of social media from the perspective of autistic sociality. Through participatory design methods, 20 autistic adults described and reflected on their social media use, and reimagined these platforms from the point of view of their autistic experiences. We identified 7 challenges participants faced when using social media, and how participants tackled them through design. We identified several ways mainstream social media platforms currently fail autistic adults, such as limited control over the user experience, unsuitable ways of expressing tone and intention, and narrow support for informational intent. Finally, we described how interest-based sociality and inter-autistic interactions can inspire the design of kinder and more considerate social media platforms.

With the design of mainstream social media clearly "*dominated by neurotypical thinking*" [16, p. 2302], designers could be complicit in the reinforcing of the social exclusion already experienced by autistic people [16]. With this paper, we hope to demonstrate how critical assessments from the perspective of autistic sociality can reveal such biases and help us address them.

ACKNOWLEDGMENTS

This work was funded by the Economic and Social Research Council (ESRC) (grant no. ES/T016507/1). We would also like to thank the autistic lay advisory board and the scientific advisory board of the Autistic Adults Online project, Autistica, Autistic Nottingham and, most importantly, all autistic participants who shared their experiences with us.

REFERENCES

- [1] Suhaib Aslam, Jelle van Dijk, and Edwin Dertien. 2019. CoCoCo: Co-designing a co-design toolkit for co-bots to empower autistic adults'. In *Proceedings of the 4th Biennial Research Through Design Conference (RTD '19)*. Delft and Rotterdam, The Netherlands, 1–16. <https://doi.org/10.6084/m9.figshare.7855904.v1>
- [2] autistica. n.d. What is autism? Retrieved September 2, 2022 from <https://www.autistica.org.uk/what-is-autism/what-is-autism>
- [3] Christopher Barber. 2017. Social media and autism spectrum conditions. *Practice Nursing* 28, 7 (2017), 292–298. <https://doi.org/10.12968/pnur.2017.28.7.292>
- [4] Ben Belek. 2018. Autism and the Proficiency of Social Ineptitude: Probing the Rules of "Appropriate" Behavior. *Ethos* 46, 2 (2018), 161–179. <https://doi.org/10.1111/etho.12202>
- [5] Hanna Bertilsdotter Rosqvist. 2019. Doing things together: Exploring meanings of different forms of sociality among autistic people in an autistic work space. *Alter* 13, 3 (2019), 168–178. <https://doi.org/10.1016/j.alter.2019.03.003>
- [6] Nomy Bitman. 2022. "Authentic" digital inclusion? Dis/ability performances on social media by users with concealable communicative disabilities. *new media & society* 24, 2 (2022), 401–419. <https://doi.org/10.1177/14614448211063183>
- [7] Janet Borgerson and Daniel Miller. 2016. Scalable sociality and "How the world changed social media": conversation with Daniel Miller. *Consumption Markets & Culture* 19, 6 (2016), 520–533. <https://doi.org/10.1080/10253866.2015.1120980>
- [8] Kristen Bottema-Beutel, Steven K. Kapp, Jessica Nina Lester, Noah J. Sasson, and Brittany N. Hand. 2021. Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood* 3, 1 (2021), 18–29. <https://doi.org/10.1089/aut.2020.0014>
- [9] Virginia Braun and Victoria Clarke. 2019. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 11, 4 (2019), 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>
- [10] Virginia Braun and Victoria Clarke. 2020. Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling & Psychotherapy Research* 21, 1 (2020), 37–47. <https://doi.org/10.1002/capr.12360>
- [11] Virginia Braun and Victoria Clarke. 2021. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology* 18, 3 (2021), 328–352. <https://doi.org/10.1080/14780887.2020.1769238>
- [12] Melissa Brough, Ioana Literat, and Amanda Ikin. 2020. "Good Social Media?": Underrepresented Youth Perspectives on the Ethical and Equitable Design of Social Media Platforms. *Social Media + Society* 6, 2 (2020). <https://doi.org/10.1177/2056305120928488> Publisher: SAGE Publications Ltd.
- [13] Moira Burke, Robert Kraut, and Diane Williams. 2010. Social use of computer-mediated communication by adults on the autism spectrum. In *Proceedings of the 2010 ACM conference on Computer supported cooperative work (CSCW '10)*. 425–434. <https://doi.org/10.1145/1718918.1718991>
- [14] Alexander Cho. 2018. Default publicness: Queer youth of color, social media, and being outed by the machine. *New Media & Society* 20, 9 (2018), 3183–3200. <https://doi.org/10.1177/1461444817744784> Publisher: SAGE Publications.
- [15] Catherine J Crompton, Danielle Ropar, Claire VM Evans-Williams, Emma G Flynn, and Sue Fletcher-Watson. 2020. Autistic peer-to-peer information transfer is highly effective. *Autism* 24, 7 (2020), 1704–1712. <https://doi.org/10.1177/1362361320919286>
- [16] Nicholas Sheep Dalton. 2013. Neurodiversity & HCI. In *CHI '13 Extended Abstracts on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 2295–2304. <https://doi.org/10.1145/2468356.2468752>
- [17] Joyce Davidson. 2008. Autistic culture online: virtual communication and cultural expression on the spectrum. *Social & Cultural Geography* 9, 7 (2008), 791–806. <https://doi.org/10.1080/14649360802382586>
- [18] Hanne De Jaegher. 2013. Embodiment and sense-making in autism. *Frontiers in Integrative Neuroscience* 7 (2013). <https://doi.org/10.3389/fnint.2013.00015>
- [19] Cat Drew. 2016. Exploring the evidence. Retrieved November 16, 2022 from <https://openpolicy.blog.gov.uk/2016/03/07/exploring-the-evidence/>
- [20] Marc Fabri, Penny C.S. Andrews, and Heta Pukki. 2016. Using Design Thinking to engage autistic students in participatory design of an online toolkit to help with transition into higher education. *Journal of Assistive Technologies* 10, 2 (2016). <https://doi.org/10.1108/JAT-02-2016-0008>
- [21] National Institute for Health and Care Research (NIHR). 2018. Reward and recognition for public contributors - a guide to the payment of fees and expenses. Retrieved September 7, 2022 from <https://www.nihr.ac.uk/documents/reward-and-recognition-for-public-contributors-a-guide-to-the->

