

ABSTRACT

Title of Thesis: AUTISTIC JOY ON TUMBLR

Sophia Wang, Master of Science, Human-Computer
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Thesis directed by: Dr. Amelia Gibson, College of
Information

Tumblr is a unique social media site with a very distinct culture and design. Many of its users are autistic or otherwise neurodivergent, queer or disabled. The site offers its users more control over the content seen and other forms of personalization than other sites, and many users are there to pursue niche interests. Although the site and its culture are different from other social media platforms, it has brought and continues to bring joy to many people. Tumblr has largely been overlooked in the academic literature. This study uses semi-structured interviews and thematic analysis to examine autistic adult Tumblr users' positive and negative experiences on the site, as well as what strategies they employ to seek out the former and avoid the latter, focusing on positive experiences overall. The themes that emerged included the

presence of communities with shared interests and identities, the ability to find useful information and resources, an overall lack of pressure to pursue fame and engagement, and aspects of the web design like the tagging system.

AUTISTIC JOY ON TUMBLR

by

Sophia Wang

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Advisory Committee:

Professor Amelia Gibson, Chair

Professor Elizabeth Bonsignore

Professor Stephanie Valencia Valencia

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Dedication

This is dedicated to all autistic people, but especially those either currently in or considering a future in academia. No matter how rough your situation might be now and no matter how much stigma you might face, there are people working to make things better, and you are one of them.

Acknowledgements

Thank you to my thesis advisor and chair, Dr. Amelia Gibson, for her advice and confidence in me, and for helping me turn an idea into a full-fledged research project. I wouldn't have known what to do without you.

Thank you to my family for their unwavering support and understanding, and for many late nights spent writing with their moral support.

Thank you especially to my cat, Roslyn, for her affection and devotion in this arduous process. Everything gets a little easier with her curled up and purring nearby.

Thank you to my friends on Discord without who I would never have thought about disability so deeply, whose unpaid labor and unseen emotional vulnerability and personal stories have taught me to be a better researcher and a better person. And thank you to all the people but especially those who are not academics, the one-off words and posts I saw on Tumblr, in discussions, and elsewhere that shaped the foundation of this paper. There is a cost and a privilege and a power in being able to go to graduate school: time and money and effort, executive function and emotion and not having had terrible experiences where systems have failed us. There are other people who have more experience than I do, who know more and have felt and experienced more about disability than I have, but because they cannot or do not want to be here, I will do my best by them.

List of Figures

Figure 1 - Screenshot of Tumblr.....	2
Figure 2 - Introduction Post on Blog, part 1.....	24
Figure 3 - Introduction Post on Blog, part 2.....	25

Table of Contents

Dedication.....	ii
Acknowledgements	iii
List of Figures.....	iv
Table of Contents.....	v
Chapter 1: Introduction	1
1.1 Research Questions	3
1.2 Positionality Statement	4
Chapter 2: Related Work.....	6
Chapter 3: Methodology and Procedures	9
3.1 Background.....	9
3.2 Eligibility	11
3.2.1 Cognitive Impairment, Informed Consent, and Decision-making Capacity.....	12
3.3 Sampling Method	16
3.3.1 Observing and Following Tumblr Cultural Norms	17
3.3.2 Identity	18
3.3.3 Ethical Considerations for Including Potential Participants	20
3.4 Recruitment.....	23
3.5 Interview Procedure.....	28

3.5.1 Confidentiality	29
Chapter 4: Findings	31
4.1 Positive Experiences and Strategies to Pursue Them	31
4.1.1 Community	31
4.1.2 Tumblr’s Nicheness	35
4.1.3 Finding Information and Resources	36
4.1.4 Finding Content	39
4.1.5 Appreciation of Others’ Skills	39
4.1.6 Tumblr Jokes, Memes, and Humor	40
4.1.7 Authenticity	41
4.1.8 Explicit Social Rules	42
4.1.10 Forming and Maintaining Relationships	43
4.1.11 Advocacy and Making a Difference	44
4.1.12 Selfcare and Hopeful Posts	45
4.1.13 Venting and Perspective	46
4.2 Negative Experiences and Strategies to Mitigate Them	46
4.2.1 Bots	47
4.2.2 A Culture of Content Curation	47
4.2.3 Anonymity and Lack of Judgment	48
4.2.4 Provoking Others for Attention	50
4.2.5 Terrible Internal and External Search	50
4.3 The Company’s Decisions and Their Effects	51

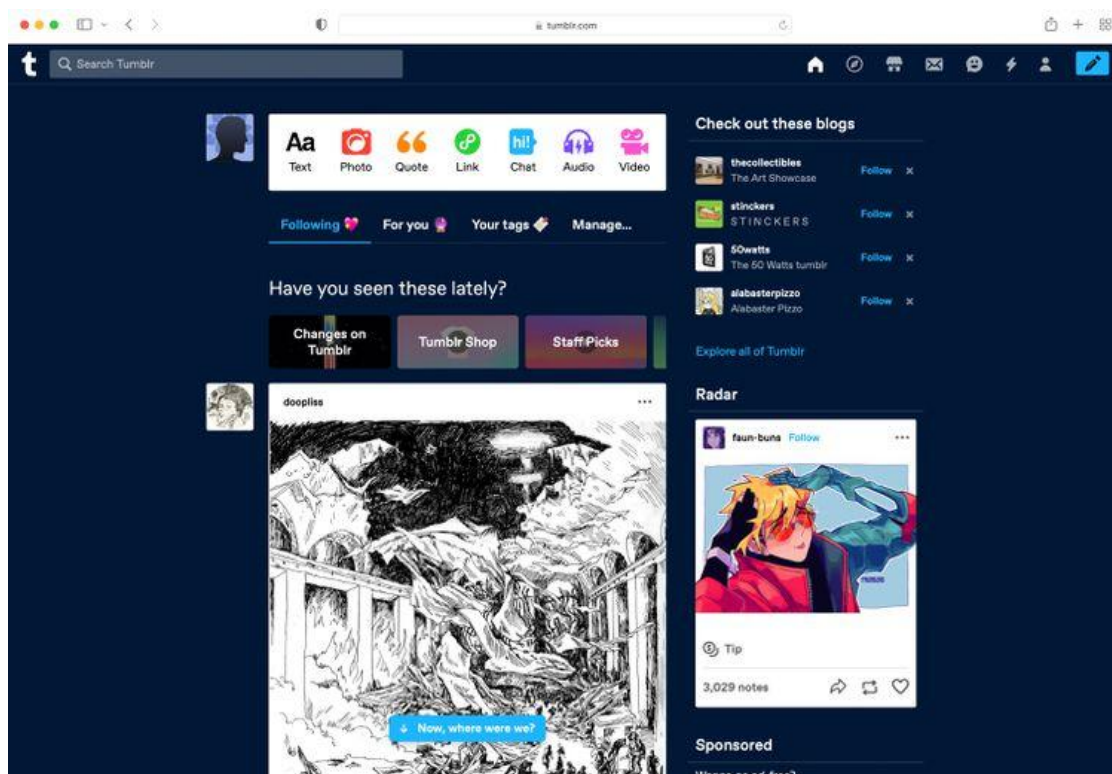
4.3.1 Less Focus on Engagement.....	51
4.3.2 The Algorithm	52
4.3.3 User Interface Changes	53
4.3.4 Tumblr is like the Older Internet	53
4.3.5 A Nonhierarchical culture.....	54
4.3.6 Writing and Reading Posts with an Open Mind.....	54
4.3.7 Multimedia Support.....	55
Chapter 5: Discussion and Conclusion.....	56
5.1 Discussion	56
5.2 Contribution to Ethical Methodology	63
5.3 Limitations	64
5.4 Conclusion	65
Appendices	69
Appendix A: Interview Script.....	69
Appendix B: List of Tags Used to Search for Potential Participant Subgroups	70
Bibliography	71

Chapter 1: Introduction

In the United States, social media is used by a large portion of the population, with about 7 in 10 Americans having ever used social media in 2021, according to the Pew Research Center (Anderson, 2021). However, not every site is used for the same purposes or by the same people. Tumblr is a social media and microblogging site that was founded in 2007 and has since developed a unique culture (McCracken et al., 2020). It has been called a “hellsite” (a designation it shares with Twitter/X), or a humorous designation for a social media site that has “issues with its design, functionality or culture” (“Hellsite,” 2023). One of the other interesting facets of Tumblr is its demographics and politics, which McCracken et al. set out to capture and describe in their book, *a tumblr book*. As they explain, Tumblr was a progressive and open space from the beginning, with its founder and first CEO, David Karp, choosing deliberately to allow sexually explicit material on the site. It was not only Karp, however; the initially small team of staff was also particularly liberal. Furthermore, early on Karp refused to have large, disruptive banner ads on the site, prioritizing its creative purpose. These decisions have rippled throughout Tumblr’s history as it has changed ownership from Karp, to Yahoo, to Verizon, to Automattic today, with Yahoo’s CEO at the time, Marissa Mayer, promising not to “screw up” the site. Aside from the cultural uniqueness of Tumblr, its design and functionality also has a few interesting quirks. Tumblr allows users to design their own blogs in early 2000s internet fashion, and to curate their experience to focus entirely on their own interests (*Customizing Your Theme*, n.d.; *Dashboard Preferences*, n.d.; *Followed Tags*, n.d.). Tumblr also features a robust tagging system (although it is difficult to search) (*Tagging Your Posts*, n.d.). Some of these tags describe

identities that are associated with mental health or disabilities, like #actually depressed or #actually ADHD or #actuallyDID, which community members used to seek shared experiences. Two of those tags are #actually autistic or #actuallyautistic which are used exclusively by Tumblr's autistic community (*Actually Autistic on Tumblr*, 2025).

Figure 1 - Screenshot of Tumblr



This study defines an “autistic individual” as someone who either has a medical diagnosis of autism or someone who self identifies as autistic (a person who strongly identifies with the autistic experience). Autistic identity is associated with a vast spectrum of social and individual experiences, and for some, self-diagnosis provides support and a sense of shared identity in the

absence of expensive, difficult to obtain medical diagnoses (Engelbrecht, 2025). Engelbrecht, co-founder of Embrace Autism, explained that even if autistic people in the U.S. manage to get an appointment for a diagnosis, they may need to wait for a very long time and pay large sum to be examined and diagnosed. Also, there are few material benefits to adult diagnosis. Autistic adults do not benefit from the educational protections and services afforded to autistic children and teens, as there are no IEPs and 504 plans in college so they must again negotiate for accommodations; in the workplace disclosing a disability is even more risky due to the stigma autistic people face (Marschall, 2024; Thurrott, 2024). This is true even without accounting for the gender and race/ethnicity disparities in autism diagnoses for children, though the latter pattern has begun to reverse. According to the Centers for Disease Control and Prevention's (CDC) page on data and statistics on autism in 2024, autism is "nearly 4 times as common among boys than among girls", and in 2023, the CDC reported on data that found that for the first time, "the percentage of 8-year-old children identified with ASD was higher among Black, Hispanic, and Asian or Pacific Islander (A/PI) children compared with White children", reversing a long historical pattern (CDC, 2024; CDC, 2023). To exclude the population who cannot get or do not want to get a medical diagnosis would be to ignore a massive swath of the autistic population. Although self-diagnosis can be controversial in research, this study focuses on how autistic people make meaning out of their lived social experiences on Tumblr, as individuals who hold "autistic identities" and as members of interest communities. From this perspective, people who self-identify as autistic contribute valuable insight to this study.

1.1 Research Questions

This study aims to explore the experience of being autistic in Tumblr through the following research questions:

1. What are the strategies autistic Tumblr users use in order to promote happiness and enjoyment while using the site?
2. What are the strategies autistic Tumblr users use in order to mitigate site flaws and minimize negative experiences like harassment while using the site?

