Autism in Affinity Spaces: Project Report

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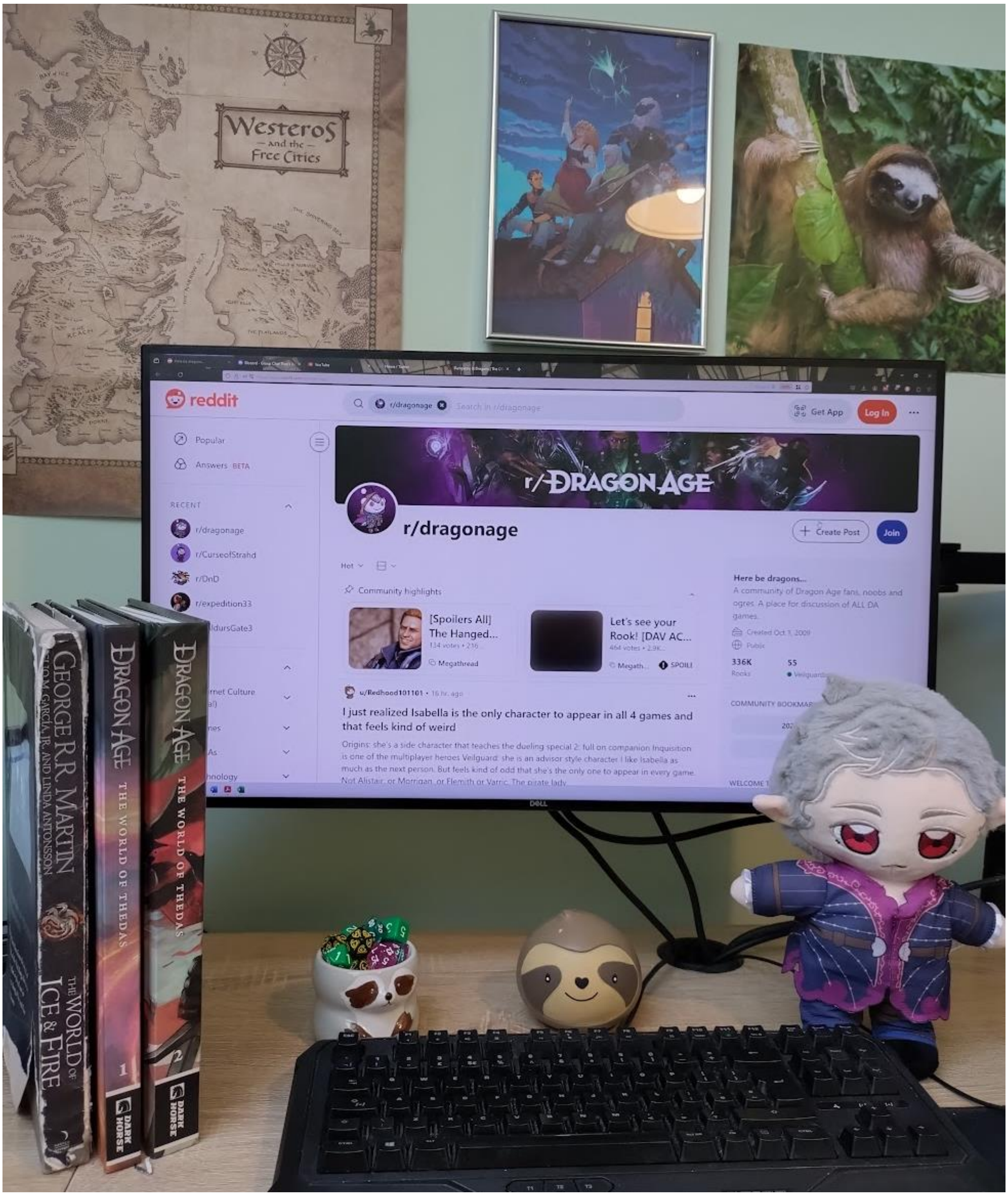

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Acknowledgements

First of all, we would like to thank all of our study participants for generously sharing their insights and knowledge with us. We would also like to thank the members of our lay and scientific advisory boards for helping to shape the project. We are grateful to the Wellcome Trust for funding the project (grant number: 225185/Z/22/Z).

