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Autistic adults' experiences with social media: Creativity, Connectedness, and Control

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1. Summary of findings

Our ‘Autistic Adults Online’ project examined how autistic users navigate and interact with diverse social media features, unravelling the complex relationship between linguistic and digital practices, individuality and connectedness.

We first show how autistic adults creatively and strategically use language and digital tools to forge connections, raise awareness, and maintain a consistent social media presence. By employing linguistic methods, we also demonstrate that they adjust their communicative style for both autistic and non-autistic audiences.

Our interviews reveal further advantages as well as challenges posed by ever-evolving social media norms and algorithms as interviewees spoke not only about creativity and belonging but also about the need to control and police their social media use.

In the final stage of our research, participatory design [see Glossary] workshops provided a canvas for autistic adults to express their communicative expectations, preferences, and sensory needs in digital networking environments. Representing a shift from passive technology users to active collaborators, these workshops empower autistic adults to shape future social media platforms, harnessing their lived experiences and expertise to develop more inclusive and empathetic spaces for digital interaction and networking.

2. What's the situation?

Today, digital tools play a significant role in our social environments and mediate many aspects of our lives.

For autistic people who cannot always get their sensory and communication needs met in physical venues and public spaces, these digital platforms and services offer unique opportunities and advantages.

Despite this, digital platforms still often fall short in meeting the specific needs of this population, shutting many people out of services and conversations as reliance on digital tools increases.

The concept of neurodiversity refers to the idea that there is no single correct way to communicate and perceive the world. Rather, people experience these things in different ways, and autism is one factor (of many) that can shape such diversity of experience.

Autistic people may allocate attention, or processing resources, in a different way to non-autistic or neurotypical people. This tendency to focus on relatively few things, and to tune out or lose track of things outside of this attention tunnel is known as *monotropism* (Murray et al. 2005). It can also be seen as having relatively few interests aroused at any given time. Such interests are often relatively intense and long term and can be an important means of providing a feeling of stability and connection.

Social media is an example of an interactive space that has been little studied with regard to a monotropic processing style. This project therefore aims to explore how autistic adults use social media, how they feel about the way the platforms work (as well as how they should ideally work), and how that impacts their interactions.

We use the term ‘autistic people’ instead of ‘people with autism’ as identity first language is preferred within the autistic community in the UK (Kenny et al, 2016). We acknowledge, however, that differences in the use of terminology exist.



Alt text: Two posters showcasing research on the project.

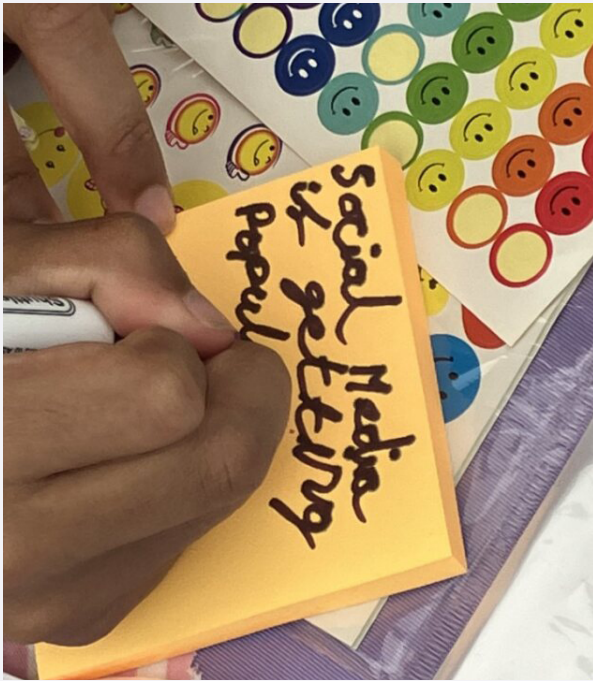
What research has told us so far

The differences in cognitive processing that autistic people have can lead to different expectations in interactions, both language-related and otherwise.

Double empathy theory (Milton, 2012) can help us understand these communicative issues. The framework states that when people with different processing styles interact they will struggle to empathise with and understand each other. As communication is a mutual process, the breakdowns that can occur are not solely the fault of autistic interactants, as is often claimed. This pressure and assumption of blame can make social interaction stressful for autistic people.

Autistic sociality (Ochs and Solomon, 2010) is a term that refers to the ways in which autistic people carry out interactions and engage in social engagements with others. An example of one feature of autistic sociality is preference for interacting with others on the topic of shared interests, rather than doing small talk. Key is the notion that autistic people are social, as all humans are, but some sociocultural contexts may impede them from carrying out this socialisation.

Some social environments, particularly involving autistic-to-autistic interactions (Crompton et al, 2020) may promote autistic sociality, and social media is often thought to be one of these spaces. On the one hand, online communication, such as on social media, is easier because one can type responses at one's own pace and doesn't need to monitor eye contact and gestures. On the other hand, social media may present other obstacles but research into autistic preferences and sensory needs during online interactions is limited.



Alt text: A child's hand writing a note 'social media is getting popular' against a background of emoji stickers.

By contrast, online interactions amongst neurotypical users have long been studied by linguists and other scholars. This research has identified both benefits and challenges for communication and interaction in social media.

Benefits include affiliating with different people from all walks of life [see Glossary] and therefore potentially expanding one's social circle. Challenges include tailoring messages to address appropriate audiences (known as 'Context design'), using language and features such as emoji to express emotion and tone [see Glossary], and avoiding misunderstandings in the absence of other cues such as body language and gaze.

The increased visibility of neurodivergent people in the last decade, as well as growing understanding of the ways they are let down by the society, brings up questions about how they navigate these interactional opportunities and challenges in social media interactions. These questions are discussed in more detail below and formed the basis of this research project.

What does research still need to find out?

Autistic people often change their behaviour to fit in with non-autistic social environment (thereby ‘camouflaging’ or masking their differences), in person and online.

The Internet is also a place where autistic people interact with each other and build community. However, research on these online behaviours is mostly focused on conscious actions people can recall when answering survey questions.