1.2 Positionality Statement

When considering my positionality, the most important aspect that is relevant to this study is that I self-identify as autistic, and I disclose this part of my identity upfront to my participants. Being autistic means that I get access to certain spaces that are autistic-exclusive, like the #actuallyautistic tag I used to gather participants for this study. Also, Milton's famous 2012 study on the double empathy problem indicates that autistic individuals may communicate more easily with each other than with neurotypical individuals, though of course I try not to assume that I understand someone fully just because we share one facet of our identities. Nonetheless, I was able to make jokes and rely on a set of presumed shared experiences when interacting with participants that may have made them feel more comfortable because they did not have to explain things from the ground up to me. However, I recognize that being autistic not as disabling for me as it is for many other people, and I recognize that as a result, I may not be able to accurately represent the experiences and voices of those with lower support needs. I have done my best to be considerate and respectful of the enormous complexity and diversity of autistic experiences throughout the study, but this is my first time conducting research and I am

aware that I have much to learn. Similarly, an important aspect of my identity was that I was already a Tumblr user. This meant that participants did not need to explain references or terms that they used, which allowed the flow of the interviews to be smoother. Also, shared Tumblr experiences allowed me to position myself as an equal and someone from the same group, rather than an outsider looking in. The last aspect of my positionality is that much of my social circle is autistic or otherwise neurodiverse, and when I approach research, I don't think of the participants as subjects to be studied. I think, what if this were my friend? What are all of the small (and large) things that I do to be respectful, thoughtful, and considerate to my friends that I should apply to the people I interview? I am in a Discord server where members of the server feel welcome and able to express deep hurts and harms they have experienced or are going through. I wished to create the same welcome and respectful space in interviews. My friends have been through a lot more of certain kinds of suffering and emotional distress than I have due to my privilege (largely wealth- and disability-related, because I have not had the negative experience with the school and medical systems that they have). Some of the things they've been through were challenging to hear but it is the truth; it is their truth, their lived reality. I wanted to give participants in the study the same respect, belief, and trust that I would give my friends, and I wanted to be compassionate and willing to listen the way I am for my friends when they are giving vent to their pain and frustration, for all that this study is meant to focus on joy. I don't know if I succeeded, in part because for some participants I may not agree with the values they hold, but this is the mindset that I brought from personal interactions into research.

Chapter 2: Related Work

There have been multiple problems with the way autism research has been conducted, historically. Firstly, most research begins from a deficit-focused view of autism (Poulsen et al., 2022). The diagnostic criteria for Autism Spectrum Disorder (ASD) in the Fifth Edition of the Diagnostic and Statistical Manual (DSM-5), which is used for formal diagnosis refers to “persistent deficits in each of three areas of social communication and interaction” and “at least two of four types of restricted, repetitive behaviors” (CDC, 2022). Most autism research does not involve autistic people at any level from ideation to execution (Chown et al., 2017; Milton and Bracher, 2013). Therefore, such research also does not reflect the experiences of autistic individuals (Milton & Bracher, 2013) or the research priorities of the autistic community (Poulsen et al., 2022). The majority of autism research has not followed the central tenet of disability activism, “nothing about us without us” (Spiel et al., 2020). Most autism research is conducted *on* autistic children rather than *with* autistic adults (Spiel et al., 2019), thus leaving a gap. The idea of autism as a terrible burden to be avoided or cured does not allow much space for the voices of autistic adults who have made their own way through life. Ymous et al. (2020) spoke strongly about how even disabled researchers were affected by the tone and framing of disability research, saying that disabled people were, and are, “systematically belittled, disregarded, ignored and dehumanized”.

In beginning to listen to autistic individuals and to move away from seeing deficits, we might consider mutual differences and challenges. One area of difference is communication.

Famously, Milton proposed the “Double Empathy Problem” as the source of difficulties in communication between allistic (non-autistic) and autistic people. In 2022 he and other authors described successful interactions as partly dependent “on two people sharing similar experiences of ways of being in the world” (Milton et al., 2022). Mitchell et al. (2021) find that allistic people more frequently misperceive autistic people, while Davis and Crompton (2021) find that autistic people are more capable of understanding and interpreting each other.

Online communication provides a different set of affordances, leading to new challenges and benefits for autistic people, but I find it disappointing that most researchers have not highlighted the positive aspects (Mazurek, 2013; Page et al., 2022; Van Driel et al., 2023). One of the main challenges is stress as while autistic people understand that there are social expectations for how to behave online, they may have different conceptions of social interactions than allistic people (Page et al, 2022) or else struggle to conform (Van Driel et al., 2023). At the same time, social media technologies might offer opportunities for social connection (Mazurek, 2013) and authenticity (Van Driel et al., 2023). Instead, I find inspiration in research that finds that online autism communities (though this term sometimes includes parents, friends, or other individuals who have a connection to autism) are empowering and supportive (Kim and Bottema-Beutel, 2019; Abel et al., 2019). One particular example is the Autcraft Minecraft community, where autism and awesomeness are combined to form “an identity that is worth embracing, rather than overcoming” (Ringland et al., 2019).

The most relevant related work for this study is Andrew Kirkconnell’s 2019 thesis which was an ethnographic study from an anthropological perspective, though it has one major flaw in that Kirkconnell was not himself autistic. Nonetheless, Kirkconnell was respectful of the autistic

community whose story he told and whose members' experiences he described. His focus was largely on community and quality of life, exploring the sense of shared identity autistic users found on Tumblr as well as community issues such as criticism of Autism Speaks, curing autism, and Applied Behavior Analysis (ABA). He discovered that many users posted about autism pride, as well. In terms of quality of life, Kirkconnell discussed autistic user having less negative interactions with neurotypical users on the site due to a variety of reasons such as having more time to plan responses in text form as well as noting that while autistic users received varying levels of support from their family (or from individual family members), those who had to work hard to gain family support or had mixed support benefited the most from having a shared community like the autistic community on Tumblr.

Overall, however, Kirkconnell's thesis is a rare outlier: Facebook and Twitter are the most well-studied social media sites. Most studies of autistic people and their social media usage are therefore on Facebook and Twitter, including Ward et al. in 2018, Van Driel et al. in 2023, and Saha and Agarwal in 2016. However, Tumblr has not been well studied in general, let alone when it comes to autistic people. However, as described by Kirkconnell in 2019 and in a tumblr book by McCracken et al. in 2020, Tumblr is a very unique social media site. It has a substantial autistic community, its demographics skew towards social outcasts, and its culture is niche and opaque to outsiders, all of which make it worthy of study.

Chapter 3: Methodology and Procedures

3.1 Background

Tumblr originated as, and still is, a microblogging site. A microblog is “[a] blog on which one posts brief, frequent updates on one's activities”, which can involve links, images, or videos, though Tumblr deviates from this Wiktionary definition by allowing for a much longer post length than other microblogging sites like Twitter/X or Instagram, with a 4096 character limit per block for 1000 blocks per post (“Microblog,” 2024, *Writing Posts*, n.d.). Tumblr also created the reblog function before Twitter’s retweet, which remains an integral part of its functionality today (McCracken et al., 2020). “Reblogging” or reposting (sharing a post someone else made by using the reblog function which causes it and any chain of replies to appear on your blog), which makes further emails or flyers unnecessary since users will naturally reblog to their own followers, thus reaching more potential participants. However, this applies only to posts or reblogged posts that I create. In order to contact people who are not reached by this initial reblogging cascade, Tumblr has two other options: Direct Messages (DMs) and the askbox. DMs function much like any other social media, though Tumblr users can set it to only allow DMs from other users that they follow. The askbox is like an “ask me anything” inbox where other Tumblr users can send multimedia messages (text, including video, photo, links). Some Tumblr users do not allow anonymous asks, which was not a concern for this research study. However, the askbox can also be closed indefinitely. Furthermore, it was only a recent update that the askbox was expanded in functionality and length from just a plaintext limit of 500 characters, so

some users will not have the full multimedia askbox. In this case, it is common to append a current #/total messages fraction at the end of an ask and to split the message into multiple asks. A time limit can be set for asks (no more than once per hour, for instance), which can complicate things and necessitate a timer to get the full length of a message across.

Another part of the Tumblr functionality is the importance of a tagging system. When posting, users can append as many (up to a very large number) or as few tags as they wish, which will then show up in the stream of the aforementioned tag, chronologically. Tags do not differentiate between upper and lowercase, but they do respect space as well as other characters. Users can follow a tag to see recent posts with said tag in their feed, or they can search the tag using Tumblr's search function. Overall, the tagging system allows for reaching a particular audience.

Like any other social media site, Tumblr has its own share of scammers and bots. There are two sides of this issue that are relevant for this study. The first is that when setting up my blog, there are certain steps that must be followed to indicate that I myself am not a scammer or bot. This involves changing the profile picture of the blog from the Tumblr preset icon and posting at least once. Tumblr users are often inundated with bots and thus quick to block any blog with the default icon and/or no posts. Also, aside from other reasons to put research study and researcher information on the blog created for this study, it is also important to put as much verifiable contact information to prove the legitimacy of the study. To ensure said information remains visible, Tumblr allows users to "pin" posts, thus forcing them to show up at the top of a blog, before any other posts.

The aim of the research was to explore the individual experiences of positive emotions that autistic users had on Tumblr. I chose to use semi-structured interviews as this allows me to adjust my questions according to the individual phrasing that participants used, to better match how they understand and experience joy, as well as to incorporate questions about topics that they bring up that were not previously included. Participation in the study was completely voluntary and the study protocol was approved by the Institutional Review Board at the University of Maryland. Compensation was \$5 for the participants who completed the interview, in the form of a gift card. More compensation would have been given, but I did not have any additional funding. In total 12 participants were recruited.

3.2 Eligibility

Eligible participants were residents of the United States, 18 years or older, proficient with English, had no cognitive impairments (which I will define for this study shortly), and had to self-identify as autistic. US residency prevented any potential issues with compensation due to the region-based nature of Amazon gift cards. This study did not limit participants only to those with medical diagnoses, with the understanding that medical diagnoses pose financial and temporal barriers, that certain demographics (specifically people who are not white and people who are not boys) were diagnosed at lower rates (CDC, 2023; CDC, 2024), and that many individuals feel that the stigma and disadvantages of having a diagnosis on their record outweigh possible advantages, especially as people age out of the school system (Engelbrecht, 2025; Marschall, 2024).

3.2.1 Cognitive Impairment, Informed Consent, and Decision-making Capacity

I state that participants in this study had no cognitive impairments. For the purposes of this study, that means that participants had no difficulty understanding 1) the purpose of the study, 2) the risks and benefits involved, 3) that they could withdraw at any time or (as included in recruitment messages that they could) refuse to respond to recruitment requests, and 4) the measures and safeguards I would take to ensure confidentiality and data privacy, and that they had no difficulty making a clear choice to consent. Defining cognitive impairment was very difficult for me, because the definition one uses depends on the context one operates in. I was, and am, most familiar with other categorizations and descriptions of *disability*, not impairment.

Firstly, I am somewhat familiar with the American with Disabilities Act (ADA) as well as Section 504 and Section 508 of the Rehabilitation Act, and more so with the former than the latter two. The ADA defines disability thusly: “A person with a disability is someone who: has a physical or mental impairment that substantially limits one or more major life activities, has a history or record of such an impairment (such as cancer that is in remission), or is perceived by others as having such an impairment (such as a person who has scars from a severe burn)” (*Introduction to the Americans with Disabilities Act*, 2025). The ADA therefore defines disability as usually involving impairment in some way but also potentially as merely being perceived by others as having an impairment. However, impairment does not need to affect more than one, or more than one area, of the major life activities; those most relevant to this study include “thinking and concentrating” as well as “reading, learning, and communicating”. This definition involving major life activities bears some similarities to the concept of activities of daily living (ADLs) originally proposed by Sidney Katz in 1950 and broadened by Lawton and

Brody in 1969 to include the instrumental ADLs (iADLs), which also break down abilities and capabilities into separate activities (Lawton & Brody, 1969; Noelker & Browdie, 2014). When providing examples of disabilities, Lawton and Brody (1969) list autism separately from “intellectual disabilities”. Aside from the fact that intelligence is a very complicated and poorly understood subject, there are also overlaps between which disabilities and conditions are included in the categories of cognitive disabilities, intellectual disabilities, developmental disabilities, and learning disabilities. I bring these varied categories up because it makes it difficult as a researcher to understand what IRB guidance or other people in general are talking about when they refer to “cognitive impairment”. Looking at existing literature is equally confusing. For example, in Van Driel et al., (2023) the authors begin describing their participants as being “selected based on having a professional diagnosis of autism or Asperger’s” and in the same breath claim that the participants have “no history of intellectual disability”. Autistic people are a vulnerable group when it comes to research; this much is certain. What is not certain is how the IRBs define cognitive impairment. Does dyslexia count as having a cognitive impairment? Does major depressive disorder count? Both have to do with the activities of the brain, but neither on their own prevent participants from understanding risks in a research study, and neither on their own make it so that someone cannot convey their decisions and consent to someone else.

There is another difficulty that arises when considering disability and impairment on a task-by-task basis: it becomes necessary to ask participants if they can do this or that task. In the case of cognitive impairment, this can lead to rather rude and offensive questions. I would not ask someone bluntly, “Can you read?” or, worse, “Can you think?”, because it would be

patronizing and disrespectful, especially when asking adults, some of whom have managed their own lives, jobs, and families perfectly fine. Using more specific medical language runs the risk of focusing too much on deficits while also requiring someone to provide medical documentation. This would impose an additional burden of stress, discomfort, and embarrassment as participants have to “prove” their (dis)ability. At some point, I decided, I have to trust the people I am interacting with. Documents can be forged and people can lie. It is not worth putting people through such trials when my goal is to be as open and understanding as possible, to let people come as they are and tell me their own experiences.

