

## Understanding Autistic Adults' Use of Social Media

Van Driel, Martine; Vines, John; Barros Pena, Belen; Koteyko, Nelya

DOI:

[10.1145/3610048](https://doi.org/10.1145/3610048)

License:

Creative Commons: Attribution (CC BY)

*Document Version*

Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*

Van Driel, M, Vines, J, Barros Pena, B & Koteyko, N 2023, 'Understanding Autistic Adults' Use of Social Media', *Proceedings of the ACM on Human-Computer Interaction*, vol. 7, no. CSCW2, 257.  
<https://doi.org/10.1145/3610048>

[Link to publication on Research at Birmingham portal](#)

### General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.



# Understanding Autistic Adults' Use of Social Media

MARTINE VAN DRIEL, University of Birmingham, UK

JOHN VINES, University of Edinburgh, UK

BELÉN BARROS PENA, City, University of London, Centre for HCI Design, UK

NELYA KOTEYKO, Queen Mary, University of London, UK

Autism is a developmental condition that impacts 1 in 100 people [48]. It affects autistic people's interactional and sensory preferences and behaviours. Autistic people can find interactions difficult in part due to sensory overwhelm. Interacting online can provide a positive alternative that allows for interactions on their own terms. However, most social media platforms are designed by neurotypical standards and can therefore inhibit full participation by autistic users. We demonstrate through the analysis of 34 semi-structured interviews with autistic adults that current social media design is not sufficient for creating an inclusive environment and enabling participation from autistic adults. We identified six themes across the interviews: (1) 'Social Media compared to In-Person Interactions', (2) 'Social Media as Enabling/Overwhelming', (3) 'Perceived Social Norms', (4) 'Keeping Connected and Finding New Communities', (5) 'Keeping Control through Systematic Practices', and (6) 'Being Authentic'. The themes demonstrate the attention that autistic adults give to online interaction, suggesting that online interactions may be just as fraught as in-person interactions have been shown to be. In order to become more inclusive of autistic adults, we recommend that social media platforms expand low-effort participation features, provide increased control over algorithmic content, support expression of intent and tone, aid discovery of interactional norms, and reinforce interest-based sociality.

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

Additional Key Words and Phrases: autism, inclusive design, participatory research, interviews, qualitative research

## ACM Reference Format:

Martine van Driel, John Vines, Belén Barros Pena, and Nelya Koteyko. 2023. Understanding Autistic Adults' Use of Social Media. *Proc. ACM Hum.-Comput. Interact.* 7, CSCW2, Article 257 (October 2023), 23 pages. <https://doi.org/10.1145/3610048>

## 1 INTRODUCTION

Autism is a developmental condition affecting a person's communicative and sensory preferences and abilities [48]. The condition is specific to each individual, and while it is generally envisioned as a horizontal spectrum, autistic communities prefer to discuss it as a circular spectrum with different affected areas that may differ per individual. The UK's National Autistic Society [48] reports that 1 in 100 people are autistic. Characteristics of autism can include repetitive and restrictive behaviours, extreme anxiety, meltdowns and shutdowns, and difficulties with social interaction [48]. While autism used to be, and sometimes still is, referred to as a disorder that causes impairments ([36], p. 139) and deficiencies [49], recent autistic-led work has moved away from this perspective. Here,

Authors' addresses: [Martine van Driel](mailto:m.a.vandriel.1@bham.ac.uk), [m.a.vandriel.1@bham.ac.uk](mailto:m.a.vandriel.1@bham.ac.uk), University of Birmingham, Birmingham, UK; [John Vines](mailto:john.vines@ed.ac.uk), [john.vines@ed.ac.uk](mailto:john.vines@ed.ac.uk), University of Edinburgh, Edinburgh, UK; [Belén Barros Pena](mailto:belen.barros-pena@city.ac.uk), [belen.barros-pena@city.ac.uk](mailto:belen.barros-pena@city.ac.uk), City, University of London, Centre for HCI Design, London, UK; [Nelya Koteyko](mailto:n.koteyko@qmul.ac.uk), [n.koteyko@qmul.ac.uk](mailto:n.koteyko@qmul.ac.uk), Queen Mary, University of London, London, UK.



This work is licensed under a Creative Commons Attribution International 4.0 License.

© 2023 Copyright held by the owner/author(s).

2573-0142/2023/10-ART257

<https://doi.org/10.1145/3610048>

autism is viewed as a neurotype, which manifests through differences in communicative and sensory behaviours that mismatch with neurotypical preferences (see the double empathy problem, [34]). Gallagher [23] proposes understanding autism from an “interaction theory” perspective which concentrates on intersubjectivity both internal: capabilities from birth, and external: capabilities that are acquired. While previous work on autism and communication placed full responsibility for breakdowns in communication with autistic individuals and their “deficiencies” [49] [6], this approach follows how communication is generally viewed in neurotypical populations: as an interaction, where all participants carry some responsibility for its success [42] [43]. This approach has led to studies that focus on understanding how autistic individuals communicate [4] [26] [37] instead of evaluating autistic communication by neurotypical standards.

Research has shown that autistic people can find belonging in autistic groups, resulting in feelings of enjoyment and happiness that are less common when interacting with neurotypical people [4] [18]. Bagatell ([4], p. 419) writes about an autistic participant who found that interacting with other autistic people helped him reposition himself as ‘normal’ for an autistic person. Similarly, Crompton et al. [18] show how time spent with other autistic people is beneficial due to participants understanding of each other and a sense of belonging. Ben, the participant in Bagatell’s ([4], p. 419) study, identified as belonging to the ‘Aspie world’, a term that was used by him and his friends. The emergence of this world is in part connected to: (1) the emergence of the disability rights/self-advocacy movement; and (2) the rising adoption and availability of computing technology, specifically access to the Internet. Through weblogs, online forums, social media and social networking sites, the internet has helped autistic people connect with others through interest-based forums including Quora and sub-Reddits, as well as maintain connections with ‘offline’ relationships through social media such as Facebook [31] [7]. This provides more control for autistic people as ‘offline’ communities, such as school friends, sports clubs, or hobby groups, often require persistent autistic ‘masking’ where autistic people make a conscious effort to mimic neurotypical behaviour [16]. An offline comparison to online community groups can be autism support groups where autistic people can meet and interact on their own terms [27]. In addition, the rise of computer-mediated communication promotes the growth of self-advocacy groups, increasing their reach and visibility. Social media in particular may be helpful to autistic people as communication that has space for delayed responses and direct connection to individuals like themselves. However, considering the differences in communicative and sensory preferences and behaviours between autistic and allistic<sup>1</sup> users, there has been a relative paucity of research investigating how autistic users interact with online platforms and environments and engage with others on social media [15] [17] [38]. This research so far indicates differences in uptake of platform features between autistic users and neurotypical users [38], and suggests a need for increased consideration of autistic perspectives in order to develop more inclusive platforms and widen participation [55].

This paper contributes to this nascent field by drawing on 34 interviews with autistic adults about their use, experiences, and feelings about and towards social media, particularly Twitter and Facebook. Our data highlights that autistic users clearly understand and perceive the current state of social media platforms, and that they identify social norms as expected behaviours throughout their social media use which affect their personal usage. While in many instances participants conform to these perceived social norms to some extent, at times, participants also discussed eschewing these norms in favour of authentic use and discussed how they prefer to use social media. Our analysis of the interviews demonstrates that the current design of social media platforms influences social norms, which in turn influences how autistic, and in fact all other users, interact with the platforms

<sup>1</sup>Non-autistic people including other neurodiverse populations such as people with ADHD

and each other. However, there is no automatic influence from the enacted use of platforms and their features into the design which this paper aims to provide. We build on existing studies and inform our design recommendations on reports of autistic participants. Based on our interviews, we show an increased need for (1) low-effort participation features, (2) control over algorithmic content, (3) tools for expressing tone and intent, (4) explicit interactional norms (expected behaviours when interacting with other users), and (5) interest-based sociality.