1. Introduction

The ‘Autism in Affinity Spaces’ project aims to explore how autistic young people participate in interest-driven spaces on social networking sites. These interest-driven spaces are also known as ‘affinity spaces.’

So far, research has mostly focused on providing ‘social skills’ training to help autistic young people join these kinds of groups. In contrast, we argue that we need to **improve the environment** so that these groups are more welcoming and accessible to autistic young people. Second, we need to **understand young people’s strengths** rather than deficits.

Therefore, our project is guided by the following question: **how and why young do autistic people join social media to post about their focused interests? And how can we make their experiences better?**

To answer this question, the project has four main aims:

1. Understand how autistic young people interact within online affinity spaces
2. Examine how autistic young people use language and other forms of communication (e.g., emojis, GIFs) within affinity spaces
3. Develop innovative creative methods to capture young people’s experiences
4. Affirm autistic neurodiversity and support autistic people’s communicative strengths

As a result of our research, we hope to create more **inclusive and accessible affinity spaces** on social media. For example, we aim to produce **guidance and support** for moderators or designers of online affinity spaces used in education and by community and charitable organizations.

2. Project Meetings

In this section, we will introduce our lay and scientific advisory boards and describe the meetings we have had with the two boards. We explain what we discussed at these meetings and what we did as a result.

2.1. Lay Advisory Board

Our lay advisory board meeting comprises four autistic young people, recruited through the National Autistic Society. To date, we have had four meetings with our lay advisory board.

In our first meeting (October 2023), the research team and the lay advisory board made introductions by discussing our favourite hobbies and interests, as well as the social media platforms we use to engage with them. The research team then provided an overview of the project and co-produced research.

Our second meeting was held in November 2023. With this meeting, we aimed to 1) improve the accessibility of our information sheets and consent forms and 2) share ideas for the survey. Following the meeting, the research team adapted the information sheets to use clearer language and clarify important details. We also changed the wording of potentially ambiguous survey questions and adopted some of the board's suggestions for survey options.

Next, we held an in-person meeting at Queen Mary campus in June 2024 in order to discuss our preliminary survey findings and the subsequent interview and 'captioned images' phases of the study. We shared ideas on how to build rapport with participants and brainstormed potential questions to add to the existing interview schedule. Moreover, based on feedback from the board, the research team later created a video to accompany the captioned images information sheet, as this could help to explain the specific procedures.

Finally, in our most recent meeting (January 2025), we shared our qualitative survey analysis and asked 1) which findings resonated the most with the advisory board and 2) what the key messages of the project should be. Based on this discussion, we agreed that the project should raise awareness of masking and implicit forms of discrimination on social media, especially its impact on women and girls. Furthermore, the board highlighted the importance of using research to raise awareness of autistic differences and sensory needs, so that the burden does not fall autistic people to request accommodations.

2.2. Scientific Advisory Board

Our scientific advisory board consists of representatives from leading autism charities (National Autistic Society, Autistic Girls Network, Ambitious About Autism, Living Autism) and academics from across the UK working within the disciplines of linguistics, psychology, and education studies.

Our first board meeting was held in person at Queen Mary campus in September 2024. In our meeting, we started by providing an overview of the project including our aims, research questions, and methodology. Following this, we discussed some of our quantitative and qualitative survey findings with the group.