- payment-of-fees-and-expenses/12248
- [22] Katie Gaudion, Ashley Hall, Jeremy Myerson, and Liz Pellicano. 2015. A designer's approach: how can autistic adults with learning disabilities be involved in the design process? *CoDesign* 11, 1 (2015), 49–69. <https://doi.org/10.1080/15710882.2014.997829>
 - [23] Kristen Gillespie-Lynch, Steven K. Kapp, Christina Shane-Simpson, David Shane Smith, and Ted Hutman. 2014. Intersections Between the Autism Spectrum and the Internet: Perceived Benefits and Preferred Functions of Computer-Mediated Communication. *Intellectual and Developmental Disabilities* 52, 6 (2014), 456–469. <https://doi.org/10.1352/1934-9556-52.6.456>
 - [24] Judith Good, Mark Brosnan, Nicola Yuill, Lisa Austin, and Sarah Parsons. 2016. Putting Technology Design into the Hands of the Users with the ASCmeI.T. App. In *Autism and Technology: Beyond Assistance & Interventions - A workshop at #CHI2016*. <http://igw.tuwien.ac.at/chi16-autismtechnology/attachments/GoodEtAl.pdf>
 - [25] Florian Grond, M. Ariel Cascio, Rossio Motta-Ochoa, Tamar Tembeck, Dan Ten Veen, and Stefanie Blain-Moraes. 2019. Participatory design of biomusic with users on the autism spectrum. In *8th International Conference on Affective Computing and Intelligent Interaction (ACII '19)*. <https://doi.org/10.1109/ACII.2019.8925484>
 - [26] Kim Halskov and Peter Dalsgård. 2006. Inspiration card workshops. In *Proceedings of the 6th conference on Designing Interactive systems (DIS '06)*. ACM, New York, NY, USA, 2–11. <https://doi.org/10.1145/1142405.1142409>
 - [27] Brett Heasman and Alex Gillespie. 2019. Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism* 23, 4 (2019), 910–921. <https://doi.org/10.1177/1362361318785172>
 - [28] Pier Jaarsma and Stellan Welin. 2012. Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement. *Health Care Analysis* 20, 1 (2012), 20–30. <https://doi.org/10.1007/s10728-011-0169-9>
 - [29] Bogoo Kim, Daehyoung Lee, Aehong Min, Seungwon Paik, Georgia Frey, Scott Bellini, Kyungsik Han, and Patrick C. Shih. 2020. PuzzleWalk: A theory-driven iterative design inquiry of a mobile game for promoting physical activity in adults with autism spectrum disorder. *PLoS ONE* 15, 9 (2020). <https://doi.org/10.1371/journal.pone.0237966>
 - [30] Emma Kinnaird, Catherine Stewart, and Kate Tchanturia. 2019. Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry* 55 (2019), 80–89. <https://doi.org/10.1016/j.eurpsy.2018.09.004>
 - [31] Nelya Koteyko, Martine van Driel, and John Vines. 2022. Autistic sociality on Twitter: Enacted affordances and affiliation strategies. *Discourse & Communication* 16, 4 (2022), 385–402. <https://doi.org/10.1177/17504813211070655>
 - [32] Andrés Lucero, Peter Dalsgaard, Kim Halskov, and Jacob Buur. 2016. Designing with Cards. In *Collaboration in Creative Design*, Panos Markopoulos, Jean-Bernard Martens, Julian Malins, Karin Coninx, and Aggelos Liapis (Eds.). Springer International Publishing, 75–95. https://doi.org/10.1007/978-3-319-29155-0_5