## 2 AUTISM AND THE ONLINE ENVIRONMENT

### 2.1 Autism and Social Networking Sites

Social media can function as a place to develop social skills in a 'safe' environment ([13], p. 191) and to connect with people over shared interests and experiences ([25], p. 13). Previous research shows that autistic people commonly use social media, with one study showing that 65 per cent of autistic respondents used social media for "*social engagement and connection*" ([32], pp. 1711–1712). It has been noted that social media is particularly useful for autistic people due to the perceived level of social and physical distance that can be maintained [5] [32], and because features of certain social media platforms can be used to compensate for different social abilities and preferences. Studies have generally found that initiating new relationships online was seen as easier by autistic people than initiating them offline [5] [13] [25], however there are conflicting reports on the use of social media in maintaining relationships. Brownlow et al. [13] report that maintaining friendships may be easier online as online communities can create a space to 'study' friendships and improve social skills. However, Gillespie-Lynch et al. [25] suggest that the lack of emotional cues and response delays may make maintaining relationships online more difficult than maintaining relationships offline. This is indicative of the idiosyncratic experience of being autistic, with each autistic person having their own preferences, challenges, and autistic characteristics.

Existing literature on autistic people's use of social media also highlights a great diversity on how features and functionalities of different platforms work for some and not for others. For instance, while some autistic users have reported finding the focus on textual interaction easier ([25], p. 13; [32], p. 1712), studies have also showed how both text and pictures are increasingly used pragmatically in online interactions by, what are assumed to be, neurotypical users [51] [52], meaning that images work in conjunction with text to create meaning. The affordances of social media can allow users to participate in ways that are not accessible to them in offline interactions and provide mitigation strategies to deal with neurotypical forms of interaction. Several technological features allow for users to find communities, such as profiles [20], 'friending' [19], posts [2], hashtags [54], and comments [24]. However, the question should be raised as to how autistic adults perceive these technological options and how they employ them in order to use social media for their individual chosen purposes. This paper builds on this existing research by expanding our knowledge in regard to how autistic people experience social media, and how its affordances both aid and constrain communication of autistic people.

### 2.2 Design Research and Autism

In HCI and CSCW research for and about autistic users, there are two general tendencies. Firstly, research includes the design of systems to help autistic people manage anxiety (see for example [11, 17, 45, 46]) and secondly, it focuses on 'translating' existing, neurotypical design so autistic users can make sense of it (see for example [22, 41, 55]). While these approaches have provided valuable insight into the potential of design in supporting autistic experiences, these studies have a tendency to center neurotypical behaviours as the standard. For example, Boyd et al. discuss a wearable device that would give the autistic user direct feedback on their "*atypical prosody*"

[11] without consideration of whether the neurotypical interlocutor should receive feedback on understanding their autistic conversation partner. More aligned with our approach is Rapp et al. who center autistic experiences in their study of urban design [40]. As a result of taking autistic experience as the standard, their design recommendations are all aimed at making autistic lives easier rather than encouraging autistic people to live by neurotypical standards.

In this sense, we subscribe to a critical stance towards inclusive design, one that recognises the existence of an inherent conflict between designing for the widest possible audience on one side, and taking differences seriously on the other side [9]. In this paper, we use the term ‘inclusive design’ as a generic way of referencing approaches to design that pursue inclusivity, i.e. that seek to serve the needs of the widest possible audience irrespective of age and ability [9]. These include the UK-centric Inclusive Design, the US-centric Universal Design, and the European-centric Design for All [9, 29]. The origins of inclusive design can be traced to the mid 1990s, when design sought to challenge established conceptions of ageing, disability, and social inclusion [29]. There is therefore a close connection between disability narratives and inclusive design [30]. Accordingly, our position towards inclusive design is shaped by the neurodiversity movement [47], which rejects medicalised notions of autism as deficit, conceptualising it instead as a different cognitive style [50]. This emphasis on difference inspires our interest in designing a world that reflects and accommodates human diversity [29]. We view inclusive design not as the matching of a single artefact to the widest possible range of capabilities [29], but as a matter of overall justice and fairness across a category of artefacts (e.g. social media platforms) within a certain social context (e.g. autistic people) [9].

Inclusive design has been justified on legal grounds, on business and economic grounds, and on social grounds [29]. This work approaches inclusive design from a different angle, focusing instead on how inclusive design can spur innovation by challenging assumptions [29] about what constitutes appropriate and desirable social media interfaces.

### 3 METHODS

We took a participatory approach [21] where the design of all material, including consent forms and interview structure, was reviewed by autistic adults. In order to identify exactly how autistic users experience social media, we used “*discourse-oriented online ethnography*” [1] [2], an approach that combines the study of the users’ own accounts with observable patterns of online behavior. The use of semi-structured interviews at the end of the observation period, allowed us to: (1) understand specific instances of online behaviours through the inclusion of participant-specific examples, (2) provide space to autistic participants to talk as much or as little as they wanted in order to find what mattered to them, (3) be able to ask for expansion on answers and ensure all topics relevant to our study were covered in addition to topics that participants brought up.

#### 3.1 Participants

The recruitment of participants took place as part of a UK research council project focused on the experiences autistic adults have of online environments. In collaboration with Autistica, a UK autism charity, a total of 35 participants were recruited. We ensured the participant group was representative of a range of ages, genders, and social media use (see Table 1). Participants were selected based on having a professional diagnosis of autism or Asperger’s<sup>2</sup>, no history of intellectual disability, and experience of using Twitter and/or Facebook. These two platforms were selected as both allow for opportunities to connect with others directly [53], for example through Facebook groups, hashtags, and comments/replies, while also containing a need for a

<sup>2</sup> Asperger’s is no longer used as a separate diagnosis following DSM-V, however as participants may have been diagnosed earlier, Asperger’s was included in our recruitment criteria.

public-facing profile/persona, i.e. a Facebook profile and wall and a Twitter feed. All consent forms and recruitment procedures were reviewed by a panel of autistic people recruited through Autistica to ensure accessibility and the entire study was approved by the Queen Mary, University of London ethics board (ethics approval number: QMERC2020/58). One participant left the study prior to the interview stage. Therefore, this paper will discuss the findings of 34 interviews. Each participant was given a code to preserve anonymity. The participant codes consist of T/F/TF standing for Twitter and Facebook indicating their social media use, followed by a number in order of recruitment.

From a total of 34 participants, 16 identified as female, 12 identified as male, 4 identified as non-binary, 1 identified as assigned male at birth (AMAB), and 1 participant did not disclose their gender. None of our participants had complex support needs nor any history of intellectual disabilities<sup>3</sup>. All participants were proficient in technology use and were familiar with video-conferencing platforms and social media platforms. The average age was 43 (median age = 42.5). Most participants had a Twitter and a Facebook profile (n=26), 4 participants had a Facebook profile only, and 4 participants had a Twitter profile only. Frequency of social media use is based on self-reports at the time of recruitment with a choice of daily, weekly, and monthly or less.

### 3.2 Data collection

As part of the study, participants consented to the research team 'following' their engagements on social media for a 3-month period. For participants who used Twitter, this involved two researchers 'following' the participants and observing daily posts. Participant Twitter profiles were also scraped on a weekly basis. Participants who used Facebook were asked to download 3 months' worth of their Facebook posts retroactively from the date of recruitment. Downloaded files were then shared with the research team. The analysis of these posts was used to inform the interview questions including the inclusion of examples from participants' own social media use in the third part of the interview.

Following the observations, participants were invited for semi-structured interviews. As recruitment started in January 2021, we used online interviews to account for Covid-19 related restrictions. However, we found online interviews to contribute positively to our study as the lack of travel requirements meant we could recruit a geographically diverse group as well as people for whom travel would be particularly stressful due to sensory challenges. A choice was given to participants to conduct interviews via a videocalling platform of their choice (Zoom, Teams, Skype) or via email to accommodate autistic preference for non-verbal communication. Four interviews were conducted in writing over email, while the remaining 30 interviews were done via video call. For the written interviews, participants were given the interview questions via email and asked to return the questions once completed. The questions were the same as the questions asked in the spoken interviews with the exception of prompt questions that were used (where relevant) in spoken interviews. Participants were also able to leave their cameras off which some chose to do. Interviews lasted between 30 and 90 minutes in duration, with most interviews around 60 minutes. They were structured around three parts. (For full interview script, see Appendix A). Firstly, participants were asked about their general experience with social media, including how long they had been using Facebook and/or Twitter and whether their use had changed over time. Secondly, we asked participants about their everyday use of social media and their online environment, which included questions around their online networks (e.g. 'how would you describe your network?') and when, where, and how often they visit social media. Finally, the third part of the interview focused on the use of specific platform features, such as comments, hashtags, and emojis. In this part, we also

---

<sup>3</sup>Following preferences from the autistic community, we do not 'classify' autistic participants with terms such as 'high- or low-functioning' and instead focus on support needs [10]