We appreciated the open and thoughtful discussion from both academic and practitioner perspectives, which contributed to shaping the next steps of the project. For example, we outlined our aim to shift perceptions of autistic people's social media use and autistic-focused interests by emphasizing enjoyment and pleasure rather than primarily highlighting risks such as cyberbullying. This emphasis on enjoyment resonated strongly with board members, some of whom noted that it could help engage the private sector—a group that previous projects have found difficult to reach. The board also recommended mapping autistic interests alongside active and passive patterns of social media use to deepen understanding of engagement, an approach we are currently pursuing through observations, data downloads, and interviews. Additionally, it was suggested that we ask interview participants about the changes they would like to see more broadly, beyond social media, to encompass the wider aims of the project. We are also grateful to board members for connecting us with a range of contacts relevant to the project—including academics, charities, and software developers!

3. Summary of Research Activities

In this next section, we will provide a summary of the main research activities, including what we did, how we did it, and what we found. First, in section 3.1. we discuss how we administered the online survey and provide a brief overview of both the quantitative and qualitative findings. Following this, we describe the interview stage of research in section 3.2. and the online observations in section 3.3.

3.1. Survey

Our first research activity was an **online survey**. By conducting a survey, we aimed to gain a broad overview of how autistic young people use social media to engage with areas of interest. Questions concerned topics such as preferred platforms, modes of engagement, feelings and emotions, experiences with masking, and changes to communication when discussing interests. Following each question, we provided an optional text box for participants to tell us more information.

The survey was administered via Qualtrics and was open between December 2023 and May 2024. To recruit participants, we shared the survey on multiple social media platforms, through our charitable partners' networks, and through external research mailing lists.

Over 300 people took part in the survey. After filtering out incomplete and ineligible responses, our final sample comprised 144 participants. The majority of participants were White (87.5%) and speaking (89.6%), with a clinical diagnosis of autism (75.7%). Just over half were female (52.8%), while 22.2% were male and 20.1% were non-binary[1]. Finally, the largest age bracket was 20-23 (39.6%) followed by 24-26 (34.7%) and 16-19 (25.7%).

3.1.1. Quantitative Findings

Most people who took the survey told us they had a particular interest they discussed or mentioned on social media. Here, the most frequently endorsed interests were **autism, mental health,** and **video games**. Other popular interests included Pokémon, dogs, Doctor Who, and books:

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[1] These numbers do not add up to 100% as some survey participants did not wish to tell us their gender. Furthermore, when asking the question about gender we explicitly mentioned that 'female' means both cisgender and transgender women (likewise for male).

Figure 1: A word cloud of all interests mentioned in the survey.

Next, the most frequently used social media platform was **Instagram**, followed by **YouTube** and **TikTok**, suggesting that visual platforms are preferred to text-based platforms. Participants explained that they had used these sites for a **long time**, found them **easy to use**, and that it was possible to **join groups** or **search** for content relating to their interests.