We wanted to find out whether it is possible to identify both community building strategies and camouflaging from the language used on social media, as some behaviours may happen without people realising it.

From the perspective of both linguistics and design research, little has been done to engage autistic people as collaborators and active users of social media technologies. To remedy this, we collaborated with autistic people through a process called participatory research (Fletcher-Watson et al., 2019).

This led to a creation of an autistic advisory board who consulted on our research practices and materials (from information sheets at the beginning of the study to the findings and the dissemination strategy at the end of the project), and to participatory design workshops described below.

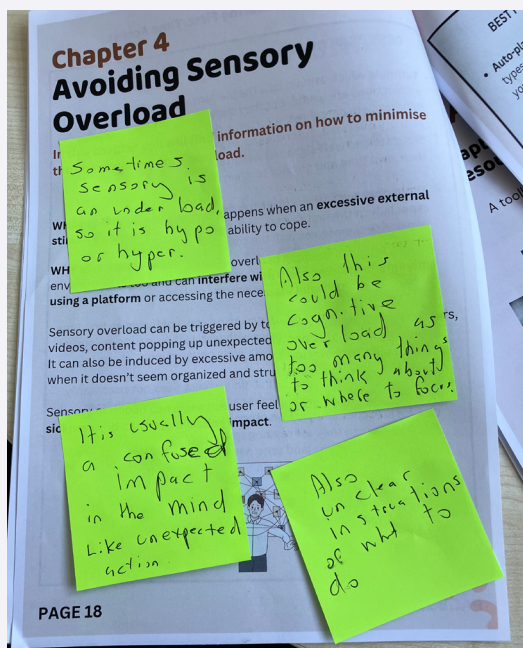
Both our participants and an autistic researcher in our team were taken as more authoritative voices on autism than the neurotypical team members.

Why this work is important

The research informs our understanding of what kinds of social media situations make autistic people feel like they fit in or feel uncomfortable.

This is important for designing online environments that are inclusive of autistic communicative expectations and sensory needs and have the potential to improve the quality of online social experiences for all.

This research also enhances our understanding of how autistic people communicate, which will help broaden our theorisations of online social behaviour and extend the boundaries of what is considered to be a typical style of socialising.



Alt text: A draft text with post-its of participant feedback.

3. What did we do?

Our project consisted of several stages. We gathered social media posts from a set of participants and analysed them with linguistic methods. We also interviewed autistic social media users.

We used a framework called linguistic ethnography, which combines observation of participants' actions and use of language while actively seeking their own reports and reflections on such practices.

This combination ensures that we understand what participants do and say in specific contexts, and how they make sense of their social world. Findings from the linguistic analysis and interviews informed our choice of topics and social media features to focus on as part of collaborative workshops.

We hosted three types of workshops focused on exploring current autistic experiences of social media use and ways of improving them¹. This section discusses the different stages in more detail, what we did to collect the data and what conclusions we were able to draw from the analysis.

¹ We thank our research collaborator Autistica for help with participant recruitment. We also gratefully acknowledge the help of postgraduate research assistants Antoaneta Dimova, Caitlin Hogan, Angeliki Lampropoulou, and Yahui Wang with data processing, transcription, and event organisation.

Stage 1: Social media analysis

We collected Twitter and Facebook posts from 35 autistic users during 3 months, from 1 March 2021 to 31 May 2021. Some participants only used Twitter or Facebook, and some used both.

In a first study², we observed autistic Twitter users daily, and downloaded all their tweets weekly, noting down and screenshotting digital activities such as ‘liking’ or tagging other users. In total, we collected over 25,000 Tweets. We wanted to understand how participants may adopt some Twitter features and perhaps ignore others, and what activities they partake in on the platform.

Affordances is a term referring to features and capabilities of online platforms, and we wanted to examine the perceptions and understandings of some key social media affordances amongst autistic users. Users of social media are influenced by affordances such as, for example, persistence (what we post may stay online for a long time), and visibility which refers to the fact that many other users can potentially see one’s social media posts.

Since audiences far beyond one’s followers might see their posts many social media users carefully choose what they post about in order to avoid matters they consider private being widely seen. Such qualities, ones most social media users are aware of, shape how we communicate online as we try to take advantage of the positive qualities of social media and minimise potential drawbacks.

2 Koteyko, N., van Driel, M., & Vines, J. (2022). Autistic sociality on Twitter: Enacted affordances and affiliation strategies. *Discourse & Communication*, 16(4), 385-402.

The affordances that emerged as important are:

Association

Association involves the ability of social media users to locate and interact with others interested in similar topics through features like hashtags, which make topics easily searchable, and replies, which help to initiate interactions.

Our informants used replies more than twice the number of times they used standard tweets – this is a much higher proportion of replies than that found in studies of social media use in the past . Participants also engaged with polls and questions posed by other autistic users across a wide range of topics, and were particularly active in answering questions posted using various autism-related hashtags such as #autism or #AskingAutistics.

Finally, our participants made use of the biography section of a Twitter profile to list their interests and therefore invite associations with others sharing those interests.

Content Persistence

This aspect refers to the fact that conversions on social media are preserved and can be viewed long after the original interaction took place. This proved helpful for revisiting conversations and/or selecting conversations to which one can initiate a response (as can be seen from the frequent use of replies).

Additionally, some participants used the affordance of persistence to search for content and reply with pre-written statements (which were often corrections of misperceptions about autism), such as “Most autistic people (80%+) actually prefer to be called autistic people”.

Quote tweets, where a tweet can be retweeted with a comment from the user added, as well as pinned tweets, which stay at the top of a user’s profile, were also frequently employed by our informants, as part of highlighting various aspects of identity.

Editability

Editability centres on the ability to edit tweets before they are sent, edit one's profile, and delete posts if necessary. This enables users to remove content after they posted it if they feel it does not represent them well, and also helps users feel that they are presenting a consistent image of themselves online.

Tweets were seldom deleted, but profile information was frequently edited with updates about life events or Twitter activity patterns. Informants also edited their profile image and included other visual resources such as photos, emoji and GIFs to reinforce the meaning behind the language in their tweets.