 - [33] Ulrik Lyngs, Kai Lukoff, Petr Slovak, Reuben Binns, Adam Slack, Michael Inzlicht, Max Van Kleek, and Nigel Shadbolt. 2019. Self-Control in Cyberspace: Applying Dual Systems Theory to a Review of Digital Self-Control Tools. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA. <https://doi.org/10.1145/3290605.3300361>
 - [34] Ulrik Lyngs, Kai Lukoff, Petr Slovak, William Seymour, Helena Webb, Marina Jirotko, Jun Zhao, Max Van Kleek, and Nigel Shadbolt. 2020. 'I Just Want to Hack Myself to Not Get Distracted': Evaluating Design Interventions for Self-Control on Facebook. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA. <https://doi.org/10.1145/3313831.3376672>
 - [35] Miriam Madsen, Rana el Kaliouby, Micah Eckhardt, Mohammed E. Hoque, Matthew S. Goodwin, and Rosalind Picard. 2009. Lessons from participatory design with adolescents on the autism spectrum. In *CHI '09 Extended Abstracts on Human Factors in Computing Systems (CHI '09)*. Association for Computing Machinery, New York, NY, USA, 3835–3840. <https://doi.org/10.1145/1520340.1520580>
 - [36] Rachael Maun, Marc Fabri, and Pip Trevorrow. 2021. Adapting Participatory Design Activities for Autistic Adults: A Review. In *Design, User Experience, and Usability: Design for Diversity, Well-being, and Social Development*, Marcelo M. Soares, Elizabeth Rosenzweig, and Aaron Marcus (Eds.). Springer International Publishing, Cham, 300–314. https://doi.org/10.1007/978-3-030-78224-5_21
 - [37] Micah O. Mazurek. 2013. Social media use among adults with autism spectrum disorders. *Computers in Human Behavior* 29, 4 (2013), 1709–1714. <https://doi.org/10.1016/j.chb.2013.02.004>
 - [38] Vincent Miller. 2008. New Media, Networking and Phatic Culture. *Convergence* 14, 4 (2008), 387–400. <https://doi.org/10.1177/1354856508094659>
 - [39] Damian E.M. Milton. 2012. On the ontological status of autism: the 'double empathy problem'. *Disability & Society* 27, 6 (2012), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
 - [40] Damian E.M. Milton. 2014. Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism* 18, 7 (2014), 794–802. <https://doi.org/10.1177/1362361314525281>
 - [41] Elinor Ochs and Olga Solomon. 2010. Autistic Sociality. *Ethos* 38, 1 (2010), 69–92. <https://doi.org/10.1111/j.1548-1352.2009.01082.x>
 - [42] Xinru Page, Andrew Capener, Spring Cullen, Tao Wang, Monica Garfield, and Pamela J. Wisniewski. 2022. Perceiving Affordances Differently: The Unintended Consequences When Young Autistic Adults Engage with Social Media. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*. ACM New York, NY. <https://doi.org/10.1145/3491102.3517596>
 - [43] Sarah Parsons, Nicola Yuill, Judith Good, Mark Brosnan, Lisa Austin, Clarence Singleton, Benoit Bossavit, and Barnabear. 2016. What Technology for Autism Needs to be Invented? Idea Generation from the Autism Community via the ASCmeI.T. App. In *Computers Helping People with Special Needs. ICCHP 2016 (Lecture Notes in Computer Science, Vol. 9759)*, Penaz P. Miesenberger K., Buhler C. (Ed.). Springer, Cham. https://doi.org/10.1007/978-3-319-41267-2_49