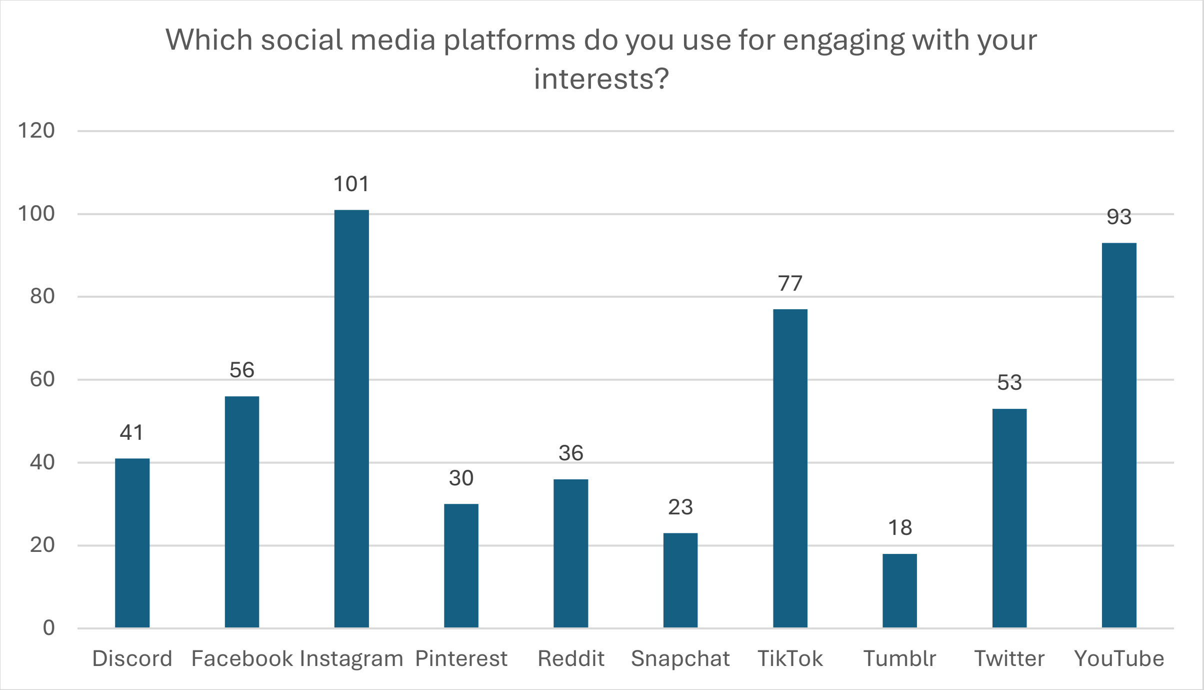

Figure 2: Most commonly used social media platforms for engaging with interests.

On these platforms, participants were able to engage in some, if not all, activities that were important to them. This included **consuming content**, **sharing** or **reposting** content, and **being part of groups or communities** which relate to areas of focused interest. When using social media in this way, participants felt **happy, excited,** or **calm**. Furthermore, respondents claimed to be **more likely to reply to posts** which concerned their interests and were **better at keeping such conversations going**, compared to posts about other topics.

However, our results also highlighted potential barriers to social media participation. Disclosure practices were mixed, with almost a third of respondents saying they **had not told other social media users that they were autistic** and more saying it would depend on the platform. The majority of participants also engaged in **masking** to try and fit in with other social media users. For some participants, social media made them feel **anxious** or **self-conscious** – especially when interacting with other users or sharing original creations like art or writing. While the majority of participants consumed other people's content, **few said they created their own content**.

We then looked at correlations between questions: how do answers relate to each other. We found that p**eople who reported having a special interest on social media** were more likely to feel like they **could take part** on social media, they reported **more engagement** for instance through posting, sharing, and conversations with other users, and they reported experiencing **more happiness and excitement** when using social media, and less tiredness. Feeling able to take part in online interactions was also correlated with being open about your autistic identity online. **People who reported being 'out' on social media, were also more likely to report feeling able to take part.** On the other hand, people who reported masking online were also less likely to report feeling happy, they were less likely to have conversations or write about their special interest online, and generally reported fewer language changes around engagement, for instance not posting longer post, not keeping the conversation going, not replying to other people. These findings are in line with the qualitative findings of the negative impact of masking on online interactions.

We also found that certain platforms were correlated with certain emotions. Discord users were more likely to report feeling happy, excited, and feeling like they can take part. TikTok users were more likely to feel confident, and Pinterest and YouTube users were more likely to feel happy. On the other hand, Reddit users more often reported feeling tired. Twitter and Instagram had mixed emotions correlated with them: Twitter users more often felt sad but also reported feeling calm, while Instagram users reported feeling excited but also self-conscious and embarrassed. This is important to understand because feeling self-conscious and embarrassed was also correlated with making fewer and shorter posts and therefore having less opportunity to engage.

3.1.2. Qualitative Findings - How autistic young people experience social media, in their own words

Next, we analysed the open text responses using an applied linguistics framework that helps understand how people talk about themselves, manage their relationships and make sure their voices are heard. It shows how our survey respondents try to be understood, deal with how people treat them, and find ways to belong.