Alt text: A participant's tweet showing a photo of an organiser drawer for socks.

By contrast, the affordance of **visibility** was less salient for our participants. Our informants used status update tweets (i.e., those not mentioning or replying to another user) infrequently, and seldom used hashtags. This suggests the overall visibility of our sample of users was quite low, as is evidenced by low numbers of widely-retweeted posts authored by our users (only seven instances among the 25,000+ tweets in the sample). Most of our participants did not alter their privacy settings, maintaining those set to ‘public’ by default.

As **association** was a popular affordance among our participants, we also analysed how they used evaluative language to associate with other users. Evaluative language such ‘it is a great cause’ plays an important role in building social relationships as we bond with others who share our opinions on a given topic. Therefore, we used users’ appraisal of topics of conversation to examine how they relate to each other and create connections [see Glossary]. We found that our participants evaluated topics by displaying a wide range of mostly positive emotions.

An example of a tweet using positive evaluation:



I’d like to say a big “Thank You” to all who are listening to us & raising awareness #ActuallyAutistic

This contradicts stereotypes and misconceptions about autistic people as being emotionally detached or avoiding social interactions. In evaluating a variety of topics and subjects of online conversation autistic users drew on different aspects of their identities, including but not limited to their autism.

Overall, we found that content persistence and association were particularly important for our participants as they met their interactional expectations and preferences such as finding shared interests with others or providing information.

Speech Acts in autistic users' tweets

Our second study³ used the methods from pragmatics [see Glossary], which is a field in linguistics, to understand how autistic participants communicate via tweets.

Since our first study showed a significant popularity of replies rather than status update tweets we decided to examine the full Threads in which replies were used. We focused on Speech Acts [see Glossary], which refer to what a speaker or author does when they say or write something. Examples of Acts include inform, thank, and apologise. We found that the most common acts were Claim, Inform, and Elaborate. Importantly, Claim and Inform were found to be common on social media in previous studies while Elaborate is unique to our collection of autistic tweets.


Claims refer to users sharing their opinions about the topic being discussed. Claims can include evaluative adjectives such as 'good' or 'beautiful' and is typically used to share opinions online.

Inform was used to share users' experiences and answer questions. Answering questions to provide information appeared as an important social move in our informants' social media experience. Such interactions have explicitly defined roles (i.e. it is clear to know what one is expected to do when answering a question) and allow users to interact without having to initiate a conversation (participants reported initiating online conversations intimidating in interviews).

Elaborations were important for avoiding miscommunication by giving additional information. For example, if they believed something could be perceived as critical or negative, our participants provided more information to ensure understanding and to prevent a potential conflict.

3 Van Driel, M. and Kotevko, N. (2022). Autistic Twitter Replies: CMC Acts and Interactional Functions. *Language@Internet*, 20, article 1.

An example of a tweet using Elaboration:

-  Beautiful painting would never have thought it was Kew Gardens the colours aren't quite what we see in England not that that deters from such a great painting.

Autism was the most common topic of discussion in this data set, and we found that when discussing autism, users employed more conversational features typical of autistic interactions. These included providing more answers and slightly less provision of users' opinions. We also noted a rather common use of the same phrases across several tweets written by individual participants which may indicate a preference for routine and avoidance of unexpected or unfamiliar situations.

We observed differences in communicative style when autistic users communicated with other autistic users compared to interactions with users who are likely to be non-autistic (as far as we know).

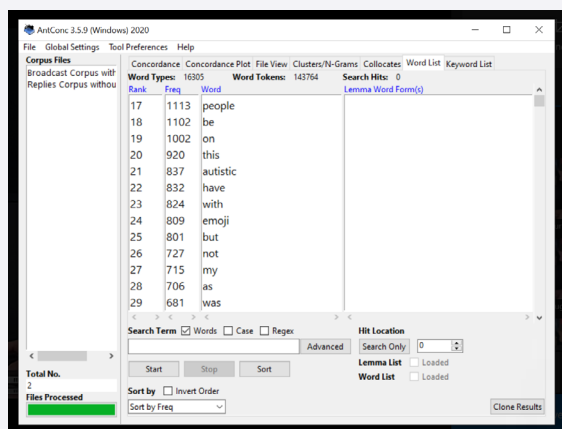
For example, our participants used elaborations and explanations when interacting with non-autistic users, in order to mitigate conflict and avoid misunderstandings. However, when talking about autism (these conversations mostly involved autistic users only) our informants made extensive use of questions and answers but limited use of emotive language and stories of their personal experiences. This suggests they were able to modify their communicative style depending on the expectations and conventions of their interlocutors as they perceived them.

These findings not only show how autistic users make use of both social conventions and technological features to manage their interactions, but also that they are adept at tweaking their interactive moves to the audience they are addressing.

Engaged communication versus tentative language

In the third study⁴ we observed where and how Twitter and Facebook users posted messages. We used corpus linguistic software [see Glossary] to compare the frequency of word use between participants who regularly mentioned autism in their posts and those who did not.

The results confirm some of the findings of the second study in that participants who mentioned autism used language in specific ways to raise awareness and connect with others (for example, using words such as ‘autistic’, ‘rights’, ‘prefer’ as well as brief statements including ‘yes’ and ‘fab’ that indicate interaction and agreement). This resulted in brief but often warm interactions with other autistic users as our participants built and maintained a variety of connections through affirming shared experiences.



Alt text: A computer screen showing a corpus linguistics software.

4 Koteyko, N., Van Driel M, Billan, S., Pena, B., Vines, J. (under review). Stigma management strategies of autistic social media users.

Participants who did not mention autism used tentative language (e.g. 'might', 'seem', 'not sure') more often in comparison with the first group and reported being worried about misunderstanding of their posts.

The use of tentative language in our data may be aimed at reducing vulnerability in social situations when autistic people are not sure they will be understood and provides linguistic evidence for practices described in the camouflaging research as 'deferential engagement' (Cook et al, 2022: 410). Like the use of Elaboration speech acts above we believe that such language is used not only to avoid coming across as overly assertive but also to avoid a potential misunderstanding and/or blame.