Besides the legal definitions of disability, the other definition and framework for disability that I am familiar with comes from Human-Computer Interaction and web design and development, including User Interface design (UI), and User Experience design (UX). Here I turned to the Web Content Accessibility Guidelines (WCAG) and their four principles that make up POUR: Perceivable, Operable, Understandable, and Robust. In these categories, disability is considered in terms of what difficulties there are in terms of successfully using web content, so disabilities that affect how a user perceives content, for example, such as blindness and low vision or D/deafness and being hard of hearing, are grouped together. This grouping aids developers, designers, and testers by breaking down the sometimes overwhelming considerations regarding disability and accessibility on the web. Autism then might be a disability that is largely covered by the Understandable principle when it comes to comprehension and reading level. However, these principles, while helpful to keep in mind for a design space, are not as useful for research design.

At this point I found these definitions more confusing than helpful, so I searched for guidance on cognitive impairment from other institutions, because I could not find more detailed definitions regarding cognitive impairment beyond the general concept of informed consent (*IRB Definitions*, n.d.) at my institution. From a broader search, however, two schools in particular had very relevant and useful advice. The University of Maryland Baltimore County (UMBC) has a page on cognitive impairment and decision-making capacity where it explains the concept of “consent capacity, which describes the participant’s ability to understand information relevant to making an informed, voluntary decision to participate in research” (*Consent for Individuals With Cognitive Impairments and Decision-Making Capacity*, n.d.). The page goes on to add that the UMBC IRB considers the following: “the purpose of the study, its experimental nature, risks and anticipated benefits, the right to withdraw, alternatives to participation, confidentiality protections, and the safeguards used to minimize risks”. Given that the IRB is evaluating this information, it seems likely that this is the information that participants must be able to understand. The UMBC IRB also advises that people with Alzheimer’s and other mental disabilities “would be considered vulnerable but do retain the capacity to consent” and that researchers should “[respect] them as autonomous individuals”. Considering this advice, autism would very neatly fall under the category of a mental disability, but one where autistic people can consent to studies. In other words, each autistic person must be considered individually.

The second IRB that provided meaningful advice for this research study was the University of California San Francisco (UCSF) IRB. Its advice largely agreed with UMBC but expanded upon the concept of decision-making capacity. Their page has a section where it explains that per the American Psychiatric Association, decision-making capacity, besides other

factors already discussed, also includes both the “[a]bility to manipulate information rationally [i.e., to reason]” and the “[a]bility to evidence a choice” (*Enrolling Individuals With Cognitive Impairments and Assessing Decisional Capacity*, 2023).

These two frameworks for understanding consent and disability were much more useful to me, and equally importantly, did not make me ask people uncomfortable questions or demand evidence: comprehension and comprehensibility (Can they understand? If not, is there something I can do to help them understand?) and the ability to make a decision and for that decision to be acknowledged. These two are the concepts that guided me when it came to thinking about eligibility and participation.

3.3 Sampling Method

Due to the age and nicheness of Tumblr as a social media site, purposive and snowball sampling were used to recruit participants. A blog was created for the study on Tumblr at <https://www.tumblr.com/blog/betweenkeyboardandchair>, with a brief description that identified myself as autistic and an adult. This was done because the main method of communication on Tumblr is through tagging posts, and I planned to use the #actuallyautistic tag on my posts to reach eligible participants. There is another similar tag that is written “actually autistic” with a space. These two tags are searched separately by Tumblr, and because I did not tag both, I may have missed out on users who only follow #actually autistic. As the name of the tag indicates, this tag is meant to be used exclusively by those who are themselves autistic, and thus to avoid the impression and consequences of a non-autistic researcher intruding on an autistic-only space,

I disclosed my own autistic identity upfront. Other tags such as #autistic exist, but they are often used by family or caretakers of autistic people.

3.3.1 Observing and Following Tumblr Cultural Norms

I did not need to familiarize myself with Tumblr's cultural norms and practices such as how to not be mistaken for a bot or how to tag because I have a personal Tumblr account. Researchers who are new to Tumblr's platform should spend some time observing and interacting (preferably in a separate non-research-study-affiliated blog) to understand the zeitgeist and expected behaviors on the site. Tumblr users helpfully provide some basic instructions and advice for people joining from other social media sites and it would be a good idea to read them. Then, once they are familiar enough to not accidentally cause harm or offense, they should still keep in mind that there are spaces where they are allowed and also spaces where they are not allowed. For example, if a nonautistic researcher wished to recruit from users who post with the #actuallyautistic tag, they might create a post themselves but not tag it with the desired tag; then, they could ask users to reblog their post instead of entering that exclusive space. The other major concern on Tumblr is making sure that one is not mistaken for a bot. Again, the relatively simple steps required to prevent this from happening are listed in Tumblr posts on the subject, but there is one other point worth bringing up that I will elaborate on more later: Tumblr posts linguistically are often lowercase and without normal punctuation; punctuation can be used in unusual ways, and both of these are noted by McCracken et al. (2020) who cite a Tumblr post

discussing the topic. Using a formal register, then, is a tradeoff between appearing authoritative vs. appearing friendly and well-adjusted to the environment.

3.3.2 Identity

Every autistic person has a different experience. That being said, different subgroups can have different experiences due to their demographics. Specifically, age, race, how long someone has used Tumblr, whether they use AAC or are not fully verbal at all times, and overall how disabling being autistic is for someone will lead to different experiences both offline and online. It was my initial intent to gather as diverse a group as possible within these demographics to wide range of what being on Tumblr is like for autistic people. As mentioned previously, however, due to ethical concerns I limited myself to participants who I was most certain would be able to understand and decide to consent.

The majority of my respondents were white or white-presenting. I noticed this as I attempted to account for multiple types of diversity and experience, but racial diversity among participants was by far the most difficult to include and search for. Part of my difficulty came from my limited knowledge related to how autistic people of color describe or tag themselves. People on Tumblr often do not use their own faces (or any part or whole of themselves) in profile pictures due to sitewide norms of anonymity as described by the participants, so it can be very difficult to tell someone's race if they do not put it in their blog description. That means that in terms of certainty I could only rely on users' self-posted tags. I knew of some tags, like for example #indigenous which in conjunction with #actually autistic would imply being both, but

beyond trying different variations of #[race] autistic(s), I admittedly hit a wall as far as how to search for people of color. I was also able to find the #autizzy tag for Black autistics. However, I struggled even more with #latino/a/x or #Asian-American autistic people; in the latter two cases I could count the number of blogs of whose identity I was sure of in the single digits.

Recruitment occurred in October into December 2024, but after the election, people became stressed over the presidential election results and politics in general. I definitely wanted to make sure that I wasn't adding to anyone's energy expenditure. As mentioned in the interviews, many people on Tumblr have very strong beliefs and care about advocacy, and so some people might have become so stressed that they were no longer willing to participate, and that as a result I may have missed out on a portion of the population. One notable example is that during the recruitment process, I did manage to contact one Tumblr user who I assumed was Black from the tags they used (tags similar to #black autistic). This user did agree to participate, but after checking back with them after the election results came in, I found that they had deleted their blog. I don't know how many people deleted their blogs or went offline because current events had become too stressful for them, but I regret that I was not able to interview those people, because the people who remained on Tumblr may very well have had differences from the people who left.

Outside of the strict rules regarding tagging posts, I recognize that having a shared identity with the participants likely encouraged them to be honest about their experiences because of the assumption of a shared understanding between researcher and participant. Specifically, autistic-autistic communication faces less difficulties than autistic-neurotypical communication as described in Milton's double empathy problem, and the sense of frustration

and effort put in provided shared experiences that could be discussed freely and without judgment (Milton, 2012).

3.3.3 Ethical Considerations for Including Potential Participants

Beyond the concrete eligibility criteria, there are other factors that are important to consider for the ethicality of including each individual potential participant in the study. First, I was concerned whether participants were in an emotionally stable and healthy state. Many people post to the #actually autistic and #actuallyautistic tags because they are angry, frustrated, afraid, or deeply sorrowful. Simply going chronologically backwards, looking at the most recent posts first, it was not uncommon to see people discussing depression, incredibly negative emotions, self-harm, or suicidality very frankly and in sometimes graphic detail. This was not only emotionally taxing on me as a researcher, but it also made it clear to me that such participants did not need additional stress and burden in their lives in the form of a research study, because their mental health was already very strained. There were also those users who would candidly post or discuss very emotionally fraught and painful circumstances such as abuse and trauma. It was also unacceptable to me to include these people because it is more important for them to heal and recover than to participate. I considered this factor by reading through users' posts and noting the language they used as well as aspects like whether they wrote a great deal of text in all capitals.

In the case of one participant, P4, I was uncertain whether to include her because she posted frequently in all capitals, venting in a very angry tone. I decided (with the help of my advisor) that P4 would lend diversity of perspective provide very different responses regarding

why she used Tumblr or what she enjoyed about Tumblr compared to the other participants who did not vent their emotions as often or as intensely. I weighed the potential scientific contributions her inclusion would have against her potential emotional burden, and I concluded that it was ethical to include P4 because of the nature of her vent posts: she was venting about workplace frustrations, but did not threaten to harm herself or others, or speak in a way that indicated that she saw no value in her life or living in general. She was just frustrated, which is an emotion we all feel, and indeed she provided a different perspective and user experience. I admit, however, that reaching out to P4 was particularly intimidating and stressful for me as the researcher.

Secondly, in a similar situation were people who were in financial distress. Users mentioned, for example, that they were homeless or recently homeless, or that they had lost their jobs, or that they had medical expenses that needed to be paid urgently. Some users posted or reblogged posts about asking for donations, sometimes for living expenses like rent, food, or utilities. I felt that it would be irresponsible and unethical to ask for these people to spend their time and energy on any research project. If a research project promised sufficient compensation, then perhaps users would feel unduly pressured to participate; scientifically speaking, this might also affect the validity of the results. As the page from the University of California San Francisco explains, aside from cognitive disability, decision-making capacity can also be affected by “severe pain, anxiety or confusion” (*Enrolling Individuals With Cognitive Impairments and Assessing Decisional Capacity*, 2023). The page goes on to provide examples including “individuals with trauma, cancer or life-threatening illness”. These examples are most relevant in the case of medical studies where a drug in the testing stage may very well save the lives of those

in the experimental group. It is also important to note that intense fear, anxiety, or confusion could change how well anyone could make decisions, including cases such as finding oneself recently homeless, where the prospect of signing up for research studies for compensation might become very appealing. However, in my case, the compensation I provided was not even equivalent to the minimum hourly wage, and so this also felt unacceptable to offer to participants because it was demeaning and verged on exploitation.

Of course, emotional and financial distress are not the only reasons that it might be unethical to include a potential participant, but these were the major concerns in this research study. I leave it to future researchers to explore other factors.

There is a third reason that is less ethically fraught as to whether a researcher should include, or even interact with, a potential participant. This is the Do Not Interact list, which is a list that some Tumblr (and potentially other social media) users put in their descriptions or a pinned post to indicate that they do not want other users from that list to interact with them. Users often do not want racists, sexists, homophobes, etc. to interact with them, but sometimes the items on the list can be less general. I encountered a user who did not wish to be interacted with by anyone who was not transgender and who was not a lesbian. I admit that this seemed a little unreasonable to me, but as I am neither transgender nor a lesbian, I did not interact with this user because I wished to respect their DNI list. It felt unethical to begin a study by trampling over potential participants' wishes; if I could not even honor this simple wish, then clearly I would have set a poor precedent for respecting any other decisions a participant might make.

When considering the ethicality of including potential participants, there is more to weigh than just the general purpose of the study and its experimental procedure (for example what

questions, experiments, or activities a participant would be involved in). There is energy and time spent communicating with the researcher, reading through the consent form and gathering the courage to ask questions, as well as having to respond to a stranger in a timely manner. There is also the energy spent in remembering and showing up to a research study, which was less but not zero even online; this includes the potential disruption to a participant's normal routine. Then there is the emotional labor in the form of vulnerability and honesty that participants do: even in a minimal risk study focusing on positive experiences, participants might (and did) allude to and speak briefly about negative experiences like harassment. One participant cried during the interview because she was overcome with emotion. Even the questions that I believed to be innocuous and lightweight could elicit strong emotional responses, and I recognized how important it is to acknowledge the work participants do and the effort it takes.