1) Fear of being treated unfairly

Many people shared that they are often scared of being judged or treated badly on social media—especially when being openly autistic. For example, participants described experiences of bullying or receiving hurtful comments from (presumably neurotypical) social media users. This was especially when talking about autism or engaging in behaviours such as stimming:

- "i sometimes am **scared people will say mean comments** when i talk about or do certain things like stimming because **lots of people online can be quite horrible to other autistic people** unfortunately”
- “I feel often **anxious** when posting and sometimes **people are mean and target autistic groups** and I get **hateful comments,** then I often have a meltdown”

In addition, participants anticipate stereotyping and misunderstanding, as neurotypical social media users often lack relevant knowledge about autism. This kind of implicit discrimination is nonetheless still harmful, as dealing with stereotypes is mentally draining.

- “If I haven’t told people [I am autistic] it’s probably because I don’t want to explain many of the nuances of the autistic experience, in addition to this **many people aren’t very educated on what it means to be autistic** and I’d rather keep quiet because **it takes a lot of energy to explain every time**”

Furthermore, female and non-binary participants talked more about being stereotyped or ignored. They often said they didn’t feel welcome in online spaces, especially when it came to gender roles or being taken seriously. We suggest that this relates to broader societal inequalities which make gender-diverse autistic people less visible, including barriers to diagnosis and gendered cultural norms which encourage masking. We did not find such patterns among participants of colour. However, this is likely due to the limited diversity of our sample.

- “if I were gonna be more involved in my interests I’d probably make a second account. **Partly because im a woman and some of the spaces aren’t that welcoming**”

2) Pressure to mask autistic behaviours

Unfortunately many autistic users said they feel they have to mask or hide parts of who they are to fit in, even in online groups meant for shared interests. They reported people judging them for being “too excited” or “too intense.”

- "Maybe **try not to seem so excited** as some people can be mean”

- “Mostly if I end up in a video/voice call/chat room type of thing **I try to appear normal** even tho we are all there to discuss the shared interests **I don’t want to over share or info dump etc**. in video calls I try to **sit still and look like im paying attention”**

3) Finding belonging in online communities

It wasn’t all negative—many found online communities where they felt accepted, encouraged, and able to express themselves. These were often interest-based groups like gaming, wrestling, or crabs!

- "I’m a gamer and I’ve made a youtube channel to **show my skill** of when playing video games and i go over **tips and tricks”**
- “I feel **most comfortable** [taking part] on the r/crab subreddit (as **other people on there are interested** in crabs too) or infodumping in Facebook autism support groups”

People also talked about how social media tools—like muting, blocking, or choosing what they see—help them feel safer and more in control.

- "Twitter is good cause you can block or mute things that don't interest you, **I use it specifically to look at what interests me.”**
- “I think it’s important that **I can choose what content I see** on my recommended page, which included the option to see nothing at all. The reason I use Discord is that **I can choose to mute notifications, join and leave servers, or only use the app for private correspondence if I so wish**. I don’t have to be greeted by walls of posts on my ‘for you page’”

We are writing academic articles on these findings and will share these when accepted.

3.2. Interviews

Following the survey, we conducted semi-structured interviews so that we could learn more detailed information about social media engagement. In total, we conducted interviews with 42 young people between September 2024 and January 2025. Two interviews were excluded, leading to a final sample of 40 interviewees. Participants were recruited from the survey, social media and the Autistica mailing list.

Like the survey, the interviewees were mostly White (75%), speaking (90%), with a clinical diagnosis of autism (90%). Over half were female (57.5%), while 22.5% were male and 20% were non-binary. The largest age group was 24-26 (45%), followed by 20-23 (35%) and 16-19 (20%). Compared to the survey, the interview sample had a slightly higher proportion of older and female participants and a slightly lower percentage of White participants.