This is confirmed in the interviews as shown below, as our participants report experiencing negative stereotyping and misunderstanding in daily interactions which is reflected in anxiety about misinterpretation of one's posts and desire to mitigate it. This means, unfortunately, that social stress and past negative experiences of 'offline' social interactions are shaping autistic users' linguistic choices on social media.

The findings of these three studies are important as they show that autistic people have specific expectations and preferences in how they communicate and express connection on social media. Some autistic adults may feel unable to follow these preferences when interacting online which contradicts previous assumptions that autistic people do not need to mask in online environments.

Stage 2: Interviews

In order to understand motivations for using specific linguistic and digital features, as well as to verify our interpretations, we conducted interviews with participants whose posts we collected in Part 1.

We conducted 34 interviews with autistic users about their feelings towards social media and how they use platforms like Twitter and Facebook⁵. These informants were diverse in terms of age, gender and experience with social media use. We interviewed 30 informants on video calls online and four over email.

We used thematic analysis to analyse the interviews, which involves identifying recurring themes by finding commonalities among participant statements. These themes were first identified by an autistic researcher and then compared with those identified by another, non-autistic member of the team. Any mismatches in the themes were discussed as we sought to resolve differences in interpretation and disagreements. Following this process, we identified five key themes in the interviews:

Platform Architecture

Platform Architecture refers to the affordances and design of social media platforms, either as they help participants to interact online, or hinder their attempts to do so. Informants said that social media was useful for keeping up with what their friends were up to without having to actively interact with them. They reported the layout of websites and apps like Twitter and Facebook to be overwhelming and jarring. Emoji, too, were reported as quite confusing, because they rely on interpreting meanings from facial expressions or sometimes even more abstract symbolic connections, which heavily rely on interpretation.

⁵ Van Driel, M, Vines, J, Pena, B. and N. Koteyko. (2023). Understanding Autistic Adults' Use of Social Media. *Proceedings of the ACM on Human-Computer Interaction*, 7, CSCW2, Article 257 (October 2023), 23 pages. <https://doi.org/10.1145/3610048>.

Another issue identified during interviews was algorithmically sorted news feeds, which sort posts according to what a computer thinks a user will like instead of a chronological order. Informants did not want someone else (or something else) deciding on their behalf what they should see on their feed. It was identified as important for participants to be able to conduct routines, if they had them, which often involved checking their entire news feed. With algorithms reorganising these feeds at random, it becomes difficult for them to engage in these routines and this proved unsettling and stressful. This design feature also made it more difficult to see what friends had posted, which made social engagement more difficult as well.

The users we spoke to explained that social media has its benefits: they can step away from an interaction if they are overwhelmed or unhappy just by putting their phone down. They can also take more time to compose their responses or process what someone has posted thanks to the written nature of social media. However, all participants were not the same, and some even said they preferred in-person interactions, because they rely on things like body language and emotional tone to interpret meaning, which are much easier to convey in person than online.



Alt text: A hand putting a phone face down.

“

I find it much easier to step away, I can literally just say, ‘Right, phone’s going down, I’m stepping away’ whereas if you’re in like a real conversation and it becomes a debate which I’m not the best in, I don’t know how to get out of it.”

Research participant

Social Norms

The difference in social norms between online and face-to-face interactions, such as how online communication is perceived in comparison to in-person conversations, emerged as a theme that participants sometimes cited as a source of stress.

In discussing social norms online, informants talked about the norms of mostly neurotypical social media users, often describing them as ‘protocols’, or rigid rules and regulations.

To achieve adherence to such regulations, they reported observing other users’ online behaviour and attempting to mimic it, similar to offline masking practices. As with offline masking, it takes a lot of effort to do this. One participant discussed in detail how they observe and mimic other users:



I really don’t know anyone that finds it so complex as I do. So with the hashtags, it’s a way of me trying to, it’s a bit like a foreign person noticing that somebody uses this sort of phrase, and it’s not part of what they’ve learned in the English lessons whatever classes they’ve gone to, but they’ve noticed a phrase and they think, ‘Oh I’ve heard people use that a lot, I’ll give that a try and use that and I might fit in a bit more’, I might use it, but I might say it in the wrong context sometimes.”

Research participant

Participants also mentioned that the Internet moves fast: norms change very quickly as new trends spread, and if one uses a lot of energy to understand social cues, this constant cycle of change can be exhausting.



...my use of Facebook is a lot about trying to – it feels a bit like mapping, it's trying to fit in, it's trying to, it feels very precarious and dangerous, because I don't really know where to tread and what's right to say. I really think that I see that only getting worse and I think you can potentially, it can potentially be quite harmful in ways that other people don't mean when they talk about social media being harmful.”

Research participant

One area of difficulty was moderation of groups, such as on Facebook. In cases where there are group rules, users may not be aware of them as they are not always explicitly stated or easy to locate within the platform design.

Breaking these rules often results in a stern warning from group moderators or even a ban from the group, which our participants mentioned may cause them to step away from the community entirely as they worry about causing further conflict in future.

Being Authentic

This theme involved participants talking about which social norms they chose not to follow, because they felt those social expectations went against their desire to be authentic. This theme also involved informants talking about using social media to further their personal interests and finding communities who share those interests.

Participants also talked about creative ways in which they adapted platform features to their personal likings and personality. One participant for example discussed her use of emojis, displaying a creative emoji use grounded in logical reasoning about effort:



I use emojis when I want to be more emphatic but words seem insincere. A carefully chosen selection of fruit (🍓🍓🍓🍓🍓 – Gift of fruit) is more meaningful than ‘Thanks a lot’ – as it shows an investment of time.”

Research participant

This participant uses emojis to demonstrate an effort made, through choosing specific fruits, as opposed to a quick emoji that may be chosen as it is a common choice or one that others have used.