- [44] Amon Rapp, Federica Cena, Claudio Mattutino, Guido Boella, Claudio Schifanella, Roberto Keller, and Stefania Brighenti. 2019. Designing an Urban Support for Autism. In *Proceedings of the 21st International Conference on Human-Computer Interaction with Mobile Devices and Services (MobileHCI '19)*. ACM New York, NY, USA, 1–6. <https://doi.org/10.1145/3338286.3344390>
- [45] Ginny Russell, Steven K. Kapp, Daisy Elliott, Chris Elphick, Ruth Gwernan-Jones, and Christabel Owens. 2019. Mapping the Autistic Advantage from the Accounts of Adults Diagnosed with Autism: A Qualitative Study. *Autism in Adulthood* 1, 2 (2019). <https://doi.org/10.1089/aut.2018.0035>
- [46] Will Simm, Maria Angela Ferrario, Adrian Gradinar, and Jon Whittle. 2014. Prototyping 'clasp': implications for designing digital technology for and with adults with autism. In *Proceedings of the 2014 conference on Designing interactive systems (DIS '14)*. Association for Computing Machinery, 345–354. <https://doi.org/10.1145/2598510.2600880>
- [47] Judy Singer. 1999. 'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference. In *Disability Discourse*, Mairian Corker and Sally French (Eds.). Open University Press, Buckingham - Philadelphia, 57–67.
- [48] Judy Singer. 2017. *NeuroDiversity: The Birth of an Idea*. Judy Singer.
- [49] Anne Fleur Spaa. 2022. *Understanding the role of design in supporting reflective practice in evidence-based policymaking*. Ph.D. Northumbria University. <http://nrl.northumbria.ac.uk/id/eprint/49196/>
- [50] Katta Spiel, Christopher Frauenberger, Os Keyes, and Geraldine Fitzpatrick. 2019. Agency of Autistic Children in Technology Research—A Critical Literature Review. *ACM Transactions on Computer-Human Interaction* 26, 6 (2019), 38:1–38:40. <https://doi.org/10.1145/3344919>
- [51] Deborah Sturm, Michael Kholodovsky, Rayan Arab, David Shane Smith, Pavel Asanov, and Kristen Gillespie-Lynch. 2019. Participatory Design of a Hybrid Kinect Game to Promote Collaboration between Autistic Players and Their Peers. *International Journal of Human-Computer Interaction* 35, 8 (2019), 706–723. <https://doi.org/10.1080/10447318.2018.1550180>
- [52] Paraskevi Triantafyllopoulou, Charlotte Clark-Hughes, and Peter E. Langdon. 2021. Social Media and Cyber-Bullying in Autistic Adults. *Journal of Autism and Developmental Disorders* (2021). <https://doi.org/10.1007/s10803-021-05361-6>
- [53] Piia Varis and Jan Blommaert. 2015. Conviviality and collectives on social media: Virality, memes, and new social structures. *Multilingual Margins: A journal of multilingualism from the periphery* 2, 1 (2015), 31–31. <https://doi.org/10.14426/mm.v2i1.55>
- [54] John Vines, Mark Blythe, Stephen Lindsay, Paul Dunphy, Andrew Monk, and Patrick Olivier. 2012. Questionable Concepts: Critique as a Resource for Designing with Eighty Somethings. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*. ACM New York, NY, USA, Austin, Texas, USA, 1169–1178. <https://doi.org/10.1145/2207676.2208567>
- [55] Tao Wang, Monica Garfield, Pamela Wisniewski, and Xinru Page. 2020. Benefits and Challenges for Social Media Users on the Autism Spectrum. In *Conference Companion Publication of the 2020 on Computer Supported Cooperative Work and Social Computing (CSCW '20)*. Association for Computing Machinery, New York, NY, USA, 419–424. <https://doi.org/10.1145/3406865.3418322>
- [56] Deborah M. Ward, Karen E. Dill-Shackleford, and Micah O. Mazurek. 2018. Social Media Use and Happiness in Adults with Autism Spectrum Disorder. *Cyberpsychology, Behavior, and Social Networking* 21, 3 (2018). <https://doi.org/10.1089/cyber.2017.0331>
- [57] Jinan Zeidan, Eric Fombonne, Julie Scora, Alaa Ibrahim, Maureen S. Durkin, Shekhar Saxena, Afqah Yusuf, Andy Shih, and Mayada Elsabbagh. 2022. Global prevalence of autism: A systematic review update. *Autism Research* 15, 5 (2022), 778–790. <https://doi.org/10.1002/aur.2696>
- [58] Annuska Zolyomi and Jaime Snyder. 2021. Social-Emotional-Sensory Design Map for Affective Computing Informed by Neurodivergent Experiences. *Proceedings of the ACM on Human-Computer Interaction* 5, CSCW1 (2021), 77:1–77:37. <https://doi.org/10.1145/3449151>