Table 1. Overview of Participants' Demographics

Participant code	Gender identity	Age	Frequency of social media use
TF1	Male	61	Daily
TF2	Not disclosed	58	Daily
TF3	Male	29	Daily
TF4	AMAB	48	Daily
TF5	NB	49	Daily
TF6	NB	40	Daily
TF7	NB	44	Daily
TF8	Female	38	Daily
TF9	Female	30	Daily
TF10	Female	27	Weekly
TF11	Female	37	Weekly
TF12	Female	50	Weekly
TF13	Female	39	Weekly
TF14	Male	58	Weekly
TF15	Female	46	Monthly or less
TF16	Male	57	Monthly or less
TF18	Female	41	Daily
TF19	Female	30	Daily
TF20	Female	30	Daily
TF21	Male	37	Weekly
TF22	Female	26	Monthly or less
TF23	Female	45	Monthly or less
TF24	Male	28	Monthly or less
TF25	Female	41	Weekly
TF26	Male	27	Daily
TF27	Male	58	Daily
F1	NB	25	Weekly
F2	Female	48	Monthly or less
F3	Male	66	Monthly or less
F4	Male	44	Monthly or less
T2	Female	50	Daily
T3	Male	56	Monthly or less
T4	Female	56	Daily
T5	Male	39	Daily

introduced two examples of observed platform use for each participant and asked them to talk a bit more about their thought process behind a specific post or comment. This was not included for participants who did not post during the 3-month observation.

Interviews were recorded and transcribed. Written interviews were used as-is. This data was combined into a single corpus for analysis.



### 3.3 Data analysis

Following transcription, the interviews were coded using thematic analysis [12], with the text being segmented by paragraphs created by the (external) transcribers. To account for reliability, the coding took place in stages. First, an autistic researcher (author 1) read all interviews and identified and grouped common codes. These themes were then tested in the second stage through the double coding of one transcript by both the autistic researcher (author 1) and the project lead (author 4). Coding was then compared, and mismatches were discussed and resolved during a meeting. This was then followed by a second round of double coding, conducted by the same two team members.

Following the second round of coding, high agreement was found in each category (above 80%, with platform architecture as barrier the only lower category at 78%, using simple percentage agreement). Differences in coding were resolved in a meeting, and the final themes were decided as follows:

- (1) **Social Media compared to In-Person Interactions.** This theme contains discussions of differences between online and face-to-face communication, often including an evaluation of online communication. This was found in 26 (out of 34) interviews and had a total of 118 instances.
- (2)(a) **Social Media as Enabling.** This theme contains discussions of how the platform design aids in participation. This was found in 33 (out of 34) interviews and had a total of 379 instances.
- (b) **Social Media as Overwhelming.** This theme contains discussions of how the platform design hinders or restricts participation. This theme was identified in 33 (out of 34) interviews and had a total of 262 instances.
- (3) **Perceived Social Norms.** This theme contains discussions of perceived social norms, either perceived only, or perceived and enacted. It was identified in 33 (out of 34) interviews and had a total of 236 instances.
- (4) **Keeping Connected and Finding New Communities.** This theme contains discussions of using social media to connect with existing offline relations as well as new online groups around special interests or shared experiences. It was found in 34 (out of 34) interviews and had a total of 622 instances.
- (5) **Keeping Control through Systematic Practices.** This theme contains discussions of control over the platform design (i.e. chronological vs algorithmic newsfeed) and control over interactions in order to manage responses, avoid misunderstandings and conflict. It was found in all 34 interviews and had a total of 339 instances.
- (6) **Being Authentic.** This theme contains discussions of perceived social norms which are discarded by participants in favour of authentic (to themselves) behaviour, and discussions of using social media for personal interests. It was identified in all 34 interviews and had a total of 844 instances.

The final themes were then applied to all interview transcripts (including those used in the first round of coding) by the autistic researcher (author 1). The Findings section will provide an overview of the findings and discuss each theme individually.

## 4 FINDINGS

The six themes that were present in the data showed overlap based on perceptions and uses of social media by the participants. Firstly, participants talked about their everyday experiences of current social media platforms and the social realities of their use. These discussions were captured in the themes 'Social Media as Enabling/Overwhelming' and 'Social Media compared to In-Person Interactions'. Secondly, participants discussed their perceptions of neurotypical norms on social



media, and how this related to their own experiences. This is captured in the theme ‘Perceived Social Norms’. Thirdly, participants talked about how they enacted specific perceived affordances of social media sites and their individual purposes of using social media. This is captured in the themes ‘Keeping Connected and Finding New Communities’, ‘Keeping Control through Systematic Practices’, and ‘Being Authentic’.

Our analysis of the data highlights a connection between each theme and current social media design. The platform designs influence how participants use the platforms and how they perceive others to be using the platforms. The themes we present here are not mutually exclusive; instead each influences the other as the purpose of this paper is to provide insight into how autistic adults enact social media affordances and how this enactment could influence the current state of social media design in order to improve the accessibility and inclusivity of social media for autistic people.

#### 4.1 The value of social media compared to in-person interactions

Twenty-six out of 34 participants reflected on their use of social media by comparing it to face-to-face communication. From the 26, three participants preferred offline interactions, four felt they used social media for different purposes than they would do in-person interaction, four felt social media and offline interactions were of similar benefit, while 15 participants showed preference for online interactions, with some reporting social media boosted their confidence to express themselves:

I just found, whenever I was on social media, it just felt easier, like I felt more confident talking [...] it felt easier to express my opinion for instance [...] like I know I would say, “Is it okay if I speak up?” or I would be constantly asking for permission, even though I don’t need to. Whereas on social media I’m like, “I’m just going to jump in here and just type a wee comment.” (F1)

Others related their preference for interacting via social media to experiences of conflict, frustration, and feelings of being overwhelmed when interacting with people in-person: “*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*” (F1). The ability to ‘step away’ from interactions allowed participants to remove themselves from overwhelming situations, both due to interactions with other users as well as the platform design, which can after continuous exposure cause meltdowns. Participants appreciated the perceived ‘space’ that online interactions provided, both as it was felt to allow for easy breaks without judgment which allows autistic users to find a calm space and reduce overwhelm, and as it allows for time to process situations, when required: “*I don’t process speech well, and I have more time to think about what I say or reply when it is online*” (TF11). Participant F1 elaborated on this:

if I’m talking in person I feel like I over-talk or I don’t know how to get a word in. Whereas on typing, like I could just wait until, [...] I know most apps you can see when they’re typing. So, the moment I saw typing I’m like, “Right, I’m getting in there”. I feel like that’s way easier [...] that’s why I would say to someone, “Please text me, don’t call me”, because it’s so much easier. (F1)

Having the additional time and space allowed the participants to manage interactions with others in their preferred way while minimising the social judgment that may arise if they were to walk away from in-person interactions. Participant TF11 went on to say that she “*tend[s] to say less in everyday life*” as online interactions allow time for her to “*check*” her posts with friends before posting.

Participants also discussed how negative offline interactions influenced their interactional preferences when interacting with other people on social media. “*If I’m out in a physical place, I have to*

*gauge what someone's intention is when they go to talk to me, because it's not a given that everyone's going to be nice, and I don't always know that until it's too late*" (TF18). Several participants talked about negative reactions they have received in face-to-face communications, which, as we will show in more detail in section 4.5, translates into a desire for control of social interactions in order to avoid conflict or misunderstandings. Participants perceived that this control is more achievable in online communications, not in the least as it allows for users to disengage with interactions when they become overwhelming.

However, not all participants preferred online communication with a few noting that the lack of social cues online, e.g. body language, tone, can more easily lead to misunderstandings: *"I think sometimes I might come across as very blunt and you can't necessarily detect the tone in written language"* (TF20). The longer time between responses, while generally perceived as positive, may also contribute to this as it creates a longer period of uncertainty in regard to how a user's post or comment is being received. This suggests a need for options to clearly indicate tone. We will elaborate further on these tensions in the pros and cons of social media use for the participants in the following themes.