Informants talked about ways of using social media platforms to suit their own preferences. This included commenting on posts that they are genuinely interested in, and posting for the sake of it rather than expecting others to comment. Some mentioned that since social norms are not explicitly listed anywhere in the online realm, they could break them as a way of staying true to themselves.

Connectedness

This theme centres around how participants use social media to keep in touch with friends or relatives from the offline world, but also how social media can provide a space for autistic people to meet new friends.



I find for me it's an ideal way of interacting with people with similar interests but without having to go to a place which I haven't been to before or go to a place and meet people I haven't met before. [...] I very much don't really interact with people, I find it very uncomfortable and very difficult. So to me Facebook and Twitter are generally if you like safe places. I know a lot of people don't think they're safe places, but for me to meet people it's sort of safe because I'm not having to meet them face-to-face.”

Research participant

It was noted as a significant benefit that participants can use social media to keep up with people they know with a minimal requirement to interact extensively.

Additionally, participants appreciated the ability to find people interested in the same topics as them, for example through searching for related hashtags. They reported that they enjoyed being part of groups centred around certain topics so they can discuss and learn about topics without having to engage in too much small talk.



...that's where groups come in because say I wanted to post about a Plushie I had, I'd go on to like [plushie Facebook Group] or [build teddy bears Facebook Group]. For autism, my autism group. If I want to be, if it's about cosplay I'll go on to a cosplay group [...] or even like I say mental health, a mental health group. [...] that's why I find groups easier because you can find your audience [...] I go on Facebook and I actually check my groups more because they're the ones that, they're my niches, they're the ones I'm interested in whereas my main one I'm like, 'Whatever'."

Research participant

However, informants reported that as social media platforms use more algorithmically-determined news feeds their opportunities to discuss and learn have been reduced.

Algorithmic sorting means participants were shown posts similar to their own instead of ones with new perspectives. This led to distrust in social media platforms and perception that algorithms cater only to neurotypical people.

Control

Participants reported specific routines and practices that they had established to maintain close control over their interactions with people in their network.

The desire for control appears to align with two types of autistic experiences. Firstly, this related to participants' preferences for routines, such as for example, checking the news feed: "I always go on it first thing in the morning, I always go on it last thing at night, I always go on it when I get in from work, lunchtimes. On Facebook, every time I go onto it, I scroll back through everything since the last time I looked at it, I stopped doing that on Twitter because it's become overwhelming."



It's great for somebody with autism to be able to interact with lots of people but you've got to control it, you have got to manage it proactively."

Research participant

Secondly, control was reflected in the way participants talked about avoiding conflict or misunderstandings in online interactions through selecting particular words or emoji.

This is potentially rooted in autistic participants' offline experiences, as autistic people may often have experiences of being misunderstood or perceived as rude: "Because obviously having autism, I've grown up with the expectation that people don't like me, because there have been many, many examples of that".

While some participants discussed struggling with emojis in regard to their social meanings (as we mention above), others talked about a reliance on emojis in order to “clarify tone”:



It’s like the wee hearts one, that’s actually become a bit of a habit for me and generally that’s me saying [...] ‘I’m not being pushy, I’m not being rude, I’m just trying to just clarify this is just what’s happening’ and it’s just, because I have noticed [...] people do misinterpret it and they think I’m being rude but that’s not the case, it’s usually just me saying, ‘No, I’m not trying to attack you or anything, I’m just explaining.’ So, that wee emoji [...] takes a wee bit of the seriousness out and it makes them realise, ‘Oh wait, this is not a confrontation.’”

Research participant

Another participant commented that they constantly had “to carefully phrase whatever I’m saying, it doesn’t come across to anybody that I’m attacking them”. While it can be said that all social media users do this to some extent including neurotypical users, our interviews suggest that autistic users pay a lot of attention to possible interpretations of their posts and experience anxiety around potential misunderstandings, while also grounding their expectations of misunderstandings in previous, offline, experiences.

To explore the topics of our interviews in more detail and learn about how autistic adults would like social media to function, we conducted participatory design [see Glossary] workshops.

Stage 3: Workshops

We organised three workshops with 20 participants, hosted online using virtual whiteboards⁶.

The 20 participants were split into four groups of five people which, as far as possible, remained unchanged across all three workshops. They were sent some materials to use in the workshops in the post, so they could choose whether to work with the physical or digital objects.

We saw the workshops as an opportunity to 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 and the concept of autistic sociality. We used thematic analysis to 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.



Alt text: A workshop participant holding a smartphone and trying out a social media feature.

⁶ Barros Pena, B., Koteyko, N., Van Driel, M., Delgado, A., & Vines, J. (2023, April). "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 (pp. 1–16).

Workshops 1 and 2: Describing experiences and imagining features

The first workshop was about the current state of social media for autistic people. We encouraged participants to describe their personal social media experiences by reviewing some of the data from previous stages of the project: social media posts and interview quotes (see Stage 1 on page 12 and Stage 2 on page 20). We selected a subset of anonymised posts and interview quotes and presented them in the form of ‘evidence cards’ for our participants to comment on.

In the second workshop we proposed some deliberately controversial, imaginary features of social media platforms in order to spark discussion and debate. Our special features were inspired by a design technique known as questionable concepts. Questionable concepts harness the ridiculous for design purposes. They aim to stimulate critique by proposing ideas that are impractical or provocative. The features, which can be tried out on our website, included the following:

- **Small Talkifier**, a tool that automatically adds small talk to social media posts to make them more similar to what neurotypical people expect. This would alleviate participants' perceived need to use social media in order to be seen to keep up with the activities of family and friends, and take away some of the exhaustion that comes with using social media in a way catered to neurotypical users.
- **Trans-NT-lator**, a tool for removing everything from a social media thread except the key parts, including a summary of what commentators are saying. This might mitigate sensory overload by removing extraneous content and allowing users access to the content they want to engage with.
- **Yr-Π “your ΠI”**, giving information about people a user may want to interact with to see if they're nice or potentially a troll. This would help mitigate participants' uncertainty about their audience, and would maintain the quality of social media posts that users are shown.