When determining whether participants were doing well enough to afford to participate, I checked their description, any pinned posts they had, as many posts as necessary, and the tags the participants used. I often felt uncertain because there were gray areas: if a participant was currently undergoing serious and painful surgery, I would definitely not include them; was that still the case if they had had surgery a few months ago and were now recovering, but still experiencing pain and other side effects? Ultimately I chose to balance caution with letting participants make decisions about their own lives, because I wanted to respect the concept of the dignity of risk as described by Perske (Perske, 1972).

3.4 Recruitment

Figure 2 - Introduction Post on Blog, part 1

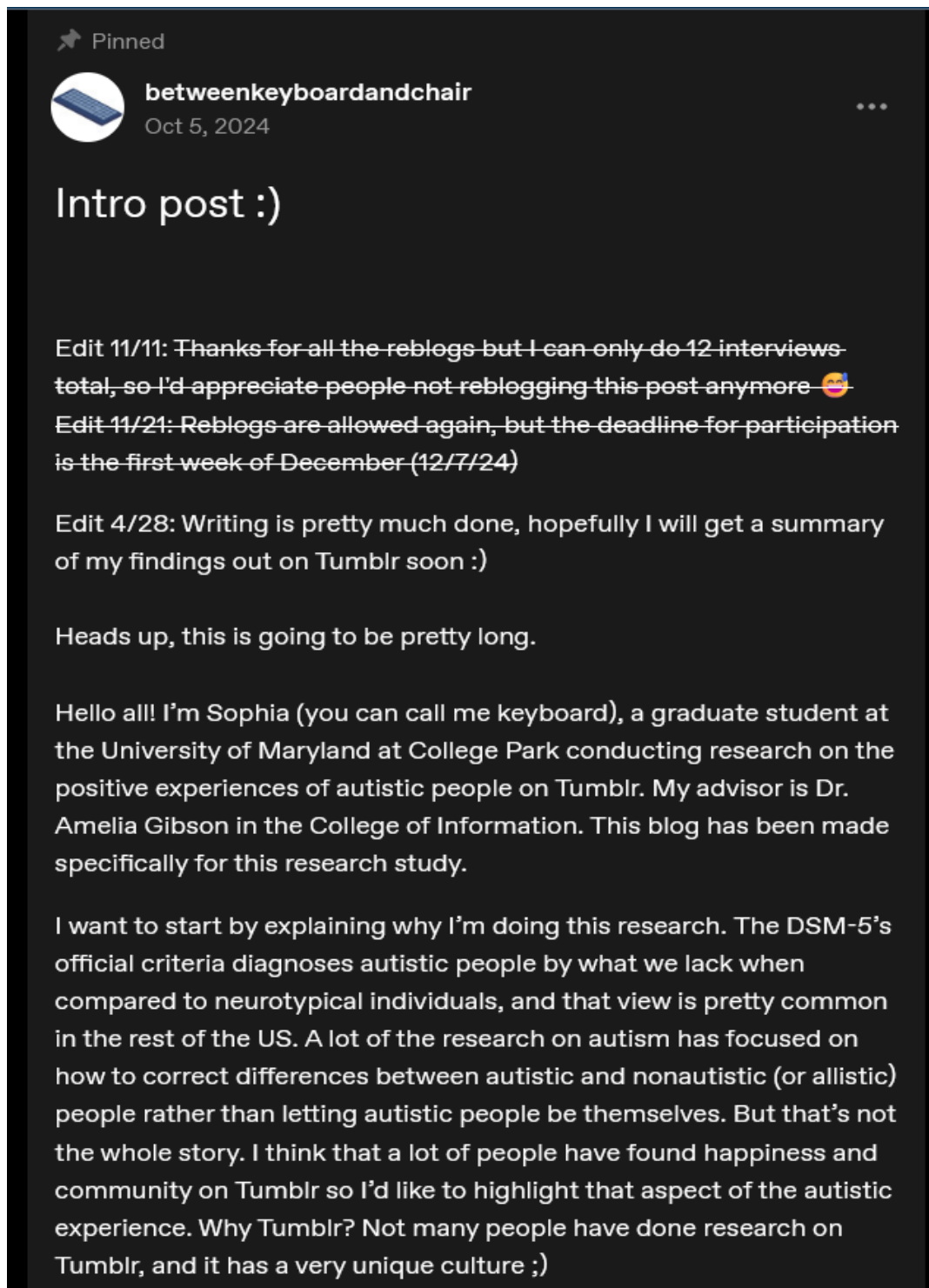


Figure 3 - Introduction Post on Blog, part 2

I will be conducting recorded video interviews of 30 minutes to an hour, and cameras will need to be on briefly at the beginning for verification. I will do my best to ensure participants' confidentiality.

Participants have to be 18+, proficient in English, a US resident, and either have an official diagnosis or a self-diagnosis. Also, if you have a cognitive impairment you should not disclose it during the interview.

If you're interested don't hesitate to DM or email me.

If you have any questions, contact me at swang137@umd.edu or my advisor at ameliag@umd.edu.

This study has been approved by the University of Maryland Institutional Review Board (IRB #2235876-1).

If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:

University of Maryland College Park

Institutional Review Board Office

1204 Marie Mount Hall

College Park, Maryland, 20742

E-mail: irb@umd.edu

Telephone: 301-405-0678

For more information regarding participant rights, please visit:

<https://research.umd.edu/resources/research-compliance/institutional-review-board-irb/research-participants>

#actuallyautistic



An introductory post was created describing the study, asking for readers of the post to contact me to participate as well as to reblog for greater reach. I also began to send Direct Messages (DMs) or asks to the blogs of users who I determined might be eligible to participate in the study based on their blog descriptions who had also posted with the #actuallyautistic tag. A full list of the tags that I used in conjunction with #actuallyautistic is provided in the appendix.

Tensions before, during, and after November 5th and 6th due to the election prompted me to add a statement to my recruitment message in recognition that people were struggling emotionally and that asking them to participate in research may be insensitive. Specifically, I mentioned that I was aware that now may not be a good time, and that participants could either refuse or just not respond to my messages for any reason. While it was the election that prompted the addition of this line, I phrased it to be relevant for any situation, not just election-related issues, because I wanted to recognize and give space for the fact that participants are also people with their own lives who do not need to disclose a reason to not participate.

My goal with the recruitment messages and overall was to be as considerate as possible. Since autism is framed so negatively in research as described by Poulsen et al. in 2022, and since research on autism has often not reflected the experiences of autistic individuals as described in Milton and Bracher in 2013, participants may have felt that participation in research studies was a waste of their time and effort. In order to encourage more people to participate, I chose my words very carefully to convey understanding and respect.

When choosing Tumblr users to recruit, it is important to go through their blog and their posts to gather information. Often users will mention their age, nationality, location, or other

pertinent information such as disabilities, etc., in their blog description under the title. Here is also often where users mention pronouns, sexual orientation, hobbies, and/or a DNI (do not interact) list. Going through a user's blog posts is also important to gather information about their interests and how they use Tumblr. Noting down their interests and passions provided material for interview questions about said interests, and it also prepared me for certain views that might come up during interviews.

Since I was studying autistic people it was necessary to prepare to interview AAC users, especially because I planned to reach out to AAC users on Tumblr. The preparation consisted of willingness to use the Zoom chat as well as being ready to give participants (including non-AAC users) the interview questions; I was advised by a committee member who works with AAC devices for her research that some AAC devices or software can pre-program customized answers to questions, but even a device cannot, typing and using AAC takes longer than speaking, so it is best to minimize the burden placed on the participant.

For some research studies keeping the questions unrevealed is important to get a candid answer, however in this study I was not as interested in an honest first reaction as making sure that the participants could express themselves clearly. Not everyone can answer a question as thoroughly as they might want if unprepared, and this is especially true with at least some autistic people (Autistic Self Advocacy Network, 2019). I encouraged participants to write or type their answers down somewhere to pull up during the interview if that would make them comfortable. Relatedly it is also important to give participants enough time to think and answer during the interview (Autistic Self Advocacy Network, 2019). I tried my best not to rush them or to give them the impression that I was impatient.

On social media there is the concept of a “pet tax”, as explained in a reddit post from Poet_Eviscerate: if you own a pet, you should provide images of said pet (Poet_Eviscerate, n.d.). I added a photo of my cat at the end of my recruitment messages. It is a small thing, but providing real, candid photos of my cat that can’t be traced back to someone else provides authenticity. Also, people tend to enjoy seeing pictures of pets in general.

As McCracken et al. note in their book, a “minimalist” typography is used on Tumblr, with a “lack of capitalization and other punctuation” (McCracken et al., 2020). My initial blog post was written in full sentences with standard grammar because it would be read by the UMD IRB, and I cannot and did not change it for Tumblr. However, I am both more comfortable with and feel that it is more appropriate to write in lowercase with emoticons and emoji on Tumblr for recruitment messages and during the interview. The goal of the interview was to meet participants at whatever informality would be most familiar for them. This caused a mismatch between the official documents’ language and personal interactions which could not be avoided.

3.5 Interview Procedure

Interviews were conducted using a University of Maryland Zoom account. Each interview was between 30 minutes and one hour and was video and audio recorded. Participants were required to turn their cameras on briefly for verification to prevent fraud but were then allowed to turn off their cameras for the rest of the interview. No participants requested to turn off their cameras. Consent was given orally, or in the case of people who use AAC, consent was typed into the chat after I read the consent form to the participants. All interviews were transcribed for data analysis. The interview protocol is included in the appendix.

As a researcher it is my duty to collect data without judgment, and therefore I tried not to react negatively to anything participants said. I also tried to keep my tone and word choice neutral. However, when it came to topics that I felt positively about, I did not hide my enthusiasm. I also made jokes or statements that referred to a shared identity (as Tumblr users, both being autistic, etc) when I felt it was conversationally beneficial.

Also, in the interest of data collection, it was important to ask participants what they meant or for more details. Sometimes this wasn't possible because participants naturally gave very short answers and did not feel it was necessary to elaborate when prompted. I did not push them for more information more than twice because I felt it was impolite and conversationally awkward.

I recorded the interviews, but I also took notes to reference later. With a semi-structured interview format, I initially followed the questions in the interview script, but then I relied on my notes or memory to ask participants relevant questions.

3.5.1 Confidentiality

Participants are referred to in this study using a number rather than their Tumblr usernames. While the participants may have disclosed that they were autistic online through the use of the #actuallyautistic tag, I tried to avoid using any information that might identify them either offline or online, because both offline and online identities should be protected.

Chapter 4: Findings

4.1 Positive Experiences and Strategies to Pursue Them

4.1.1 Community

4.1.1.1 Shared interests

Social media in general is there for people to find a community, and when it comes to Tumblr this is no different. Specifically, finding a community with the same interests was mentioned by multiple people as something very important to them. The way Tumblr works involves a great deal of self-differentiation into communities with shared interests that do not necessarily interact with each other but nonetheless are incredibly varied and diverse. Whatever hobby or interest one might have, there is almost certainly an established community on Tumblr that they can join. P1 described Tumblr as “kind of like an archive. You can find almost anything you want on there barring not safe for work topics which is not something I focus on so that's fine with me, but like it's, I can find dogs, I can find anime, I can find almost any fandom thing on there.” Tumblr in general is also a hotspot of fandom activity where people will post their live reactions, their art, their writing, and anything else about the media that they love. Even after a show has ended, for example, or a movie has become old news, there will still be many people on Tumblr talking excitedly and in-depth about it.

4.1.1.2 Friendly and welcoming communities

Communities on Tumblr can be more friendly and welcoming than on other social media sites. For example, one participant said, “I found the knitting community on Tumblr is really welcoming, especially to beginners and stuff, as well as the visible mending community, They're

always really responsive to questions and even if someone has made a mistake or whatever, everyone's very...I guess whimsical is the word about it.” Not every community is supportive of people looking for help, especially if the questions have obvious or simple solutions. Beginners, people with questions, and people who have run into difficulties technical or otherwise, are a challenge to the smooth flow of a community, so the community’s response to these troublemakers is an indication of how supportive the community is. Mistakes in particular are quick to be ridiculed in many spaces online and offline, so it is notable that on Tumblr, at least some communities have a more forgiving and understanding culture around it. P2 also mentioned that Tumblr had changed for the better and that “especially if you use tags like #autistic I'm especially thinking of, it's all full of positivity lately, which makes me really happy. I mean you have posts that are negative, but largely it seems to be a space of, as you said, autistic joy.”