## 4.2 Social media as enabling yet overwhelming

Beyond the broader comparison to offline communications, participants went into detail on the design of the different social media platforms. This primarily covered Facebook and Twitter as those were the platforms our participants primarily used as part of our study, although participants also brought up other platforms including Instagram, Reddit, and LinkedIn. The architecture and design of a platform was found to be both facilitative and constraining. As shown in Table 2, participants more often described social media as enabling than overwhelming. Participants found social media particularly helpful in facilitating social interaction as it was felt to be a low-effort way of connecting. For example, certain platform features allow for pre-packaged communication such as Twitter Retweets: *"[Retweeting is] a way to very low value interaction, because essentially you're saying to the creator, I agree with this. It's like a like, but it's also letting your audience know a limited bit about you. [...] it's also a sort of way for me to bookmark something and save something [...] otherwise I don't tend to make original tweet content on Twitter"* (TF10). Retweeting was also seen as a way to *"succinctly express a commonly held opinion or truth"* (T4) and when participants wanted *"to post something but I don't feel I'm going to get my point across"* (F1). Some platforms support greater degrees of multimodal interaction, providing different options for autistic people to express themselves, such as searching for GIFs and including them in the content of posts:

GIFs are just an easier way to express maybe emotional context, which I think can be lost in text. So it's quick. They can be funny and I think they can convey something quicker and easier than just writing, and also if you write *"well done, you've done really well"*, it can come across as contrived I think, and so less so with GIFs. I find GIFs very useful to avoid confusion. (T5)

Participants also referred to a number of other pre-packaged interactions [15] that they felt allowed for low-effort participation. This includes *"prompted"* connections (TF15), where Facebook suggests friends which participant TF15 then friend requested, and polls: *"with a poll, I pretty much always will [respond] because it's just a click of the button, it's anonymous and it's fun, and I like seeing the results"* (TF19). These pre-packaged interactional means provide autistic users with low-effort ways to engage with others, which require less energy from the autistic user as an open-ended post or comment would require.

Similarly, participants found social media to provide a way of staying connected to others without active participation through comments or posts: *"I can vaguely see what other people are doing from*

*time to time so you still feel a bit involved in the world but without having to necessarily make much effort*" (F2). Prior research has also noted how passive use of social media is a common practice for autistic people [28] and mimics a form of autistic socialising through being in the presence of others without the pressure or requirement to actively interact ([4], p. 421; [27], p. 132). While this method of socialising appears specific to autistic adults, the importance of proximity without interaction has also been shown in other groups such as those managing depression [14], demonstrating the usefulness of this study beyond only autistic users.

While these features provided low-effort participation options, and participants on the whole had a preference for interactions online compared to in-person, the overall experience of social media platforms was generally disliked. The overall lay-out of different platforms was found to be overwhelming and disjointed by participants, and the reliance on algorithmic social and newsfeeds on most platforms was generally disliked. The social feeds on both Twitter and Facebook were found to be *"like [a] weirdly disjointed selection of information which was 'quite jarring'"* (TF10) and the reliance on algorithmic newsfeeds was seen as a loss of control over what participants could see or access which led in some cases to distress: *"No, I do not want you deciding what I see, I want to see it in order please. I was last on here 24 hours ago so I want to see what's been in the last 24 hours, you telling me something that happened in the middle of last week is no use to me!"* (TF2). As autistic people can struggle with sensory overload, and generally exhibit a preference for ordered routines [3], the common changes and updates to platforms as well as the seemingly disordered algorithmic newsfeeds lie in contrast to autistic preferences. We return to these issues in later themes where we discuss how participants attempt to regain control over their algorithmic social feeds.

### 4.3 Understanding online social norms

One of the major challenges with social media participants reported in interviews was being able to understand what is, and what is not, perceived to be appropriate ways to interact with others on social media. For instance, participant F1 made observations around how others used and appropriated emojis in order to shape their own emoji use: *"I have noticed in, if I look at comments that are like arguing there's no emojis, there's no, there is sometimes punctuation but there's no emojis whereas the lighter ones have emojis. So, I think that's where my brain has maybe thought, 'Oh, let's use emojis in the lighter ones and no emojis in the more serious ones.'" (F1). Fifteen participants discussed how they attempt to observe how others use social media and mimic that use to blend in, with one participant referring to social media as a *"mask"* (TF15). The conception of social media this way seems based on 'masking', when autistic people hide their autism in order to 'pass' as neurotypical. While masking is no way solely related to social norms, as it also includes behaviours like suppressing stimming, autistic researchers have found one part of masking to be the adaptation to neurotypical behaviours and social norms [33]. This practice was explicitly described as an attempt to follow *"rules"* or *"protocols"* by participants, where many of them perceived social media as comprising a rigid set of interactional norms that should be followed: *"I just tend to follow the protocol I've seen other people doing, and also to be mindful of the kind of rules as well"* (TF21). The way participants discussed social interactions was presented as a form of 'rules', 'protocol', or something that can be observed and copied. Social norms are generally established implicitly, whereas autistic people have a general preference for more explicit explanations [44]. This is demonstrated in how participants talked about expected behaviours as 'rules' rather than norms or preferences. TF8 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, or

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." So it's almost like you're trying to, I'm trying to fit in and join in and things by using this hashtag thing, whereas logically I see, I understand the use for it logically, but there's other things there I put a hashtag in front of something, or an @ symbol, and an @ symbol is obviously to try and find somebody, copy somebody in or mention somebody. But with the hashtag, sometimes I'll think, so I understand the rule of it, which is, or the idea is to try and capture a topic or a leading phrase or something, so that people will more easily find your tweets. But then I might put something in and find that hashtag doesn't exist, or it's not maybe got so many things associated with it. (TF8)

This participant compares social norms to a "foreign language" and social media norms as things that are not explicitly taught but picked up through observation and practice. She also differentiates between "logical" use, seemingly relating to the action that is accomplished through the use of @ or #, and some context-specific use that is less clear. This relates to a characteristic of autism that makes it difficult to detect implied meanings or social norms, which was also highlighted in participants' discussions of emojis as having underlying meanings that are understood by all neurotypicals: *"People send me all these emojis and I'm like I haven't got a clue what they mean"* (F2).

In their interview, participant TF8 continues to discuss the attempts that she makes to understand how hashtags are used and to use a hashtag in the same way, again highlighting the effort it can take for autistic people to interact in a neurotypically acceptable way. Other participants picked up on the potential for harmful interactions with others when they have not understood the implications of using certain features or language:

I think maybe especially for people with autism who maybe aren't quite as, shall we say, I know I'm not always so not that great at picking up maybe cues or cultural things. And I think because of the pace the internet moves, you can very easily be left behind and then, and then if you do a faux pas not everyone is that forgiving so, and it can really make you feel kind of lousy. (TF3)

Our data suggests that autistic adults have a clear understanding of the potential for harm on social media and an overt awareness that social media has interactional norms as face-to-face interactions do. However, there is also a perception that neurotypical users have a universal understanding of social media, most likely heavily influenced by offline experiences where many of our participants reported being chastised for not 'correctly' following social norms. This seems to impact interaction on social media, possibly leading to effortful, and excessively careful use in order to avoid misunderstandings and conflict.

#### 4.4 Keeping connected and finding new communities

Participants discussed the value they found in using social media to connect with others. Social media was valued for keeping in contact with existing friends and family. As discussed previously, participants particularly talked positively about the low-effort required to keep in contact with friends and family that social media provided:

I think I use all these things as very quick convenient ways to see what's going on with my friends and family, and in the things I'm interested in what's going on, has somebody discovered something new, has somebody found something new, got something new to talk about, and it's just a very quick and easy way to keep in touch. (TF27)

Perhaps more importantly however, participants felt that social media was especially valuable in enabling them to find new communities and social connections, in ways that they had always

struggled to do with offline relationships. Some participants recognised they had niche interests, and that they had struggled to find groups and peers within their social circles who had similar interests to themselves. Because of this, groups on Facebook and discussions around specific Twitter hashtags were seen to enabling them to find communities around clear topics of interest to them: *“It’s helpful in some ways, as I say, because I found groups related to my writing or to my son’s needs or to my needs and so in many ways it’s been helpful”* (F2). This was further elaborated by participant F1:

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 cos play I’ll go on to a cos play 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”. (F1)

Having a clearly delineated purpose to a group and its social interactions, aligns with autistic preferences for information-based interactions over small talk [4] [27]. This also highlights an autistic strength for openness and interest in learning about specific interest topics [4] as participants talked about the open access nature particularly of Twitter, allowing them to connect with people they would normally never interact with:

That’s the value of something like Twitter: the variety and the difference in people’s styles and mode of communication, that differs to mine. That’s where you get things that you might see or spot that you might have not thought of before or might get a different way of thinking that you didn’t consider, and that’s a huge benefit in itself. (TF26)

Aligning with discussions within the theme on the enabling yet overwhelming qualities of social media, participants discussed the slow reduction of these types of interactions as platforms moved to algorithmic feeds and showing users similar posts to their own. There was a clear lack of trust in the platforms to be able to accurately predict what autistic users wanted to see, potentially highlighting an algorithm geared towards neurotypical social media use. We discuss this further in the next theme.