Participants noted that this exercise helped them learn more about their autism as well, through evaluating our proposed features against their own experiences and preferences.



Alt text: Cards representing questionable concepts laid out on a table.

Analysis of workshop data

Participant responses in Workshops 1 and 2 enabled us to identify challenges in using social media, while Workshop 3 helped to understand the strategies participants had used to cope with those challenges. The key challenges identified were summarised into seven themes:

1. Autistic sociality on social media

As we mention above, autistic sociality can find reflection in the preference for interest-driven communication. However, social media is primarily geared towards affective interactions through small talk and sharing of memes, and social spheres are not organised by topic but rather a milieu of all types of people and content in one place. Participants described how Facebook, Instagram and Twitter were therefore not ideally suited to their preferred style of socialising.

For instance, Twitter was described 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". For another participant, Twitter was "so, so diverse and so much different content goes on Twitter" that it became "hard to know how or what to share". Facebook, in spite of 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".

2. Interpreting emotional intent

Features like emoji, GIFs and hashtags are central to most social media sites, but they proved problematic for our participants for a number of reasons. Firstly, workshop members mentioned their difficulties in mapping the pictorial depictions of emoji onto their own, or others', emotions, so did not know which emoji were appropriate to use in a given situation, nor how to interpret emoji sent by others.

“

It is totally confusing, emojis. I don't know how I'm feeling. How do I know which one to use?"

Research participant

For participants 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 one participant called "the little yellow circle".

Emoji can also have context dependent meanings, which makes them more difficult to interpret.



“

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?"

Research participant

Alt text: An emoji made of a paper plate and paper cut outs to represent facial features.

3. Quality of content on social media

Workshop members said they found the kinds of things posted to social media irrelevant and often the cause of discomfort or distress.



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."

Research participant

Additionally, the propensity for social media to harbour disagreements or even hate speech was deeply affecting for participants, who explained they often got quite upset with the conflict they sometimes encountered.

4. Sensory overload

The amount of content and the quick succession in which it is presented on social media was also an issues. Some participants felt they only had the capacity to handle a small amount of the content social media platforms throw at them.

Features like repeating GIFs, videos starting to play automatically while visiting a page, and sudden noises were all cited as very uncomfortable. Most social media platforms offer little in the way of customisation options to manage these issues for affected users.



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.”

Research participant

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.”

Research participant

5. Audience uncertainty

Due to the public nature of social media and the fact that an indeterminate audience of strangers could possibly come across one's social media posts was worrying for participants, as was the fact that posts online can be accessed long after they have been created.



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.”

Research participant

These uncertainties, along with the ambiguous privacy settings offered by most mainstream social media platforms, left users feeling like they have a lack of control over their audience and its management.

6. Compulsion to use social media

Participants said they felt that they had to be on social media and would miss important updates or events if they were to disconnect entirely.

Some said they felt like they must react in the way other users on social media would expect them to, in case friends interpret their lack of response to a post as socially loaded in a way they did not intend.

Another worry for our participants was how easy social media sites make it to scroll endlessly, meaning it can be difficult to step away and manage one's time or use of the platform.

Some participants described it as a "fear of missing out on something". Others connected their drive to engage with aspects of their autistic personality. For instance, some participants described their difficulties extricating themselves from "aggressive" 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."

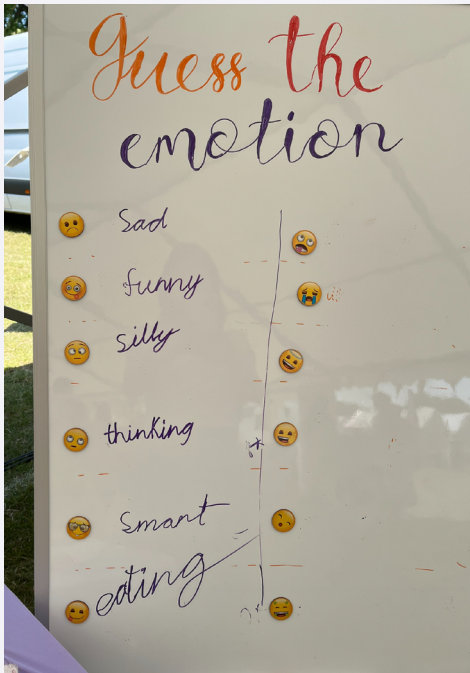
Research participant

7. Conveying and interpreting meaning

The understanding of intention behind social media posts, as well as how to express sentiment in a way that could be understood by others, took a great deal of participants' energy and time.

The fear of being misunderstood and catalysing conflict meant they dissected their draft posts repeatedly in an attempt to ensure they would convey their intended meaning correctly.

Some 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, one participant found it "really hard to read a situation", another believed that she misunderstood "other people's meaning quite frequently". Adapting their personal style of communication to perceived social norms 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."

Research participant

Alt text: A whiteboard with inscription 'Guess the emotion' below which magnetic emoticons are matched with a word describing a feeling they represent.

Workshop 3: Addressing the challenges through imagined features

To continue the conversation from Workshop 2, we encouraged participants to design social media features they would like to see in Workshop 3. This process involved 17 action cards (e.g., mute, search, edit, or filter out), 17 orange component cards (e.g., hashtags, text, rudeness, or friend requests), as well as blank cards where they could add anything else not covered by the other cards.

Workshop members made 38 features. Below we present some of the participants' suggestions based on how these features address the challenges identified in previous workshops.

1. Enabling autistic sociality on social media

To address this challenge, participants suggested features such as the ability to search for other users based on their interests, recommendations of other users to follow based on their interests, and spotlighting conversation threads on interest-driven topics. This allows for easy connections based on mutual interests without having to extensively search or engage in tiring trial-and-error interactions.



Alt text: Two workshop participants sitting side by side and looking through design cards laid out on a desk in front of them.

2. Suggestions for developing or using specific features

Suggestions included features to interpret emoji usage both as a reader and a post author. This would allow for explanation of how a post and emoji combination may be interpreted by neurotypical users, so emoji that are congruent with the written text can be easily chosen. Another proposed option was the ability to replace an emoji with a picture that the author feels captures the tone they intend in a way that is clearer to them.