4.1.1.3 Shared (Autistic) Experiences

Multiple participants have commented that they were able to find a community with shared autistic experiences on Tumblr. P4 said, “I started out for my son, looking for autistic people for my son. And then I realized that I kind of found my people. And all of a sudden all these things that I did made sense.” Even for someone who wasn’t looking for people who shared experiences with them personally, P4 saw posts and content on Tumblr that resonated with her, which allowed her to recontextualize her own experiences and find a place where she felt like she belonged. P3 shared their trajectory from an earlier forum onto Tumblr, “And I remember in the 90’s there was this forum called WrongPlanet.net...it was one of the first places I think autistics were able to connect to one another, and then they migrated onto places like LiveJournal and then even Tumblr”. I don’t know if any other autistic users on Tumblr followed

the same path as P3, but many autistic people have found Tumblr one way or another and to this day there is a large autistic community on the site that performs some of the same supportive functions as the forums from the earlier internet. And P2 attested to the wide variety of autistic experiences shared on Tumblr, saying “honestly I like to see other people's experiences and I think that's where the tag really shines because there's people who are nonverbal and use AAC and there are other people who are more high functioning than I am, or more low functioning than I am, whichever labels you want to use, I know functioning is kind of eh. It's really interesting how we can all interact on this space together. I think it brings a lot of people from all different backgrounds and we're all united in being autistic, it's cool.” P1 also mentioned how helpful seeing posts from the autistic community on Tumblr was compared to information from nonautistic people, saying “Tumblr was kind of how I got the first clue that I was autistic because there was people posting about their experiences on there. And my boss had told me I was probably autistic but I looked up stuff on Google and you know it was all the stuff I don't recognize because they're describing it from an outsider's perspective. Whereas on Tumblr people are talking about their own perspectives and then I was looking at this stuff and how it was defined and what they described like, that actually sounds very familiar.”

4.1.1.4 Shared ADHD experiences

Other than being autistic, multiple participants who self-identified as having ADHD during their interviews were similarly able to find community around the ADHD experience on Tumblr. 50-70% of people who are autistic also have ADHD (Hours et al., 2022). This overlap in diagnoses is also reflected in the overlap between the two communities on Tumblr. P5 said, “if I see a particularly good joke about something related to the autistic experience or ADHD, like I'll

take a screenshot and I'll send it to one of my friends". The jokes and memes that are made on Tumblr within and by the autistic and ADHD communities are relatable enough for people to share them offline.

4.1.1.5 Socially marginalized communities

Many participants described Tumblr as a space full of queer, neurodivergent, and disabled people. Many users, including participants, boldly declare their sexual orientations, pronouns, and even medical diagnoses on their blog descriptions. While from personal experience and the recruitment process it appears the majority of Tumblr's population is white, the fact that many people with marginalized identities are able to find others with shared experiences and form communities indicates that Tumblr is a sort of haven for social outcasts. P3 remarks on their friends, saying, "There's a bunch of people on Tumblr that I would consider friends now...and most of them are autistic or ADHD or both. And the ones who aren't still understand." The sheer number of people who have one or more marginalized identities makes it so that even people who don't share those identities are likely to be more understanding because that is part of Tumblr's demographics. P1 acknowledged this as well, saying "because Tumblr is kind of the place for people who are considered social outcasts I think we're a little bit more drawn there."

4.1.1.6 Shared beliefs

Another form of community that Tumblr offers is finding other users with shared beliefs. P12 said Tumblr "gave me a space to feel secure and connected" and that Tumblr also "helped me find like-minded people". They tie the security and connection that Tumblr offers to the presence of people with shared or similar beliefs. Tumblr draws a lot of people with strong

beliefs and provides a place for them to find each other. A second participant, P9, also lists similar beliefs as part of why she is on Tumblr, saying “There's a lot of cool fandom stuff, a lot of people who I agree with who are pretty chill to hang out with”.

4.1.2 Tumblr's Nicheness

Tumblr is not as popular as other social media sites: it doesn't even register on Pew Research Center's survey of American use of social media sites, and in comparison to Reddit's 2 billion monthly visitors, it only gets less than one tenth as many (Anderson, 2021; Bianchi, 2024). This is, as Wiktionary's definition for a hellsite explains, due to its issues with design, usability, and culture (“Hellsite,” 2023). Tumblr is, in short, weird, finicky, and niche. P10's comments reflect the pride and satisfaction that many Tumblr have regarding Tumblr's nicheness: “I would say it's a good thing just because I don't want to see a commercial for it or anything, like keep the regulars off of it.” P10 also goes further and connects what is positive about having a reputation that serves as a form of deterrence to their experience, saying that because of Tumblr's reputation as a “hellsite”, “it has a lot more intact culture”. For Tumblr users, the culture is a combination of having enough people who share interests, experiences, and beliefs, as well as not having their communities be drowned out by the broader public that can be found everywhere else, which both contribute to them being able to be authentic. And it is precisely that authenticity that puts many people off from the site. P10 was the only participant to explicitly verbalize this shared sentiment, but other participants did engage in the sort of good-

natured complaining and joking about Tumblr as a site with the shared understanding that no one was truly attacking or criticizing Tumblr in earnest.

4.1.3 Finding Information and Resources

On Tumblr, within the autistic community, there is a broad understanding of the spectrum of autistic experience. There are many blogs that focus on providing resources like infographics or articles on specific issues like executive dysfunction and how to overcome it with methods like body doubling, or what auditory processing disorder is, or what hyper- and hypo-sensitivity in multiple senses looks like, such as my-autism-adhd-blog. Similarly, many people often blog about something they personally experienced, including many participants in this study, which can also lead to explanations of how they found out something was related to being autistic or what helps for them. This kind of information is often much more immediately useful in terms of applicability. Someone might know they are having a particular issue, but not know how to support or resolve it or why they feel that way in the first place, which can be very frustrating.

One of the most consistent positive aspects of Tumblr that participants have mentioned is the ability to find information and resources. The first subject that they have been able to find resources on is the autistic experience. While most participants did not specify what sorts of information or resources they found, such as in P10's case, who merely stated that there was "a lot of good resources" in the #actually autistic tag, some participants had more to say. P4 remarked, "That was one thing actually, that got me started, was fighting for his IEP. So, got me

looking for people who had been through it, either themselves or with their children.” Accessing accommodations for disabilities often requires a lot of paperwork, documentation, meetings, and evaluations, and as a result the effort necessary for their acquisition can be overwhelming (Gibson & Martin III, 2019). There is a limit to how much Google can tell you about the specifics of what to do in a meaningful way. Instead, it is much more of a relief to hear from people who have been through the process themselves, who can tell you what to expect and what to do in concrete details. Tumblr is a place where, due to the demographics and communities as mentioned previously, people can find a wealth of in-depth, personal posts by people who have been through similar situations, as participants mentioned in the interviews. And while sometimes a larger community such as the autistic community in general may not be able to provide directly relevant advice, as in the case of P12, who uses AAC, going down a level to a smaller subcommunity, such as the AAC user community within the autistic community, can yield better results: “I feel like I get to be heard a lot better on this side of the autistic community, and that it's a lot easier to find supports and advice that works for me over there.” P1 also provided an account of the sort of specific information someone can find on Tumblr, saying “I have gone from the last 4 years of having very intense rejection sensitivity to this year having significantly reduced rejection sensitivity and when I do go when I do react strongly to stuff which I did a few days ago I have learned tools to handle it better and I have reduced a lot of my own intrusive thoughts and stuff” from the information they learned on Tumblr from people with similar issues.

Tumblr is not just able to provide information and resources on serious topics like the autistic or disabled experience but also can provide information and resources for one’s interests

and hobbies. As a hub of fandom activity, Tumblr is a place where one can find “a lot of good resources, a lot of inspiration”, as P9 says about writing. P8 provides an anecdote about finding information on Tumblr that would be very difficult to find elsewhere, saying “I posted a while ago about a sweater project I was looking to make and how the pattern itself wasn't size inclusive, and knitting Tumblr totally steps up when questions like that are asked to link alternative patterns or tell people how to alter a pattern. And in general, knitting Tumblr is extremely welcoming and size inclusive in a way that the rest of the knitting community online is not at all.” People on Tumblr are very passionate about their interests, and often have a variety of unusual skills or depth of knowledge that makes Tumblr a good place to look for resources. P3 provides an example of the level of dedication that Tumblr users can have to their hobbies, saying that though they had not kept up with their favorite comics for a long time, they could turn to users who had blogs containing comic issues if they needed a recap.

Some participants used Tumblr as their primary news source. P5 says, “Tumblr is almost always the first place that I hear about a product or a food recall, or a political thing that happened”. Few people personally pay attention to the FDA food recall web page themselves (Hallman et al., 2009). However, it is the sort of personally relevant and impactful information that is passed around on Tumblr to raise awareness. And with regards to political news, most people are just tired and don't want to deal with news reporting themselves (Robertson, 2025), but it worth noting that on Tumblr, the news often comes in the form of jokes or memes (the supernatural meme in particular), which participants do enjoy.

4.1.4 Finding Content

While people are often on Tumblr to find others to talk to about their interests, beliefs, or experiences, sometimes people are less interested in the social aspects and just want to find creative content like writing or art. Multiple participants, including those who either could not or did not want to make friends and connections. For example, P7 said, “I haven't really made any friends on Tumblr. Mostly I follow Ace Attorney blogs.” She treats Tumblr much as many people treat YouTube: as a place to find content on a particular (if often niche) subject. P5 had a similar experience where she was not quite able to make friends, yet remained because even though “shows will go off, you know, they'll end,” on Tumblr “there are still people who will blog about it every day. Like there are still people making gifsets for those shows.” And even for people who are or are also interested in community spaces, being able to find the content, separate from finding people to talk to about said content, is also part of why they are on Tumblr. P10 remarked, “I find it to be like the main fandom hub for me. Like if I want to see new content for something I'm interested in, I'll go there”. P10 and other participants were mostly talking about fandom, but content about many different topics and hobbies can be found on Tumblr, especially those that are more niche. And as many participants have also noted, Tumblr is very much a multimedia hub.

4.1.5 Appreciation of Others' Skills

While only one participant mentioned being impressed with others' skills and offering praise on Tumblr, validation and recognition is also an important part of any social media site.

P11 said that when they find art on Tumblr, “I will usually praise that artist because it is generally high above what I can do. And I'm just genuinely impressed by it. And I want to express that.” Though giving and receiving praise is not unique to Tumblr, it is worth noting that not only do people find a great deal of content of their interests, they also express admiration for the creators of said content, sometimes effusively.

4.1.6 Tumblr Jokes, Memes, and Humor

A distinctly Tumblr sense of humor was also something that many participants enjoyed about the site. P8 captured this sentiment clearly when she said “I also just love seeing what goes viral on there because it's a sense of humor that I really connect with”. While people find different things funny, and indeed different participants disagreed on what they liked, with P5 saying she preferred “lightweight” humor while P3 liked gallows humor, it is interesting that more than half of the participants were able to find jokes or memes that they liked enough to comment on. Jokes may not be the main reason why users are on Tumblr, but it is definitely something that brings a smile and a laugh to many, at the very least being enough to like before moving on, in P11’s case. P3 also explicitly names the gimmick or joke blogs on Tumblr, like blogs that repost the same picture of a rock every day, or blogs that do a particular thing, like determining which species’ genome most closely matches with a section of text. It is not just the jokes themselves but the social customs surrounding them that might contribute to why autistic users appreciate Tumblr humor. P8 said that in contrast to other sites like Instagram and Tiktok, “on Tumblr for the most part, the joke is fairly self-explanatory, which I appreciate. There's no

like, what's the joke? What am I not getting? And then everyone in the comments is like, oh, we're not going to tell you because you're not cool if you don't get the joke, but on Tumblr, it's like, if I ask what the joke is, I've had people literally explain the joke to me in the comments.” It could be the case that jokes on Tumblr are genuinely more straightforward, or that autistic users are able to communicate with each other more effectively overall as described in Milton’s double empathy problem (2012). P10 also made a similar statement, describing Tumblr jokes as “inoffensive simple jokes” that the users then run with, such as making an entire meme image out of a single misspelling.