#### 4.5 Keeping control through systematic practices

Aligning with the lack of trust in the algorithms, participants reported a range of practices they had established to regain control over the types of posts, content, and media that is shared in their news and social feeds. One participant made basic attempts to “manipulate” the algorithm:

I’m dependent on the algorithm of Facebook as to what it actually shows me day by day, but I don’t know how to manipulate the algorithm other than every now and again, just throwing in a search for something totally obscure, just to confuse the algorithm. (F3)

Other participants reported carefully enacted 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 [3]: *“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.”* (TF12). This was echoed by TF13: *“I go through the recent tab and I just*

*literally scroll through until I'm caught up, is what I do. [...] I'm not sure if it shows you every single thing, which is annoying. I'd rather just have every single thing and hide it if I don't want to see it because it's too much"* (TF13). Here TF13 demonstrates an attitude displayed by multiple participants regarding their preference for control over what they see on their newsfeed, and a common practice of carefully scrolling through the entire newsfeed until familiar posts appear. Similar uses described by participants were activities like checking every single notification, checking birthday lists on Facebook, and wishing each person 'happy birthday'. While not everyone checked their entire newsfeed, most participants did discuss their own individual routines that they followed when they used social media, illustrating almost systematic approaches of working through the various platforms to mitigate concerns around missing posts and content being hidden by algorithms.

Participants also appropriated certain social media features as ways to reassert control over their algorithmic feeds. One participant used the notifications system as a way to remain in control of Twitter content: *"I've set Twitter up so that it notifies me whether people I'm particularly interested in post. They pop up as notifications [...] the notifications are a select view of things I'm really interested in or people that I don't want to feel I'm severing the connection with"* (TF12). Ten participants used the blocking, muting, or hiding functions to keep Facebook content manageable:

I have made use of the hide function to make Facebook less overwhelming so you're not scrolling forever just seeing things you're not interested in in the slightest, or people that you didn't really know that well anyway that just happen to be in your tutor group or something. [...] I hide who I see to make it less overwhelming and just stick to the people I am actually interested in. (TF13)

This kind of appropriation, where people use features for purposes other than what was intended by the designers, demonstrates how sophisticated and imaginative autistic social media users are.

The second type of control was displayed in participants' desire to control social interactions, manifesting in discussions of preventing misunderstandings and avoiding conflicts. This is potentially rooted in autistic participants' offline experiences, as autistic people may often have experiences of being misunderstood or be 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"* (TF15). In order to avoid misunderstandings and avoid being drawn into larger, potentially overwhelming, conflicts, participants talked about the care and attention they put into writing posts and comments in order to ensure that the intention and tone is portrayed accurately:

Well, I think certainly when you're talking to a person [online], emojis help to convey the kind of tone that you're perhaps trying to say something, which has previously perhaps been difficult, or people might misread or misinterpret. So something like an emoji might help to indicate that you might not be saying something seriously or trying to criticise someone. Written messages are quite different to verbal communication, where you lack the tone of voice or facial expression to help aid what you're trying to say. (TF26)

As the quote demonstrates, while some participants discussed struggling with emojis in particular in regards to their social meanings (see section 4.3), eight participants talked about a reliance on emojis in order to *"clarify tone"* (TF10). Used emojis were often the 'simpler' facial expressions such as 😊, or shapes with standard meanings like a heart:

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”. (F1)

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 potential interpretations of their posts and experience anxiety around potential misunderstandings, while also grounding their expectations of misunderstandings in previous, offline, experiences.

#### 4.6 Being Authentic

Finally, participants discussed how they prefer to use social media in a way that is authentic to them, at times subverting social norms in favour of individual preferences. This included, for instance, posting for the sake of posting rather than expecting engagement, only commenting or engaging with posts they were genuinely interested in, and using platform features in a way that they felt was authentic to them. Participants also talked about creative ways in which they adapted platform features to their personal likings and personality. Participant T4 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”* (T4). Here this participant displays a logical reasoning behind the emoji use, as T4 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.

Additionally, participants talked about posts as a way of expressing themselves rather than invoking a response or creating an interaction. Participant TF10 drew a comparison between social media posts and artwork:

With everything that I put out I don’t expect or anticipate a response, and I’m certainly surprised sometimes when things pick up. [...] It’s like putting art up on your walls and having friends over, and instead of going, yeah, and asking them for response to it and what they think of it, you’re just inviting your friends over and might go, wow I love this painting up here on this wall, and you go, thanks I did it myself, and then you have a chat about it. It’s like that. You just put things out there and if it sticks, it sticks and that’s cool, but I don’t expect, especially with tagging people in memes. So I’ll always respond. If I get tagged in a meme I’ll always respond to it or at the very minimum I’ll do an emoji react to it, but I don’t necessarily have the anticipation that people always will, because I know that people use social media in different ways. [...] But people have a different way of using social media, don’t they, so I don’t really expect, yeah, I’ve no expectations, which sounds really depressing but it’s not. It’s just I don’t care. It’s like [inaudible] apathy, if that makes sense. (TF10)

As demonstrated in the example, participants talked about using social media for their own, individual purposes, with social interaction as a positive extra. Profiles or homefeeds are a way of sharing personal interests, but not to invite or expect responses, rather as a way of self-presentation.

## 5 DISCUSSION

Our findings support previous research that found social media to be a valuable tool for meeting new people and finding ‘safe’ spaces around mutual interests [13, 15, 25, 32]. However, our study sheds more light on how autistic adults view Twitter and Facebook from their perspective, as opposed to the immediate assignment of social media as an interactional space. While social interaction was still a much-discussed topic, participants also talked about the use of social media



for non-interactive purposes including using their profile as a photo album or diary that happens to be public.

Participants generally preferred social media over in-person interactions, as online communication allows for less sensory stimulation (see also [15]) as well as more control over when to engage. However, while the social interaction side of social media was preferred over in-person socialising, the algorithm and general design of platforms were described as overwhelming. The constantly updating newsfeed on both Twitter and Facebook created additional stress, in particular the algorithmic newsfeed that both Twitter and Facebook now use as standard was described as confusing. The existing features that allow users to change the newsfeed to their preferences, e.g. by setting it to chronological, were found to be useful by participants but they also resorted to their own approaches including one participant who described trying to “confuse” (F3) the algorithm in order to regain some control over their newsfeed. These findings demonstrate that social media research in regards to autistic users needs to go beyond a focus on social interaction and include consideration of the websites themselves. Our recommendations in the following section aim to be some of the first to address these particular issues.

This desire for control was also found in social interactions online. Participants discussed finding (neurotypical) social norms difficult to understand, similarly to offline interactions [18]. Participants developed strategies to deal with this including mimicking other users, and retreating from groups all together. Burke et al. already demonstrated these issues [15], highlighting the lack of trust in online interactions as well as high potential for misunderstandings through a lack of additional cues. Participants again developed strategies including the use of emojis, relying on the text-image connection to develop meaning [51]. Our design recommendations build on these strategies already developed by autistic users in order to create platforms that are in line with autistic preferences.

Following a general trend in autism research [35], HCI and CSCW scholarship has mostly focused on autistic children and adolescents [46]. Research that has focused on autistic adults has found that with increasing difficulties such as mobility issues, social media becomes increasingly important for keeping social connections alive [8]. As a result, not many design-oriented studies exist about social media and autistic adults. Within these, those of Burke et al. [15] and Page et al. [38] include design recommendations. Burke et al. suggest the use of information visualisation to represent how individual behaviour (e.g. messaging frequency, number of posts) compares “*against a descriptive norm*” [15, p. 432]; and the provision of “*trust metrics for potential friends*” [15, p. 432]. Page et al. recommend removing ambiguity and being explicit (e.g. in the naming of features); providing real time and well structured social guidance; and designing for safety [38]. In addition, in their study about video conferencing use by autistic adults, Zolyomi et al. provide general design directions targeted at all computer-mediated communication [55]. They recommend bolstering attention by limiting distractions; supporting translation and interpretation of social and emotional cues; and providing conversational assistance. In all cases, the authors highlight how many of their recommendations would also benefit non-autistic social media users. The emphasis here is on “resonant design” [39], i.e. on identifying how the needs of autistic and non-autistic people overlap so that social media interfaces can address the widest possible audience [9]. Our design recommendations are perhaps less concerned with resonance between autistic and non-autistic social media use, relying instead on flexibility, choice, and customisation as strategies for inclusive design [9]. We recognise that some of the design considerations we outline in the next section may contribute little to neurotypical social media use. We argue that such design considerations are desirable nonetheless, since they will result in social media systems that acknowledge and accommodate human difference.