3. Managing content quality

The ability to filter or hide uninteresting content on social media was popular among workshop members. Filters that would block specific language, such as those associated with rudeness or conflict, or any content posted by strangers, were cited as useful ideas. Other ideas included sorting content in terms of relevance to the user instead of randomly, as well as a concrete end to a feed, rather than an infinite supply of posts. This would help autistic users disengage more easily once they have seen all posts that may be interesting to them, and help mitigate sensory overload.

4. Preventing sensory overload

Strategies to prevent sensory overload included removing all moving images, leaving just text and still images. Similarly, the ability to filter out different types of content at the user's discretion are also useful for tailoring content to the current sensory capacity of the user. To-do lists were also suggested as a useful tool, so that autistic users could be reminded about messages needing replies or content they planned to read, without having to store all those items in memory.



Alt text: An example of a feature created by a workshop participant. It is titled 'activate stillness' and consists of five design cards.

5. Managing audience uncertainty

The features addressing audience uncertainty can largely be grouped into two sections: those aimed at giving users more information about potential new friends on social media, and those giving users control over who sees their posts and for how long.

The first category consisted of features including providing information before accepting someone new as a friend, including mutual connections, interests and political views. The latter included options such as more flexible control over who is able to see certain posts, and a way to automatically delete content after a certain amount of time.

6. Managing compulsion to use social media

Features aimed at reducing participants' perceived need to remain on social media included providing an 'out of office' style message to indicate if a user was not currently in the right headspace for online interactions. This helps mitigate the sense of urgency participants said they sometimes felt when responding to comments or replies.

Another proposal was a time limit feature which blocked users out of social media after a certain amount of time, in addition to a feature to limit the amount of negative content a user might see after having seen other negative or scary posts (sometimes known as doomscrolling), interspersing it with happier and more comforting content.

7. Conveying and interpreting meaning

Both expressing and understanding intended meaning were catered for by the features participants suggested. These included audio previews of posts before they are sent, a way to share drafts with other users the poster knows so they can provide interpretation checks, and the ability to recall or edit posts once they have been made. Participants also 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 and therefore avoid misinterpretation.

Echoing the findings from our interviews, the lack of control social media users have over how their social media feed looks, and what they are able to do with it, was a source of stress. Thus, a common theme amongst the above features was the ability for social media users to exert control over aspects of their experience on the platform.

Participants wanted control over: 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 are grounded in sensory issues, and seem associated with the sensitivity to sensory stimuli that is currently recognised as one of the main characteristics of autism. From this perspective, the personalisation features suggested in Workshop 3 are important for making social media a more welcoming environment for autistic people.

8. What are the potential weaknesses of the research?

Although our participants exhibited a range of internet skills, they may represent a subgroup that is particularly inclined towards social media usage and interaction.

This means that our findings may not apply for autistic adults with learning difficulties, for example. Our sample also includes only speaking individuals which means that the experiences of non-speaking autistic people are not represented.

4. What happens next?

Responses and suggestions of our participants highlight the importance of including autistic people in conversations about social interactions in general and in social media design.

We have shown that autistic sociality has a significant online component which means that digital networking platforms of all kinds (from website-based support groups to social media) can incorporate our findings into their platform design **in order to promote interest-driven discussions and alleviate some of the stress and anxiety** experienced by autistic users.

On the basis of these findings, we developed a **policy brief*** in collaboration with Autistica and two **toolkits** to encourage efforts in adapting digital platforms to better support the needs of autistic users. Each toolkit addresses a different area of practice.

Our first toolkit is aimed at software developers and web designers who possess the technical skills to design digital platforms. This toolkit contains an introduction to neurodiversity in order to provide a framework of reference to professionals who might not be familiar with this approach and its implications in design. It also details the methods we used in the workshops (e.g. evidence safari and design cards).

By engaging with the evidence cards developed in our research, designers can get a tangible sense of how autistic users' preferences and needs can shape innovative approaches to the design of digital spaces. The toolkit encourages the use of these methods in participatory efforts with neurodivergent users whenever possible. At the initial stage of toolkit development, we presented these methods to a group of UX designers and incorporated their feedback into the final version.

* The policy brief can be found online [at autistica.org.uk/news/accessible-online-spaces](https://autistica.org.uk/news/accessible-online-spaces).

The second toolkit supports digital managers and content creators working in the third and public sectors, who might not be able to re-design digital platforms, but could use our recommendations for tailoring the content and adapting individual platform features to accommodate autistic users. This includes content creation professionals from a range of fields – from those who manage government and NHS websites that do not specifically target autistic users (but are likely to include a large proportion of them, including undiagnosed users) to digital managers at autism charities.

This toolkit was developed through conversations with representatives of these professional groups and with autistic participants recruited through the research charity Autistica. We first ran a workshop and three focused groups to discuss some areas of practice (facilitating first-time access; avoiding sensory overload; moderating online communities; providing guidance) which are particularly pressing for neurodivergent users in the context of the third and public sectors. We then developed the toolkit to address each of these four areas by defining their scope and relevance, and by incorporating best practice advice co-developed with our focus groups' participants.

We presented the first draft of this toolkit at a public engagement event attended by autistic people and their allies (held in July 2023 at Queen Mary University of London). The attendees' written and oral feedback on the draft was then incorporated to produce the latest version.

Both toolkits are available to download from **autisticadultonline.com** and Queen Mary University of London research archive.