4.1.7 Authenticity

Tumblr seems to foster and support a sense of authenticity in its users. Multiple users expressed that they felt like they could be themselves in a way that they could not either in real life or on other social media sites. When asked whether they felt that on Tumblr they “can be who they are without having to hide anything”, they agreed and said that other social media sites made them feel like they had to put on a face that wasn’t who they really were. P9 felt similarly, remarking that on “Instagram, Facebook, etc. there's too many people you already know from real life so people are less honest, and everyone's trying to impress everybody.” It is true that Tumblr users’ online identities are tied to their usernames, not their real life names, which provides a screen of anonymity compared to other social media sites, and that as P9 claims, this level of anonymity might legitimately make people feel more able to be authentic when they do not have to face potential negative reactions or consequences from close friends or family. P8

commented on the unrealistic standards and desire to show off on other social media sites, saying that on Tumblr in the fiber arts communities, it's just "real people posting their real projects". And P4 brought up a point that might be particularly relevant to autistic people. They said, "I feel like I'm much more authentic on Tumblr, like I don't filter myself the way I do at work or around even some of my family." Autistic people can be seen as too much or troublesome when it comes to following neurotypical social norms, as some participants have discussed, but on Tumblr, they might not feel that way for a variety of reasons, including Tumblr's large neurodivergent user base, the passionate communities of users centered on their beloved interests and hobbies, and as P10 also described, Tumblr users' individual content curation which gave them the space to be themselves, take it or leave it.

4.1.8 Explicit Social Rules

One of the interesting features of Tumblr is that Tumblr users will explicitly list out the social customs and best practices. P8 brings this up in the context of users fleeing from other social media sites, Twitter/X in particular. She said, "on Tumblr, I log in and it's like, hey, Twitter users who came here. Here are all the rules for engaging with Tumblr. And I'm like, well, gee, thanks for writing it all out for us.". Users on Tumblr are aware that Tumblr culture can be particularly opaque and unusual, with multiple participants discussing how long it took them to learn and adapt. Even outside of waves of users leaving other social media sites en masse, posts do get passed around giving detailed instructions on how to style one's blog or the importance of content curation. While this is not an official, company-provided onboarding process, P8 also

draws a distinction between Tumblr and other sites where “it's just kind of getting thrown in like a soup of people and everyone being like, how do you already not know how this works? And I'm like, I don't know anything.”

4.1.10 Forming and Maintaining Relationships

Other than looking for a community, one of the reasons that people are on social media is to make friends, and this is true on Tumblr as well. Many participants have mentioned that they are looking to reach out and make friends. P11 even said that they explicitly posted on their blog that they were looking to talk to people to make friends, remarking that on Tumblr for the first time they understood how someone “can just meet a complete stranger on the internet and then on the internet and then eventually that leads to some deep real life connection”. P11 was far from the only person to have formed a deep relationship with someone they met on Tumblr. P10, for example, recounted that the best experience they had related to Tumblr was meeting their Tumblr friends in person. They said that as soon as they were old enough, they felt comfortable trying to meet “because we've known each other for years at that point and we had a pretty good idea of who each other was and what we all look like and stuff like that. And we've had a few calls, some more than others, but we just knew it would work out fine.” Other participants, P1 and P6, even met their significant others on Tumblr, not just friends.

And even participants who are not on Tumblr to make friends (or to make new friends) have spoken about the strong relationships that they have with other people on Tumblr that doesn't necessarily fit the traditional shape of a friendship. The concept of mutuals, people who

follow each others' blogs, who might end up hearing about each other's fears and hopes and struggles even though they might never see each other in person or know each other's names or faces, is very much part of the experience of Tumblr. For P8, even though social relationships are difficult to maintain, she expressed that they are comfortable with her mutuals, saying "Friends is a strong word. I think that a lot of it comes down to parallel play. I'm familiar with and engage with a lot of my mutuals, but like. I've never moved any of those relationships off of Tumblr. I've never really felt the need to." The lower stakes and asynchronous nature of Tumblr mutuals and Tumblr interaction in general was much easier for P8 and for some other participants as well.

4.1.11 Advocacy and Making a Difference

A lot of people on Tumblr are involved in advocacy, which often but not always involves some aspect of their identity, like the participants who were involved in advocacy around autism. P12 provides a striking example of how being on Tumblr and seeing posts from others can encourage someone to take action even in real life. They mentioned how Tumblr "set [them] on [their] path of activism", adding that when they "see people talking about actionable steps and like how that will improve the overall picture of things on a local, personal, and societal level it gets a lot easier. I feel less like I'm trapped by the bad things, and almost more like I'm being fueled by them. The injustices, and more accurately how I feel about those injustices, become a source of motivation instead of a shackle, and I feel better overall." And while P9 might only be posting to her blog which is a comparatively less impactful form of activism, she acknowledged

the impact it had on her mental health if nothing else, saying that doing so “ makes me feel less helpless.” Then there are people who may not be described as obviously activist but are still concerned with making a difference in the world. P6’s hobbies, taking requests from others and making AAC symbols to literally give people the words and symbols they need to speak their own thoughts, is also driven by a similar desire.

4.1.12 Selfcare and Hopeful Posts

Another aspect of Tumblr that sets it apart from other social media sites is the existence and importance of self-care posts and hopeful posts. P12 provided an explicit example, explaining that they “make sure to follow blogs that fall into like ‘hopecore’ and ‘radical compassion’ and stuff” and that they also “follow blogs that focus on improving your mental health and checking in with yourself”. Users will post or reblog posts to get up, stretch, eat, or drink. In my brief time looking for participants for my study, I have also seen and benefited from those posts. P8 also alluded to the existence of hopeful and selfcare posts in their content curation efforts, saying “I was getting sad from all the doomer posts on Reddit and then you see the same thing on Instagram where regardless of what they believe, everyone on Instagram thinks the world is ending. So you see that a lot less on Tumblr or if you do, it's more like, oh, well, if the world's ending, at least we have each other.” Even in the more serious and distressing posts, often about real life events, there are definitely users that comfort each other and try to frame things positively.

4.1.13 Venting and Perspective

Since Tumblr offers both anonymity and communities with shared experiences, it can definitely be a place to vent and to seek advice or perspective. Only two of the participants spoke about venting and getting their frustrations out on Tumblr rather than letting it spill over into the rest of their life, but for P4 it was an important part of being on Tumblr and also a startlingly high proportion of their posts. P4 explained that venting about her frustrations on Tumblr “keeps me from bringing it home”. P4 added that due to how small the field she works in, everyone knows everyone else, unlike on Tumblr where she can post anonymously. P4 also described how she compares her own experiences and reactions to those of others in the notes of her posts, saying that maybe she is “too in my head on this thing. Or sometimes I post and people are like, oh my god I can't believe that. And I'm like, right? It is insane, right? Like I have not lost it.” (italics mine). Venting can be done either to get perspective from others who have had a similar experience to compare one's own reaction, or from people entirely unfamiliar with the situation to get their initial impression. P8 also spoke about doing the former when she created a post “venting about how terrible it is that you can't buy quality fabrics anymore and that it's no wonder that everyone's making their own garments now because you can't buy quality clothing even if you pay for it”. They immediately got a response of around 500 notes, with users saying things like “yes, drag their asses,” or “this is so relatable, I went to the store yesterday [for a sweater] and it was marketed as a wool sweater, but it's only 5% wool”. P8 felt much better after hearing that others had a similar point of view.

4.2 Negative Experiences and Strategies to Mitigate Them

4.2.1 Bots

Just as on any other social media site, there are a lot of bots and porn bots in particular on Tumblr. Both P3 and P4 mentioned having to take steps to deal with bots as well as other unwanted content (largely in the form of blocking). P4 said that they screen new people who follow them, saying that they will “look through their stuff and see if this is somebody that I would want to interact with.” Screening people can be necessary not just to determine if their beliefs or posts are something you want to see but also to see if they are a bot or not by checking the profile picture and first few posts. P3 also mentioned the sheer number of bots, but said that blocking was part of their overall Tumblr content curation process which involved other actions to keep their blog a safe space.

4.2.2 A Culture of Content Curation

Compared to other social media sites, Tumblr has a culture where people are encouraged to aggressively curate their individual experience to make being on Tumblr something positive. And aside from the website functionality and company goals supporting that, other users also understand that that is your goal and so take it less personally when you block or unfollow. People are here for content about their interests, so blocking someone or unfollowing someone can occur for a reason as simple as them not posting the content that you are interested in anymore. As P2 said, “it's important to use the block button as you see fit. And people I think are afraid of it because it feels so final but it doesn't have to be, you can unblock someone, it's not the end of the world. And I realize a long time ago that me blocking someone is going to hurt

them a lot more than hurts me and it's really...for me it's not that deep. It's like if you like macaroni and cheese and I'm like talking to you and you're like, oh I hate it, then like whatever, goodbye.” Similarly, P4 said, “yeah, the people that I talk to regularly, I don't have to worry if I'm bothering them with my infodump, because they can unfollow me. Like they don't have to be there. They're *choosing* to be there and I don't have to worry about what I'm putting out there because people are choosing that content.” For autistic people in particular, it can feel really bad to know that you are placing a conversational burden on someone to put up with your rambling, an experience that P5 went through with in-person relationships. On Tumblr, each individual user contributes to the overall acceptance and normalization of content curation, which helps to alleviate that concern.

4.2.3 Anonymity and Lack of Judgment

Participants in the study often mentioned Tumblr's sense of anonymity and framed it as an absence of other negative factors. The first and most obvious negative factor on other social media sites is that it's tied to your “government identity”, as P5 called it. P5 explained that she prefers Tumblr because “it's an interesting space where you can sort of simultaneously preserve anonymity while also getting to know people on a very personal level, like if you choose to be fully separate from your in-person identity.” P10 agreed, saying that on Tumblr it is “not as normal to show your face, on other social platforms you're expected to have your face as your profile picture and post a selfie sometimes. And the [Instagram] story, like apps with stories, it's very common to see people post themselves. That's not a thing on Tumblr.” As mentioned

before, Tumblr users are identified by their username and profile picture, which are usually completely separate from their names. People might never post their names or faces, and while not all users adhere to older rules about internet safety and anonymity, many participants spoke about how their stances on anonymity were shaped by the experiences on the early internet and their long tenures on Tumblr; as P10 said, on Tumblr it's "not as normal" to show your face. Nonetheless as P5 said, users on Tumblr are still able to form deep relationships without giving up that private information.

P8 mentions another factor that Tumblr users may be trying to avoid. On other social media sites, users will probably have to engage at least a little with their friends' or families' interests and activities because that is the main purpose of the site. On Tumblr, however, P8 specifically says that the main way people use the site is that "you follow tags and people will just kind of randomly follow you." Your own interests and hobbies are front and center, and you will gain friends and followers from those interests and from what you post, not from prior relationships in the real world. In this way, Tumblr allows users to engage in their own interests without other social entanglements. P1 also mentioned this, saying "for example on Facebook I've learned over the years that I probably shouldn't [overshare] especially because people have given me backlash for some of the things I share. Like Tumblr there's less people I actually know personally on Tumblr so I kind of just say whatever I want on there."

4.2.4 Provoking Others for Attention

As with any other site on the internet where people interact, on Tumblr it is also possible to provoke other users for a reaction, positive or negative. While only one participant spoke at length about looking for attention, other participants have mentioned getting negative attention as well. P9 described how she is deliberately “inflammatory on purpose to get attention and reactions”. While many people on Tumblr are actively involved in content curation because they are tired or uninterested in attention and negative attention in particular, many are not. Furthermore, it is quite possible to do the opposite and curate things to allow for maximum engagement. P9 also said that she leaves her askbox open and with anonymous asks turned on, stating that she loves “hate mail” and wants people to be “ridiculous”.

4.2.5 Terrible Internal and External Search

Most users would agree that the Tumblr search functionality is terrible, and this was commented on by participants as well. Tumblr search is case-insensitive, which is not mentioned on the Tumblr Help center Page, and furthermore, Tumblr search does not allow for the standard boolean operators such as AND, OR, and NOT (*Search and Filtering Basics*, n.d.). However, Tumblr search does allow for exact text matches, but in order to use that functionality, it is necessary for users to remember an exact fragment to begin with, which defeats the purpose of searching. P5 directly acknowledged this difficulty in our interview, saying that Tumblr users are “pretty well known for writing kind of commentary in tags since tags don't do anything in the search engine”. Here the tags are referring to users’ personal tags in their reblogs of a post or chain of posts. This places a huge burden on the users to tag correctly and consistently, and to

remember both what they have posted and tagged, and what other users have posted and tagged. P6 also agreed that Tumblr's search was and is terrible, but indicated that this was a surmountable or else tolerable obstacle. And P2 put it rather bluntly: "I'll just tag something like autism and that will get a huge audience of a lot of people. But if I tagged it in a different way or if I misspelled or something it just wouldn't work. Then people wouldn't be able to look up the tag. I know Tumblr's tagging system is shit, so bad, doesn't work half the time." I will admit to having another personal grievance with Tumblr's site-specific search, which is that it will not execute a search if one presses enter; it is necessary to click on the suggestion below the search box instead of pressing enter like everywhere else on the internet.