## 6 DESIGN CONSIDERATIONS

Our findings reveal how existing social media platforms are found to be very valuable to our autistic participants. However, these platforms are also generally designed to suit neurotypical sensibilities and communication styles, making autistic users solely responsible for navigating their difference. Social media designers could take inspiration from interaction theory approaches [23], which distribute responsibility for successful communication across all participants, both neurotypical and autistic. This perspective would entail inviting neurotypical users to discover and engage with autistic people on their own terms. Autistic people, on the other hand, should be provided with ways to express their efforts, frustrations, and struggles, as well as to enact forms of use and interaction styles that feel authentic to them.

It is the ultimate goal of this paper to encourage and support researchers and designers of social media platforms to become more receptive to autistic sensibilities. Based on the perspectives and experiences of our participants, we introduce a set of design concerns and action areas for social media platforms that wish to become more inclusive of autistic adults. These include expanding low-effort participation features, providing increased control over algorithmic content, supporting expression of intent and tone, aiding discovery of interactional norms and reinforcing interest-based sociality. We discuss these in the following sections.

### 6.1 Expanding low-effort participation features

Well-defined, low-effort communication features and social interactions [15] such as ‘likes’ and ‘reactions’ were well received by our autistic participants. The appeal of these pre-packaged interactions is justified, in light of the extraordinary effort our participants invested in crafting their user-generated content in an attempt to avoid misunderstandings and conflict. Back in 2010, Burke et al. listed ‘likes’; and birthday reminders as examples of pre-packaged social interactions [15]. Our participants also mentioned polls, the expanded pool of Facebook reactions, the ability to share other people’s posts (e.g. via retweets), tagging people, and automated posting.

The benefits of these pre-packaged interactions for autistic social media users should encourage platforms to continue experimenting and adding such features. For instance, one of our participants mentioned having “*a series of standardised responses*” (T4) they would reuse as part of their autism advocacy via social media. Platforms could enable this practice by providing a personalised space to save pre-written user-generated content for reuse, and by offering standardised textual responses similar to the ones currently available through some email clients.

### 6.2 Increased control over algorithmic content

Our participants described the problems derived from algorithmic content feeds. These interfere with their carefully crafted usage routines and serve content of dubious relevance. In addition, they do not take into account autistic preferences for limited amounts of content to manage sensory overload, as well as for finite feeds, i.e. streams of content one can reach the end of, rather than scroll infinitely.

Autistic social media users would benefit from a higher degree of control over the content served to them by social media platforms. This control should cover the amount of content, the nature and format of the content (textual, visual, auditory), the content sources (e.g. direct contacts vs. strangers), and particularly the rules governing ordering and delivery.

Platforms could consider the provision of different content selection and ordering options, expanded filters, the ability to create fine-grained rules, and the possibility of configuring different feed versions one can easily switch between. Such features would empower autistic users to enact

their preferred use routines and rules, including limiting the amount of content in feeds to suit their sensory needs.

### 6.3 Supporting the expression of intent and tone

Our participants crafted their social media interactions with great attention and care in order to prevent misunderstandings and confrontation. This concern is potentially rooted in autistic participants' negative offline social experiences. Ensuring that intention and tone are conveyed accurately was therefore crucial for our autistic participants when using social media.

More could be done to aid the expression of intent and tone in social media platforms. Support for this task is currently provided mostly through emojis and, to a lesser extent, through animated GIFs. However, as observed in the Findings section, emojis are a contentious feature between autistic adults. Although some of our participants used them extensively and creatively, others experienced difficulties with them. Emojis over-reliance on facial expressions made them hard to interpret for autistic people. Their standard or default meaning remains hidden in most platforms, forcing users to figure out how to use them by themselves through observation, trial and error, or collaboration with trusted others. Social media platforms could enable customisation of existing emoji collections to support self-expression and authentic self-presentation. They could also experiment with alternative visual representations of emotion, tone, and intent. For instance, Zolyomi et al. described suggestions from autistic Twitter users such as 'a side-eye' button, to indicate that one is choosing not to respond to a tweet they have seen; and 'a joke button', to clearly identify sarcasm and humour [56].

### 6.4 Aiding discovery of interactional norms

One of the major challenges experienced by our participants was the discovery and enacting of what they perceived as interactional rules or protocols, i.e. what is and what is not appropriate when engaging with others through social media. In existing social media platforms, it falls to autistic people to uncover the unwritten rules that govern interactions. Our participants received no help with this task and were left to their own devices while attempting to make sense of these norms. The strategies deployed included observation, mimicking, and trial and error. These approaches, however, generated significant anxiety, and several participants reported negative experiences and responses connected to not following the implied rules.

Platforms should support the discovery and enacting of social media practices and interactional norms underpinning the 'neurotypically acceptable way' of using social media. Although autistic people should not have to conform to neurotypical norms, having the choice and being better able to do so may be useful, given the stigma that still surrounds autism, and the lack of acceptance of autistic norms by the general public.

Even if these neurotypically acceptable ways do not strictly exist or are fluid, some explicit articulation of a standard or default would provide autistic users with a starting point for experimentation, and a safety net when clashing with others over their style or approach to social media use. Explanations of interactional norms should be displayed through consistent design patterns, so that they can be easily found for any new features and interface elements.

### 6.5 Reinforcing interest-based sociality

One of the main strengths of social media identified by autistic participants was the ability to connect with others through shared interests, and to form communities around clear topics. Social media engagement with a clear purpose aligns with autistic preferences for information-based interactions. Several participants in our study took advantage of this affordance, creating and moderating their own social media groups. The importance of this special interest-based approach to sociality has also been highlighted by prior research [38].

Features like groups and hashtags currently provide a space for communities of interest to come together. However, discovering others who share one's interests, experiences, and hobbies remains difficult. Platforms building networks through individual identities and common personal connections should consider surfacing interest-based information and providing ways of finding others based on shared interests.

## 7 CONCLUSIONS

While there has been more recent attention to the experiences of autistic adults, they still constitute an under-researched group of users, in particular considering the lack of research that does not draw on proxy participants like parents of autistic people or support workers. By drawing on the analysis of 34 semi-structured interviews, we showed not only how autistic participants use and experience social media and what their preferences are, but also that autistic adults have clear and useful insights into social media platforms that can lead to improved experiences for all users.

The perspectives of our autistic participants can be separated into six themes. Firstly, participants talked about their everyday experiences of current social media platforms and the social realities of their use in the themes 'social media compared to in-person interactions' and 'social media as enabling and/or overwhelming'. Secondly, participants discussed their perceptions of neurotypical norms on social media in the theme 'perceived social norms'. Thirdly, participants talked about how they enacted specific perceived affordances of social media sites and their individual purposes of using social media in the themes 'keeping connected and finding new communities', 'keeping control through systematic practices', and 'being authentic'. While platforms provide low-stakes, low-effort opportunities to interact through for example likes, as well as means of passive socialising, often preferred by autistic people, it can also be constraining to have a limit on posts and comments as on Twitter, and the amount of information present on newsfeeds both on Facebook and Twitter can be overwhelming for autistic users. The lack of control over what is shown was generally perceived negatively by all participants. In the second theme, we showed how autistic participants perceive social norms on platforms. Participants discussed that they can struggle with implicit social norms, or 'rules' as they often referred to them, which leads to some participants avoiding specific groups completely. In the third theme, we see how these perceptions and observations of both platform design and uses are mitigated by participants with current affordances and what preferences they have for additional features. Participants discussed using social media to stay connected with offline relationships and connect with interest-based groups. There was a clear preference for control both in terms of the platform itself, e.g. newsfeed content, and interactions with other users to avoid conflict and misunderstandings. The final code 'being authentic' demonstrated that if participants did not feel comfortable or could not identify clear behavioural norms, some would disengage. This demonstrates the necessity for adaptations to platforms to increase inclusivity as autistic people may rely on social media for connections [32].