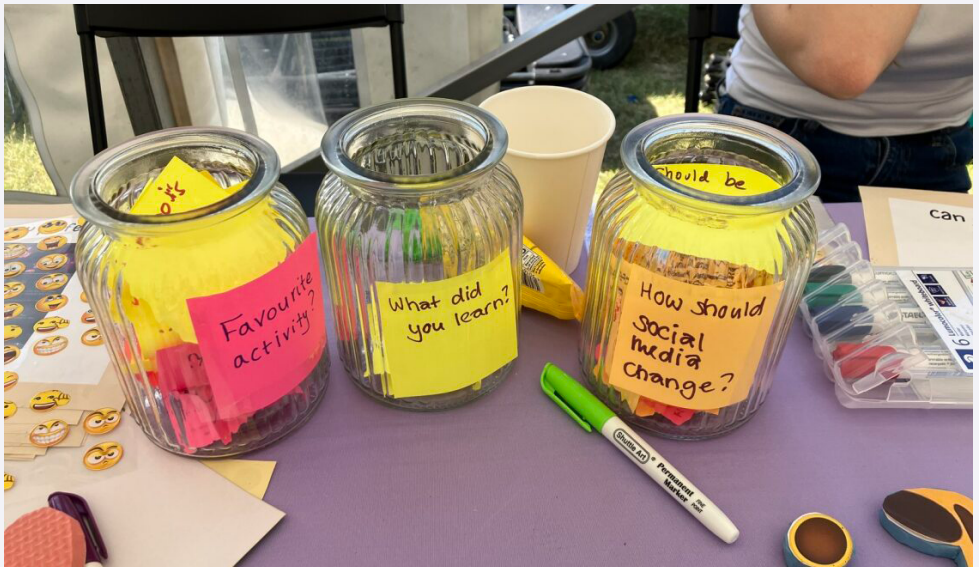


If you used the toolkits or our research findings in general and want to leave feedback you can do this by scanning the QR code.

5. Future research

Through this research, we learned that autistic people are still an under-represented group both in the field of computer-mediated communication and in design studies.

This needs to change so that truly diverse experiences and communicative abilities are accommodated on social media, as well as taken into account in theorisations of online behaviour. We hope that the methodology developed in our project, which focuses on both language analysis and reports of personal experiences, illustrates the great potential of working with and learning from autistic users, both from theoretical and practical standpoints.



All text: Three transparent jars for collecting participant feedback notes. The first jar from the right is titled 'Favourite activity?', the middle one 'What did you learn?' and the third one 'How should social media change?'.

From the perspective of design research, understanding the impact of algorithms on social feeds and exploring platform-specific affordances is crucial for enhancing social experiences for autistic individuals. The acknowledgment by our participants that the political ideologies inherent to different platforms significantly impacted their selection of which platforms to engage with and which to abstain from also underscores the need for further research in this area.

Future research in the field of computer mediated communication should focus not only on how autistic people approach interactions with neurotypical social media users, but also how non-autistic users act in these online interactions.

This is particularly relevant in two avenues of research: autistic masking practices in digital environments and moderation policies in online communities. Understanding autistic masking or camouflaging behaviours in diverse digital environments is crucial due to their significant impact on mental wellbeing.

Further research is also essential to explore the intricacies of moderation within online communities that involve the active participation of autistic adults. Focusing on moderation becomes crucial in mitigating potential misunderstandings that can arise between autistic and non-autistic users in these spaces. Presently, moderation guidance primarily caters to all autistic online groups, leaving a gap in addressing the interactions within mixed communities.

By investigating and developing tailored moderation strategies that account for the diverse communication styles and sensitivities, we can foster environments where both autistic and non-autistic users can engage meaningfully while minimizing potential conflicts or misconceptions.

Glossary

Ambient affiliation

Scholars have created several theories for how interaction occurs in vastly different online contexts. One of these theories is called ambient affiliation, and it explains how people can come together while talking about similar topics, such as through hashtags, memes, as well as evaluative language.

Even without directly interacting with others, users can be seen as part of the same community that is talking about the same topic. This joint attention to topics creates connections between users, also known as affiliations.

Appraisal Theory

Appraisal Theory explains how we use language to express what we think about anything and everything. The way we feel about things – how we evaluate them – also has consequences for how we position ourselves relative to others and their evaluations of the object at hand.

Autistic Sociality

The notion of autistic sociality refers to the ways in which autistic people interact with each other as a result of both individual and group preferences and capabilities for certain types of interaction.

Autistic sociality as a term advocates for the idea that autistic people are social, despite the differences that may be observed from neurotypical social coordination patterns. Autistic sociality asserts that certain social and cultural contexts may promote or impede autistic people engaging in social interactions, and it is therefore imperative to create spaces in which autistic sociality can flourish.

Context Design

Context design centres around how one's diverse social circles, which otherwise exist separately offline, are brought together on social media, and there can be difficulties in making online posts to cater to all of these groups at one time.

Social media users carefully manage their audience to create posts that appeal to certain social groups specifically. Users may create multiple accounts on a social media platform, so they can use different accounts for different purposes and identities.

Corpus Linguistics

Corpus linguistics is a way of studying language by analysing large collection of words with computer software in order to investigate how language is used in different situations. It studies how often certain words or phrases show up to help us understand how language works in real life.

Participatory Design

In participatory design, technology users are not customers or consumers. They are neither a source of information for technologists, nor evaluators of a final product. Instead, they become active contributors of design ideas, and decision-makers in the technology design process.

Pragmatics

Pragmatics studies how language is used to facilitate communication between people, and can include exploring how different tools are used to convey meaning beyond the words and sentences we utter or write.

Platform Affordance

Affordances refer to the capabilities a certain website, platform or app has. Usually, affordances are characteristic of a certain platform, such as the retweet function on Twitter.

Affordances can be used and made sense of by the people who use a certain platform in a range of ways, sometimes carrying a great deal of social meaning, and sometimes being used in a very different way to their intended use.

Speech act

A Speech Act refers to when we write or utter something which impacts the world in a material way. Common examples include 'I now pronounce you man and wife' which begins a legal and social contract known as a marriage, but speech acts can occur throughout daily life in more mundane ways as well.

Tone Indicators

Tone indicators are short symbols written at the end of utterances to indicate the intended tone behind the utterance when this may be ambiguous. Often on social media like Twitter, combinations of letters at the slash (/) symbol are used, for example /j (joking) and /srs (serious).

At the moment, tone indicators are not built into any social media platforms as affordances, rather users have found ways to engineer tone indicators from the affordances that are provided, such as the ability to compose and post text.

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