4.3 The Company's Decisions and Their Effects

4.3.1 Less Focus on Engagement

While I have discussed many different actions or strategies that Tumblr users can take to affect their user experience, the users are not the only party with the ability to change their own experience on Tumblr; the company that owns Tumblr also has a great deal of influence over the user interface and monetization, among other aspects. Many people are on Tumblr precisely because they like the set of features and UI that Tumblr has (or rather, as expressed in the interviews, because they dislike the monetization and experience on other sites). P12 was very emphatic on this point, saying that "Tumblr is WAY different [compared to other social media sites]. They have the "For You" page on Tumblr, but they still have the "Following" page which is more true to the original Tumblr experience. You don't get bombarded by ads (and the ones on

here are WEIRD)”. They then went on to explain how the company’s decision not to push engagement and monetization in that way led to an environment where “likes and follower counts don't really matter”, which is something that they and many other participants appreciate. P10 also added that they would only be driven off of Tumblr if “the platform takes several bad turns”, which they described thusly: if things got “unavoidably bad, then I would feel differently. Like if they started pushing AI features, for example, that would probably push me away, but they're not doing anything like that right now. So like right now they have an algorithm, but nobody—if you don't want to look at it, you don't have to look at it.”

4.3.2 The Algorithm

Many Tumblr users have very strong feelings about personal control, which is part of why they chose to be on Tumblr after evaluating their options. Tumblr is much less insistent on users using its algorithm to access content in contrast to other social media sites. P6 remarked on this explicitly, saying, “Tumblr is different than other sites because you have much more control over the posts that you see because unlike Instagram or TikTok there is barely an algorithm.” P4 also felt similarly, complaining that “you get on Instagram and god knows what's gonna be put in front of you”. And while Tumblr users do have some measure of control even over largely company-decided aspects like the user interface with templates and third-party tools, by and large users have to deal with whatever experience the company decides to give them, no matter how much it infuriates them.

4.3.3 User Interface Changes

Whether Tumblr's user interface changes more or less often as much as other social media sites, another theme that came up was that of the importance of things staying the same. P4 commented on Tumblr's changes, expressing her relief that she only uses Tumblr on the app: "it sounds like on the computer some things have changed, but the app has stayed pretty much how it's always been."

4.3.4 Tumblr is like the Older Internet

Participants, especially those who have been on Tumblr and on the internet in general for several years, have also commented that Tumblr feels like the older internet. P10 recalled that Tumblr "takes a lot of its roots from older websites. And because it's not as popular as it used to be, it's not really evolving with the times. And so, you know, you have a lot of traditionally rooted people that are on there and that respect how it works." Other than the culture and norms, customization of one's blog is also a contributor to this feeling. On Tumblr, users can not only use themes, but also directly change and implement their own HTML, CSS, and Javascript code, which is a level of control and expression that is unheard of on other social media sites (*Customizing Your Theme*, n.d.). Users can change what tabs show up as well as where the textboxes are; they can also change what mouse cursor is used on their blog as well as the colors and background images, which can also be animated. In this way, Tumblr has created a space for self-expression.

4.3.5 A Nonhierarchical culture

Yet another result of the companies that own Tumblr deciding not to push engagement is a nonhierarchical culture where there is neither benefit nor even usefulness of fame and follower counts. As P5 says, “you don't get to be a social media influencer on Tumblr”. Whereas on other sites users can be desperate to go viral or to promote themselves and their products, on Tumblr, as P11 says, “Tumblr is much more chill. It's just you kind of throw out a post, whoever sees it, sees it. It's not a competition”. On Tumblr everyone has their own experience where no two users might interact with the same parts of Tumblr, and many users are satisfied with staying in their own carefully curated bubble. P8 expressed just how useless and foreign the concept of internet fame is on Tumblr, saying “it's more common [on Tumblr] to see someone saying, guys please don't give this post more notes, like clout chasing on Tumblr? Nobody clout chases on Tumblr. What are you getting from tumblr notes, you know?”

4.3.6 Writing and Reading Posts with an Open Mind

A visible knock-on effect of not pushing engagement and not stoking negative emotions is that people are more thoughtful about their posts and more understanding and patient when engaging with others. Currently, Tumblr allows for 4096 characters per block and 1000 blocks per post, which means that users have the character limit to explain in detail and to be thoughtful, which may also make people less willing to jump on them for perceived errors or bad takes (*Writing Posts – Tumblr Help Center*, n.d.). P4 said, “[Tumblr] was the first place I could post things online where people did not read it the wrong way. On Facebook it feels like when I post

things people always read the worst thing into it or they read it like I'm stupid, and I don't mean it either of those ways.”. While part of P4’s experience might be due to the large number of neurodivergent users who can understand each other’s ways of communication better, it is also probably in part due to the calmer atmosphere. This atmosphere is also supported by the company through the design of the site, which allows for much longer posts than other social media sites do.

4.3.7 Multimedia Support

One of the points where participants were more split on Tumblr’s usefulness and benefits is how effectively one can share different forms of media on Tumblr. Initially Tumblr was created as one of the first places with multimedia support, with users who have been on it for longer like P3 aware of its history. P3 recounted hearing about Tumblr from others: “They kind of said, it's kind of like LiveJournal, you can add pictures more, you can add video. It was like this sort of brand new thing.” However, over 15 years after its creation, some users find other sites and platforms better for different forms of interaction. P11 commented on some of the difficulties, saying that “we stopped talking on Tumblr because we found it was annoying for sharing videos and things like that. So we moved over to discord so we could talk more. And now we're just talking on there.”

Chapter 5: Discussion and Conclusion

5.1 Discussion

Overall, many of the themes that surfaced during the interviews were particularly relevant to autistic people. Having a large community of autistic and otherwise neurodivergent users means that autistic users can unmask within those communities, which takes the burden of interpretation and conformity to nonautistic social norms from the double empathy problem Milton described in 2012 off of them. And Tumblr users are also generally unfazed in the face of unusual and less socially acceptable behavior, creating a particularly judgment-free environment that many participants remarked upon. Also, autistic users being free to pursue their own interests with an intensity that is matched by other users and the content curation that allows people to see what posts they do want to see and to not see what they do not want removes potential sources of friction; because people come to Tumblr with different goals than they do other social media sites (that is, to pursue their own interests), the sorts of interactions that happen are more favorable for autistic people as evidenced by the participants.

Tumblr is very under-researched, and research that also focuses on neurodivergent individuals or groups on Tumblr is even more rare. One of the only other academic sources discussing autistic users' experience on Tumblr is a thesis by Andrew Kirkconnell in 2019. Many of the themes from interviews echo the themes that I gathered from the participants in this study as well. The first theme is that of community, where autistic users on Tumblr very much feel that they have found a *community of people with shared experiences*. Kirkconnell even used a quote to this effect for the title of his thesis, quoting Tumblr user sin-cordura in 2018, "it's like

i finally found a community where everyone waddles like me.” He also found that there are a lot of autistic users on Tumblr, which contributes to the overall size and presence of the autistic community on the site. And while people join Tumblr for multiple reasons, including their interests and advocacy, Kirkconnell says, “[b]y far the most relevant factor influencing these people to join the community was exposure to the experiences of other autistic people”.

Similarly, I found that while not every person I interviewed was active in the autistic community on Tumblr, almost all of them found the information and resources provided there to be useful. Kirkconnell also says that “the autistic community on Tumblr is an excellent resource for those looking for information on a possible autism diagnosis, professional or otherwise.” While he is more focused on information surrounding a diagnosis, he also mentions that Tumblr and its autistic community attract “people who might have traits congruent with” autism, and information and experiences all along the autistic spectrum is what I found. There are affirmations, medical advice, venting posts, jokes, and anything else that users want to talk about regarding being autistic.

Another aspect of Tumblr that Kirkconnell highlights is the *prevalence and intensity of content curation*. Kirkconnell mentions one participant who had nine themed blogs, three of which were “explicitly autism-themed”, which is an example of how Tumblr users “are not simply curating what they experience through following specific users and/or tags, but by curating the content of specific themed blogs.” The first step of content curation is to pick and choose what you see through deliberate following of users and tags, but going beyond that, when creating a blog dedicated to a specific topic, a user can then choose when to engage with that particular topic and keep their blogs neat and separate. It’s not just about what content someone

is consuming, it is also about what they themselves are producing, because when users start splitting up their own blogs' content, they make it easier for other people to curate as well, at least by topic. This is something that I found as well; multiple participants had specific themed blogs, two of which in particular had advocacy/politics focused sideblogs. Right now, due to current events, a lot of people are pretty tired and emotionally drained when it comes to politics and advocacy work, so the choice to make a separate blog is probably something those users are very relieved about and also something that everyone who sees their posts are probably relieved about as well, because the point of content curation is not just to see what you want but to not see what you don't want.

One of the other rare few resources on Tumblr is a collection of essays edited by McCracken et al. in 2020 titled, "a tumblr book". In chapter 1, You Must Be New Here, McCracken et al. give an introduction of what Tumblr is, its demographics, and some of how the design affects how users engage with it. They describe Tumblr's demographics thusly: "From 2007 to 2018, Tumblr thus became a home and hub for many who were socially and politically disenfranchised: youth, LGBTQ+ and nonbinary persons, people of color, progressives and activists, feminist and queer fans, queer and alternative porn consumers, sex workers, the disabled, and those with mental illness, chronic pain, or bodies that didn't reflect social ideals.". Both the participants I recruited as well as the experiences they shared with me were in agreement with this description, except for the part about people of color, which I had difficulty finding. Nonetheless, Tumblr's communities of people with marginalized identities is a core feature of the site and is notable in comparison to other social media sites which neither set out to be such a hub nor are they currently.

Another point of agreement was on the “more egalitarian, nonhierarchical, uncensored media environment”, which created a culture that supported “those who did not want to be easily surveilled or identified”. Many participants felt a sense of positive anonymity and lack of judgment from others in the Tumblr community, and McCracken et al. point to many features of the design of the site that facilitate that environment, listing “control over the design and appearance of their public-facing blogs”, pseudonyms, a wider content pool, and a Dashboard (feed) organized by reverse chronology as some of the factors. When participants in this study said things like there are no social media influencers on Tumblr or mentioned that even people famous elsewhere were just another blog on Tumblr, these design aspects of Tumblr were what they were alluding to. Users on Tumblr may not have the words or training to speak about web design, but they are definitely feeling the effects and capable of commenting on what they like and do not like.

McCracken et al. also make a point of the support that Tumblr offers many of its subgroups, including information, resources, and community. They say, “Tumblr was, from its beginnings, a crucial site for LGBTQ+ community resources, support, education, acculturation, fandom, and networking...Tumblr in particular facilitated the development and popularization of new identity formations for sexual and gender minorities. In a similar way, Tumblr also became a foundational space for group support, validation, and identity development around experiences of mental illness, chronic pain, disability, and non-normative bodies.” McCracken et al. were not as much focused on neurodivergent users, but the stories that I heard from my participants were completely in line with this view. Over time, autistic people from other sites and forums migrated or were drawn to Tumblr, which is likely one of the largest remaining places on the

internet that provides all of these kinds of support. Regardless about whether Tumblr stays up or not, it has helped a lot of people who really needed it and had nowhere else to turn to.

It is worth mentioning that in many of the interviews, participants expressed frustration or dissatisfaction with other social media sites in comparison to Tumblr. They consistently mentioned how *they felt misunderstood and harassed*, and how other sites generally contributed to negative mental health or emotions, to the point that some of the participants said that they either don't use other sites, never learned how to, or don't see the appeal. And while they were frustrated with Tumblr's lack of usability in a lot of aspects like its terrible search system, they were also quick to point out their frustration with many trends in the internet overall, like intrusive ads or overbearing algorithms, that diminish users' control and privacy. In the pursuit of financial gain, while sites might write off people like the participants in this study as acceptable losses, it's worth mentioning that this reflects broader frustration not just among autistic people. A lot of sites like Youtube or search engine result pages have become less and less usable, and people might only stick with the options they have now because they don't know of a suitable alternative. While it may never be the case that people stop using social media sites that make them feel terrible, I don't feel that the unhappiness of so many people on sites that they use so much and so frequently that have also become so integral to our social fabric is a good thing. In comparison, when participants use Tumblr, the frustration and the joy that it brings tend to balance out in a net positive; they feel better and happier for having it in their lives.