We therefore suggest that platforms should take inspiration from interaction theory [23] approaches and acknowledge the responsibility of neurotypical people and interfaces in ensuring successful communication with autistic counterparts. We recommend that social media designers continue adding pre-packaged communication options, increase user control over algorithmic content, better support expressions of intent and tone, make explicit platform interactional norms, and enhance interest-based sociality. These recommendations will increase the possibilities for participation and lower sensory and social overwhelm for autistic users. In addition, these improvements could benefit other neurodiverse and neurotypical users and improve inclusivity on a broader basis beyond solely autistic users.

## ACKNOWLEDGMENTS

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

## REFERENCES

- [1] Jannis Androutsopoulos. 2008. Potentials and Limitations of Discourse-Centred Online Ethnography. *Language@Internet* 5, 8 (2008). <http://nbn-resolving.de/urn:nbn:de:0009-7-16100>
- [2] Jannis Androutsopoulos. 2014. Moments of sharing: Entextualization and linguistic repertoires in social networking. *Journal of Pragmatics* 73 (2014), 4–18. <https://doi.org/10.1016/j.pragma.2014.07.013>
- [3] M.E. Anzalone and G.G. Williamson. 2000. Sensory processing and motor performance in autism spectrum disorders. In *Autism spectrum disorders: A transactional developmental perspective*, B. Prizant and A. Wetherby (Eds.). Paul H. Brooks Publishing Company, Baltimore, 143–166.
- [4] Nancy Bagatell. 2007. Orchestrating voices: autism, identity and the power of discourse. *Disability & Society* 22, 4 (2007), 413–426. <https://doi.org/10.1080/09687590701337967>
- [5] 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>
- [6] Simon Baron-Cohen. 2001. Theory of Mind in normal development and autism. *Prisme* 34 (2001), 174–183.
- [7] 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* (Hamburg, Germany) (CHI '23). ACM New York, NY, USA, Hamburg, Germany. <https://doi.org/10.1145/3544548.3580673>
- [8] Caroline Bell, Cara Fausset, Sarah Farmer, Julie Nguyen, Linda Harley, and W. Bradley Fain. 2023. Examining social media use among older adults. In *Proceedings of the 24th ACM Conference on Hypertext and Social Media (HT '13)*. ACM New York, NY, USA, 158–163. <https://doi.org/10.1145/2481492.2481509>
- [9] Matteo Bianchin and Ann Heylighen. 2018. Just design. *Design Studies* 54 (2018). <https://doi.org/10.1016/j.destud.2017.10.001>
- [10] 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>
- [11] LouAnne E. Boyd, Alejandro Rangel, Helen Tomimbang, Andrea Conejo-Toledo, Kanika Patel, Monica Tentori, and Gillian R. Hayes. 2016. SayWAT: Augmenting Face-to-Face Conversations for Adults with Autism. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (San Jose, California, USA) (CHI '16). Association for Computing Machinery, New York, NY, USA, 4872–4883. <https://doi.org/10.1145/2858036.2858215>
- [12] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- [13] Charlotte Brownlow, Hanna Bertilsdotter Rosqvist, and Lindsay O'Dell. 2015. Exploring the potential for social networking among people with autism: Challenging dominant ideas of 'friendship'. *Scandinavian Journal of Disability Research* 17, 2 (2015), 188–193. <https://doi.org/10.1080/15017419.2013.859174>
- [14] Eleanor R. Burgess, Kathryn E. Ringland, Jennifer Nicholas, Ashley A. Knapp, Jordan Eschler, David C. Mohr, and Madhu C. Reddy. 2019. "I Think People Are Powerful": The Sociality of Individuals Managing Depression. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW, Article 41 (nov 2019), 29 pages. <https://doi.org/10.1145/3359143>
- [15] 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* (Savannah, Georgia, USA) (CSCW '10). Association for Computing Machinery, New York, NY, USA, 425–434. <https://doi.org/10.1145/1718918.1718991>
- [16] Julia Cook, Laura Crane, Laura Bourne, Laura Hull, and William Mandy. 2021. Camouflaging in an everyday social context: An interpersonal recall study. *Autism* 25, 5 (2021), 1444–1456. <https://doi.org/10.1177/1362361321992641>
- [17] Rafael F. Cordeiro, Williby S. Ferreira, Yuska P. C. Aguiar, Juliana A. G. Saraiva, Carole Tardif, and Edith Galy. 2018. The Brazilian Challenge to Accessibility and Digital Inclusion for People With Autistic Spectrum Disorders. In *Proceedings of the 17th Brazilian Symposium on Human Factors in Computing Systems* (Belém, Brazil) (IHC 2018). Association for Computing Machinery, New York, NY, USA, Article 37, 9 pages. <https://doi.org/10.1145/3274192.3274229>
- [18] Catherine J Crompton, Sonny Hallett, Danielle Ropar, Emma Flynn, and Sue Fletcher-Watson. 2020. 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with



- autistic and neurotypical friends and family. *Autism* 24, 6 (2020), 1438–1448. <https://doi.org/10.1177/1362361320908976>
- [19] Nicole B Ellison and danah boyd. 2013. Sociality through social network sites. In *The Oxford Handbook of Internet Studies*, William H. Dutton (Ed.). Oxford University Press, Oxford, 151–172. <https://doi.org/10.1093/oxfordhb/9780199589074.013.0008>
- [20] Nicole B. Ellison and Jessica Vitak. 2015. Social network site affordances and their relationship to social capital processes. In *The Handbook of the Psychology of Communication Technology*, S. Shyam Sundar (Ed.). John Wiley & Sons, Ltd, Chapter 9, 203–227. <https://doi.org/10.1002/9781118426456.ch9>
- [21] Sue Fletcher-Watson, Jon Adams, Kabie Brook, Tony Charman, Laura Crane, James Cusack, Susan Leekam, Damian Milton, Jeremy R Parr, and Elizabeth Pellicano. 2019. Making the future together: Shaping autism research through meaningful participation. *Autism* 23, 4 (2019), 943–953. <https://doi.org/10.1177/1362361318786721>
- [22] Elliot Fox, Shane Baden, Justin Greene, Nick Ziegler, and Moushumi Sharmin. 2019. Connection: Assisting Neurodiverse Individuals in Forming Lasting Relationships Through a Digital Medium. In *Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility* (Pittsburgh, PA, USA) (ASSETS '19). Association for Computing Machinery, New York, NY, USA, 633–635. <https://doi.org/10.1145/3308561.3354641>
- [23] Shaun Gallagher. 2004. Understanding interpersonal problems in autism: Interaction theory as an alternative to theory of mind. *Philosophy, Psychiatry, & Psychology* 11, 3 (2004), 199–217. <https://doi.org/10.1353/ppp.2004.0063>
- [24] Alexandra Georgakopoulou. 2016. ‘Friendly’ comments: Interactional displays of alignment on Facebook and YouTube. In *Social Media Discourse, (Dis)identifications and Diversities*, Elina Westinen Sirpa Leppanen and Samu Kytola (Eds.). Routledge, New York, 189–218. <https://doi.org/10.4324/9781315624822>
- [25] 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 (12 2014), 456–469. <https://doi.org/10.1352/1934-9556-52.6.456>
- [26] 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>
- [27] Cara Ryan Idriss. 2021. Invisible Autistic Infrastructure: Ethnographic Reflections on an Autistic Community. *Medical Anthropology* 40, 2 (2021), 129–140. <https://doi.org/10.1080/01459740.2020.1849185>
- [28] Alicja Jedrzejewska and Jessica Dewey. 2022. Camouflaging in autistic and non-autistic adolescents in the modern context of social media. *Journal of Autism and Developmental Disorders* 52, 2 (2022), 630–646. <https://doi.org/10.1007/s10803-021-04953-6>
- [29] P. John Clarkson and Roger Coleman. 2015. History of Inclusive Design in the UK. *Applied Ergonomics* 46 (2015), 235–247. <https://doi.org/10.1016/j.apergo.2013.03.002>
- [30] Luka Kille-Speckter and Farnaz Nickpour. 2022. The evolution of inclusive design: A first timeline review of narratives and milestones of design for disability. In *DRS Biennial Conference Series*. Bilbao. <https://doi.org/10.21606/drs.2022.690>
- [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] 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>
- [33] Danielle Miller, Jon Rees, and Amy Pearson. 2021. “Masking Is Life”: Experiences of Masking in Autistic and Nonautistic Adults. *Autism in Adulthood* 3, 4 (2021), 330–338. <https://doi.org/10.1089/aut.2020.0083>
- [34] 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>
- [35] Clodagh M Murphy, C Ellie Wilson, Dene M Robertson, Christine Ecker, Eileen M Daly, Neil Hammond, Anastasios Galanopoulos, Iulia Dud, Declan G Murphy, and Grainne M McAlonan. 2016. Autism spectrum disorder in adults: diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment* 12 (2016), 1669–1686. <https://doi.org/10.2147/NDT.S65455>
- [36] Elinor Ochs and Olga Solomon. 2004. Introduction: Discourse and Autism. *Discourse Studies* 6, 2 (2004), 139–146. <https://doi.org/10.1177/1461445604041763>
- [37] Michelle O’Reilly, Jessica Nina Lester, and Tom Muskett. 2016. Discourse/Conversation Analysis and Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 46, 2 (2016), 355–359. <https://doi.org/10.1007/s10803-015-2665-5>
- [38] 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 *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems* (New Orleans, LA, USA) (CHI ’22). Association for Computing Machinery, New York, NY, USA, Article 144, 21 pages. <https://doi.org/10.1145/3491102.3517596>