To accommodate diverse communication preferences, participants were able to choose how they were interviewed. 29 participants chose videoconferencing software (Teams or Zoom), while five chose email. We also held two focus groups via live text chat, each of which was attended by three participants.

During the interview, we asked questions about interests, using social media interests, positive and negative experiences, and the future of social media.

We are currently in the process of reading through all the interviews and identifying common themes.

3.3. Online Observations

Following the interview, we invited participants to take part in the next stage of research which involved **online ethnography** (i.e., observation). In total 28 participants took part, nearly all of whom also took part in the previous interview.

We followed participants on a social media platform for a total of four months (January – May 2025). Alternatively, we asked participants download a copy of their social media activity over this period and send it to us.

The platforms included in the study were: Bluesky, Facebook, Instagram, TikTok, Tumblr, Reddit, Twitter, and YouTube. We intentionally used a wide variety of platforms (including text-based, image-based, and video-based platforms) so that we could capture a large range of activities that people participate in. However, from the survey and interviews, we knew that many participants preferred to ‘lurk’ on social media - i.e., reading but not actively contributing. Therefore, to capture these practices, we also asked participants to send us screen-recordings or screenshots of them scrolling through social media.

Over the four-month period, we selectively recorded and made notes about participants' online content which related to areas of interest (identified during the initial interview), including text posts, photos, stories, comments, and accounts followed.

Currently, we are going through all the data we have collected and preparing for a second stage of interviews. In these next interviews, we will ask participants to tell us about their practices in more detail.

4. Outputs

In this final section, we will provide a summary of the project outputs. First, in section 4.1. we will describe our written publications and our future publications. Next, in section 4.2. we describe the presentations we have given at conferences and at university events.

4.1. Written Publications

In February 2025, the first paper from the project was published in *Applied Linguistics:* "Discourse-based approaches to autistic focussed interests: Understanding shared focus, mutual accommodation, and multimodal expression."

In this position paper, we critically review previous literature into autistic communication and advocate for more participatory, neuro-affirmative research that considers the role of focused interests and the double empathy problem. We show that discourse analysis is a valuable tool for helping to understand such interest-driven interactions, specifically for understanding shared focus, mutual accommodation, and multimodal expression.

Next, we have written an empirical paper based on our qualitative survey findings. This paper is currently awaiting peer review. Finally, we are currently preparing a book chapter to appear in the forthcoming volume *Routledge Handbook of Language and Mental Health.* In this chapter, we review previous literature regarding autism and mental health and discuss how intense interests can help to manage anxiety and promote wellbeing, drawing on insights from our survey and the first round of interviews.

We also submitted written evidence to the House of Lords Select Committee on Autism's Call for Evidence in May 2025. The submission, titled *Public Understanding, Acceptance, and Community Inclusion of Autistic People – The Critical Role of Inclusive Digital Environments*, draws on findings from our previous 'Autistic Adults Online' and this 'Autism in Affinity Spaces' project and addresses key questions relating to public understanding, acceptance, and inclusion of autistic people in digital contexts.

4.2. Presentations

The project team have given several presentations concerning the results of the survey, both nationally and internationally. Nationally, we have given one presentation at University of Leeds in November 2024 and another for the Language, Ideology and Power research group at Lancaster University in March 2025.

Most recently (May 2025), Nelya Koteyko, Jessica Aiston, and Martine van Driel travelled to Tilburg University, Netherlands, to present at 'Approaches to Digital Discourse' (ADDA 5). Next, in September 2025, Jessica Aiston will travel to Dublin to present our findings at the biannual 'Autism Europe' conference, as part of a panel on autism and communication.

Finally, the project team are putting together plans for a two-day workshop, to be held over two days – 8-9 January 2025 at Queen Mary University. With this workshop, we will bring together leading academics and advocates to discuss focused interests, identity, and autistic communication across contexts. We will try to answer questions such as: How are focused interests linguistically valued, socially received, and differently constructed? How can we centre them a strength rather than a symptom?