Tumblr isn't earning money, and it hasn't been earning money for a long time (McCracken et al., 2020). Users know that Tumblr has hovered on the brink of shutdown for

years (dduane, 2023). Three sales in its history, to Yahoo, to Verizon, and to Automattic, paint a bleak picture of its finances. The first sale was for just over a billion dollars, by the next Yahoo had devalued it by 700 million, and by the time Automattic bought it was worth less than 3 million (Alexander, 2019; McCracken et al., 2020). And in 2023 Automattic pulled most of the staff from Tumblr and put them to work on more profitable projects (Robertson, 2023). And posts from the site also express frustration, with a reblog of a post from Tumblr user and former staff member jv saying, “We tried hard: Post+, the merch store, blaze, ad-free...all those were attempts to make tumblr a platform funded by its community. The results were...not great. Like, two orders of magnitude worse than they needed to be. That let (sic) tumblr in the hands of advertising money (that even if tiny compared with other sites, it still is the main Tumblr source of money by far). And for that, if you want to make the site stop burning millions per month you need way more people than we tumblrinas are right now” (dduane, 2023).

Even if Tumblr isn’t sustainable, which by now is clear to pretty much everyone (certainly not in the traditional sense of an “investment” which increases earnings per quarter or year), the site still provides a lot of value and a lot of joy to a lot of people. And the services and functions that Tumblr provides, and the design of its site and the people that it attracts, as participants attested, are not something that can be found anywhere else on the internet.

There is also the matter of who uses and enjoys Tumblr. Facebook, Twitter/X, Youtube, Discord, and Tiktok are all sites for everyone: for people who are accepted by society, who are not in society’s margins and shadows. Sites like Facebook and Twitter/X are marketed to everyone, and they try to entice every single person to use their platform. Tumblr does not. Tumblr is for many different marginalized groups that cannot find a place elsewhere for

themselves: the queer, the neurodivergent, the disabled. If Tumblr goes down, I would be hard-pressed to find another social media site that would be, if not welcoming, then at least as sheltering as Tumblr has been for these groups and their communities. So on top of considering the value Tumblr brings to everyone, it is important to consider who in particular would be hurt by its loss. It has always been easier to market something for broad public appeal, to be the least problematic, the least challenging, the least niche; it is a lot harder to maintain, let alone to make, space for the opposite.

In a Forbes article, Steinhurst talks about his own experiences with the attention economy of modern social media sites, which was described in 1971 by Herbert Simon, a psychologist and economist, where “a wealth of information creates a poverty of attention” as people and information fight to be noticed and prioritized (Steinhurst, 2024). The attention economy also shows up in which Google search results are on the first page as opposed to the twentieth and in which posts on social media go viral. Tumblr, however, with its nonhierarchical culture and democratizing reverse chronological feed where a post with 10k notes gets the same space as a post with 10, does not operate under an attention economy. As a result, Tumblr does not foster a culture of attention (and thus revenue) generation in the way that other social media sites do. Just as posts do not compete for attention and clicks, ads, too, cannot and do not fight for attention due to the combination of (older) company policy from the founder and the resulting culture he created. There are also other ways that Tumblr does not follow an attention economy: many users on Tumblr are frustrated with intrusive ads and are on Tumblr specifically to avoid them, as several participants have expressed. As a result, Tumblr users, at least on the browser version, can be quite resourceful when it comes to avoiding ads and other sponsored content, which

makes it difficult to earn money that way. Through a combination of these factors, there is no conception of a Tumblr influencer who earns money by making content on Tumblr, as participants have said, which fundamentally changes the goals and motivations of the users on the site. From a human-computer interaction point of view, this means that Tumblr's user base is different from the general population in a significant way that impacts how Tumblr and sites like Tumblr should be designed to align with the users.

5.2 Contribution to Ethical Methodology

This research study provides a contribution to ethical methodology in both the consideration of eligibility regarding cognitive impairment and for the ethical inclusion of participants. Ethical considerations in this study were confusing and unclear to me due to the difficulty in reconciling different understandings of disability and impairment from different frameworks with the IRB's definitions and guidance and due to the fact that this was my first research project. I considered the guidance of the IRBs of multiple different schools regarding informed consent and decision-making capacity as well as the definitions and descriptions of disability in the Americans with Disabilities Act, the activities of daily living (ADLs), and the Web Content Accessibility Guidelines (WCAG) principles (Perceivable, Operable, Understandable, Robust (POUR)), as well as personal experience and training and the experiences of family and friends, disabled or otherwise. I would like to emphasize that this contribution would not have been possible without the time, energy, and emotional labor that my disabled friends have spent teaching me and teaching other people. Certain kinds of work are more visible and lauded than others; writing a thesis is more visible than quiet conversations in

Discord DMs, for example. But doing good science means citing my sources, so I would like to bring to your attention the people whose voices are not here but whose personal experiences had a strong impact on this work. I cannot name them because I wish to protect their privacy, but it would be unethical to claim that I did everything on my own; prior knowledge like the activities of daily living (ADLs) are things that I heard from them and incorporated here.

5.3 Limitations

I have almost certainly not hit thematic saturation. In the last five interviews, every single participant brought up at least one theme or topic that had not been mentioned previously. Given the limitations on time and the number of participants, and considering the gaps in the demographics of the participants involved like race and potentially socioeconomic status, it is quite possible that other users might have parts of their Tumblr experience that differ from what I have discovered. While Tumblr is a haven for certain marginalized identities, it is not the case that every single marginalized identity is equally welcome. Just the fact that I had so much difficulty recruiting autistic people of color is evidence of either that or different groups' willingness or ability to participate in a study. I know autistic people of color exist and exist on Tumblr in particular, but I did not and do not know what tags they might be using so it was remarkably difficult to find them. However, I also do not know how someone would go about finding those tags. In hindsight, the difficulty I had finding the appropriate meant that I should have reached out to other people who do have that knowledge, and if there is in fact no commonly agreed-upon tag, then I should have switched over to snowball sampling. This is an area where I lack expertise and knowledge, and that means that I should have worked

collaboratively instead of alone. When reflecting on this difficulty, it also occurred to me that I don't even know what tags I, as an Asian-American autistic person, would use to describe specifically Asian-American autistic issues.

I will also briefly mention that the format of doing interviews was an issue for some participants. Not everyone is able to answer questions on the spot without preparation, and while I gave people the option to read the questions and prepare answers in advance, they still might have had information come to mind after the interview that I was not able to capture.

Accessibility was not much of an issue with the users I interacted with because while I did interview people who use AAC, they were able to either type in chat or have their AAC speak. I did have one potential participant tell me that they are deaf, though they did not end up participating in the study. Had they participated, that might have been more difficult of an interview because I would have had to type my questions and responses in chat. Tumblr is, however, infamously inaccessible to screen reader users, who might have had much more negative things to say about their user experience.

5.4 Conclusion

Autistic users on Tumblr use many strategies to seek out experiences of joy, which includes finding community with people with shared interests and identity, being able to be your authentic self, and emotional regulation in the form of finding hope and letting out negative emotions in a safe way in a safe place. They also seek to avoid negative experiences largely through aggressive content curation, striving to make their blogs and their Tumblr experience overall a source of safety and comfort. The company that owns Tumblr also plays a large role, a

fact that remains consistent despite Tumblr's multiple acquisitions, shaping the actions of the users and therefore the resulting environment and culture of the site.

The results of the study have some important broader implications. The first is the importance of community for people of marginalized identities. Being alone or feeling that no one nearby understands you is a terrible experience and leads to poor mental health or worse.

And when the online spaces that other people would go to to socialize, like the most popular social media sites and apps, are neither marketed toward nor supportive of people who share your identity, you will most likely not be able to find community there. Autism occurs in the general population at around 1%, so it's very possible for people to not know someone else in real life who is also autistic. And also due to the stigma around autism, many people will not feel comfortable disclosing their condition, so others may never find out unless they are very close. Having a critical mass of users who share your identity and having an exclusive space for said identity are thus very important, because it provides a relatively judgment-free and understanding environment, at least regarding shared experiences.

The second implication of the findings is that sanitizing social media sites to remove what is socially undesirable, the way Verizon did by banning porn, but also the way other companies remove or dial back mentions of queer or disabled or racialized experiences, puts an unfair burden on people of those identities, because it's not like it isn't real and it's not like isn't happening. And on a less heavy note, but one that is also in a similar vein, very niche hobbies or interests and fandoms with very small fan bases also face a similar issue of representation and inclusion. Overall when trying to appeal to the largest audience, inevitably those on the margins will be cut out as acceptable losses in the move towards the center. However, if every site caves

to the pressure to fit what is “normal”, then people fundamentally will not be able to find places and information that they need.

The third point of note is that none of the themes and findings from this study are exclusive to autistic people. Autistic people are not the only people who want community, who have hobbies, who appreciate clear communication, who want to be able to be themselves, or who want to find hope in an emotionally challenging reality. Autistic people are also not the only people who want a usable website, who want interaction design that means that they are able to do their jobs or reach their goals as easily as possible, and who understandably complain about bots or a poor tagging and search system. Just as accessibility for one group benefits everyone, the findings of this study might be particularly relevant to autistic people but are also generalizable to everyone else as well.

The last broad finding is that Tumblr users are incredibly frustrated and disillusioned with current trends towards the loss of user control and autonomy, towards intrusive ads and attempts to wring them dry of their money and attention. What Tumblr users are encountering is enshittification, which Wiktionary defines as the “phenomenon of online platforms gradually degrading the quality of their services, often by promoting advertisements and sponsored content, in order to increase profits”. Users have posted, and do continue to post, angrily, that they want Tumblr to lose money, to keep losing money, to never earn money from its users. As a few more examples, user sreegs commented on the anger towards the staff post about ad-free Tumblr in 2022, which continued “to get thousands of notes telling staff to fuck off in the tags”, and user andiest chided the people who wanted Tumblr to be run as a nonprofit and compared it to Archive of Our Own (AO3), saying “AO3 is an anomaly being a massive platform

successfully running as a non-profit. They have a *legion* of volunteers and work their asses off fundraising every year to keep the servers up. All their financials are open to the public and people still act they're evil money-grubbing assholes" (dduane, n.d.). Yes, websites, and not just websites but everything else, must be financially sustainable in order to keep providing services, and yes, demanding that a company earn zero profits or continue to operate at a massive loss is unreasonable. However, the fact that these long, emotional threads exist and are passed around so widely is a very strong sign of just how deeply exhausted and even resentful users have become. And while it may well be the case that Tumblr users are more outspoken or feel more strongly about this issue, this is a sentiment that is likely echoed elsewhere as well. Users are tired of corporations running roughshod over them to provide the least services for the most cost, whether that cost is in money, information and data privacy, or control. Overlooking Tumblr means not listening to the voices of users who have the most to say about design and how it impacts users and shapes website environments and cultures.

Future work should investigate why users might choose Tumblr over other social media sites or otherwise be uninterested in or unable to pick up and use other social media. Also, research should be done into what activities Tumblr users are doing to reshape sites and code into what they want, with third party tools like xkit, with adblockers, with writing or using scripts, etc, and why they choose to do so, as well as investigating what, if anything, could convince users to stop. Researchers should also start by asking, how can we preserve, replicate, or foster the positive aspects of Tumblr in a sustainable way while taking users' frustrations seriously and treating them as legitimate? How can we start to undo the prioritization of money and engagement at all costs and start to take better care of our users, autistic or otherwise?

Appendices

Appendix A: Interview Script

1. Can you introduce yourself?
2. How long have you been on Tumblr?
3. Is your experience of using Tumblr different from using other social media sites, and if so how?
4. Would you consider your experience on Tumblr a largely positive, negative, or mixed experience?
5. How do you find happiness and enjoyment on Tumblr?
6. Have you been able to find community or friends online on Tumblr?
7. If so, why do you think so, if not, why not?
8. Is there anything else you want to share about autistic joy online?
9. Thank you for your time.

Appendix B: List of Tags Used to Search for Potential Participant Subgroups

Autistic people of color:

Tags: #poc, #people of color, #autistics of color (includes autistic, autist, autists)

Black autistic people:

Tags: #black¹, #black autistic(s, autist(s)), #autizzy, #black tumblr, #African American

Hispanic/Latino autistic people:

Tags: #hispanic, #latino, #mexican american, #latinx, #latina

Indigenous autistic people:

Tags: #indigenous, #native american, #native

Asian autistic people:

Tags: #asian, #asian american, #chinese/japanese/korean american, #east asian, #southeast asian, #south asian, #SEA²

Self-diagnosed autistic people:

Tags: #self diagnosed, #self dx

Autistic AAC users:

Tags: #AAC users, #AAC

Note: All tags were used in conjunction with the #actuallyautistic tag, which resulted in an AND search where both tags must be present on a post for it to appear in the search results

¹ This tag provided images of stimboards (panels of GIFs meant for visual stimulation) and other aesthetic boards that focused on the color black

² Since Tumblr search is not case-sensitive, this provided pictures of the sea and the ocean; I meant to use SEA as short for South East Asian

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