- [39] Graham Pullin and Alan Newell. 2007. Focussing on Extra-Ordinary Users. In *Universal Access in Human Computer Interaction. Coping with Diversity (Lecture Notes in Computer Science)*, Constantine Stephanidis (Ed.). Springer, Berlin, Heidelberg, 253–262. [https://doi.org/10.1007/978-3-540-73279-2\\_29](https://doi.org/10.1007/978-3-540-73279-2_29)
- [40] Amon Rapp, Federica Cena, Romina Castaldo, Roberto Keller, and Maurizio Tirassa. 2018. Designing technology for spatial needs: Routines, control and social competences of people with autism. *International Journal of Human-Computer Studies* 120 (2018), 49–65. <https://doi.org/10.1016/j.ijhcs.2018.07.005>
- [41] Kathryn E. Ringland, Christine T. Wolf, Heather Faucett, Lynn Dombrowski, and Gillian R. Hayes. 2016. "Will I Always Be Not Social?": Re-Conceptualizing Sociality in the Context of a Minecraft Community for Autism. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (San Jose, California, USA) (CHI '16). Association for Computing Machinery, New York, NY, USA, 1256–1269. <https://doi.org/10.1145/2858036.2858038>
- [42] Emanuel A. Schegloff. 1987. Analyzing Single Episodes of Interaction: An Exercise in Conversation Analysis. *Social Psychology Quarterly* 50, 2 (1987), 101–114. <https://doi.org/10.2307/2786745>
- [43] Emanuel A. Schegloff. 1990. On the organization of sequences as a source of "coherence" in talk-in-interaction. In *Conversational Organization and its Development*, Bruce Dorval (Ed.). Ablex, Norwood, NJ, 51–77.
- [44] David Nathaniel Shope. 2021. *Autism, Allocentrism and the Moral Significance of Manners*. Ph. D. Dissertation. University of California, Riverside. <https://www.proquest.com/docview/2597518171> Order No. 28717750.
- [45] Will Simm, Maria Angela Ferrario, Adrian Gradinar, Marcia Tavares Smith, Stephen Forshaw, Ian Smith, and Jon Whittle. 2016. Anxiety and Autism: Towards Personalized Digital Health (CHI '16). Association for Computing Machinery, New York, NY, USA, 1270–1281. <https://doi.org/10.1145/2858036.2858259>
- [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, New York, NY, USA, 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] National Autistic Society. 2021. What is autism. Retrieved January 27, 2021 from <https://www.autism.org.uk/advice-and-guidance/what-is-autism>
- [49] Olga Solomon. 2004. Narrative introductions: discourse competence of children with autistic spectrum disorders. *Discourse Studies* 6, 2 (2004), 253–276. <https://doi.org/10.1177/1461445604041770>
- [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). <https://doi.org/10.1145/3344919>
- [51] Peter Wikstrom. 2019. Acting out on Twitter: Affordances for animating reported speech in written computer-mediated communication. *Text & Talk* 39, 1 (2019), 121–145. <https://doi.org/10.1515/text-2018-2021>
- [52] Michele Zappavigna. 2011. Ambient affiliation: A linguistic perspective on Twitter. *New Media & Society* 13, 5 (2011), 788–806. <https://doi.org/10.1177/1461444810385097>
- [53] Michele Zappavigna. 2012. *Discourse of Twitter and Social Media, How We Use Language to Create Affiliation on the Web*. Bloomsbury Publishing.
- [54] Michele Zappavigna and J.R. Martin. 2018. #Communing affiliation: Social tagging as a resource for aligning around values in social media. *Discourse, Context & Media* 22 (2018), 4–12. <https://doi.org/10.1016/j.dcm.2017.08.001> Discourse of Social Tagging.
- [55] Annuska Zolyomi, Andrew Begel, Jennifer Frances Waldern, John Tang, Michael Barnett, Edward Cutrell, Daniel McDuff, Sean Andrist, and Meredith Ringel Morris. 2019. Managing Stress: The Needs of Autistic Adults in Video Calling. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW, Article 134 (nov 2019), 29 pages. <https://doi.org/10.1145/3359236>
- [56] Annuska Zolyomi, Ridley Jones, and Tomer Kaftan. 2020. #ActuallyAutistic Sense-Making on Twitter. In *Proceedings of the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20)*. Association for Computing Machinery, New York, NY, USA. <https://doi.org/10.1145/3373625.3418001>

## A INTERVIEW SCRIPT

*Irrelevant questions to individual participants were excluded based on our observation of their social media activity, for example no questions about Twitter if the participant had no Twitter profile.*

### Section 1 (past and present). 15 min



I would like to ask you some questions about your life and use of the Internet in the past few years. We are interested in anything you would like to share about yourself.

- Can you introduce yourself? Prompts: And then what happened? What did you do after that? How did you feel about that?
- How come you started using the platform (Twitter or Facebook)?
- Is your experience of using the social media platform to connect with your social circles different from using other technology (such as autism support websites or using WhatsApp with friends)? If so, how?
- If you use both Twitter and Facebook, do you use these platforms for different activities/purposes?

## **Section 2 Everyday use of online networking and the environment. Time 20 min**

- How do you use Facebook/Twitter and where? Prompts: do you usually use it in home setting out a specific time for browsing/posting or are you a more 'on the go' person, accessing the site periodically throughout the day, via a smartphone, for example?
- How would you describe the role of online networking in your life? Prompts: e.g. some people find that social media helps them to present themselves in a particular way professionally or with friends
- Do you participate in Facebook groups or hashtag-driven discussions on Twitter? Or do you mostly read and observe the content without posting?
- How do you decide when and where to post (e.g. to post a status update or a comment in a Facebook Group? Could you give examples?
- Do you feel the use of the Internet and Facebook/Twitter has been a positive experience or have there been any experiences you are not happy about? Can you elaborate?
- What would you describe as the main benefits or disadvantages of using online social networking by autistic adults? Are there any reasons for or against longterm use?
- (if the participant is a long term user) Do you think the way you use (and feel about) online networking has changed since you first registered on the site? How?

## **Section 3 Using specific platform features Time 15-20 min**

I'd like to talk a bit more about your ways of using the Facebook/Twitter platform. You can share your screen if you wanted to show me which pages/groups/features you usually access/contribute to, or talk me through any other relevant content. I also have copies of some of your posts (downloaded during the observation phase of the study) which I had shared with you before the interview. I would like to use some of these posts now to facilitate our discussion.

- Can you tell me a bit more about your experiences of using Facebook/Twitter specific feature such as posting in specific pages/groups, and/or using hashtags to contribute to specific discussions?
- Facebook/Twitter is said to be about 'social networking'. How would you describe your 'network'? Prompt: what are the main components or who are the main actors? (You can show me these on the site if you wish).
- In social media it is often difficult to understand or foresee who will read and engage with your message. Have you experienced this?
- Do you have a particular audience in mind when you write a post? Prompt: do you imagine particular people will read your post?
- (If the participant uses platform specific means of address) How do you decide when to use tagging, mentioning name, using @ ?

- (If the participant uses retweets) Why do you retweet and/or use 'Quote Tweets' (and/or 'share' on Facebook)?
- When looking at your online activity I could see that you use language as well as images or videos in your posts: in this example (looking at example shared on screen), why did you decide to use this image/this combination of language and image? (Or: why did you decide to add this emoticon/emoji/punctuation – what does it help you to convey?)
- If you could change anything about the site's features or about online networking in general, what would it be?

Many thanks for your time and your participation! Do you have any questions?

Received July 2022; revised January 2023; accepted March 2023