

WHERE EVERYONE WADDLES LIKE ME – AUTISM ON TUMBLR

**“WHERE EVERYONE WADDLES LIKE ME”: AN EXAMINATION OF THE
AUTISTIC COMMUNITY ON TUMBLR.COM**

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**A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the
Requirements for the Degree Master of Arts**

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LAY ABSTRACT: Using a purpose-built blog to learn about site culture and a series of online interviews to discover participant experiences, this study explores the culture of the autistic community on Tumblr and its impact on its members. The autistic community on Tumblr is a place that its members have more freedom to act and express themselves (through art, videos, shared stories etc.) than in the physical world. Through being a way to vent difficult experiences, get information, and enjoy site content made by and for them (in addition to broader appeal media), site users report a neutral to positive effect on their overall quality of life because of the site. Further research is required to confirm any of the patterns in the work.

ABSTRACT: This study used a novel combination of interview methodologies, made possible through the nature of instant messaging, and ethnographic methods in order to determine the value of the autistic community on Tumblr.com to its members.

Ethnographic study yielded insights about the dialectic quality of any community on Tumblr, autistic community included, as well as the sense of autonomy users have on the site that is different if not greater than what they may practice in the physical world.

Interview data suggest a neutral to positive view of the community and its culture overall, though further research with a greater sample of participants is required in order to confirm these findings. Information can be shared quickly between members, and this information provides greater insight into a given user's autism, be it diagnosed or otherwise, or insight into navigating the neurotypical world. Autism positivity and neurodiversity advocacy is common among participants and the blogs they subscribe to, popularising the idea thereof in the mainstream while validating the identity of autistic people online and offline. This ethos makes its way into more casual site discussions, with memes and other entertainment being shaped by these experiences. The autistic community on Tumblr is an excellent example of a modern biosocial community online, and serves as Hacking's engine of normalisation both on the site outside of the autistic community and in the physical world through real life events and adoption of site terminology and discourse.

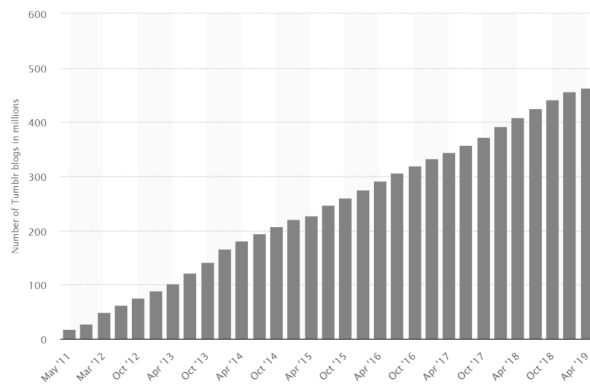
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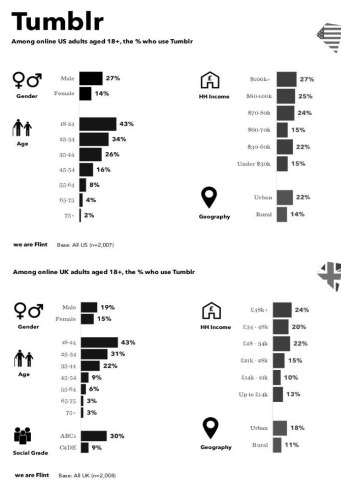
Lastly, and most importantly, I would like to thank all the participants in this study who have lent their stories, expertise, insights, and enthusiasm. I know that autism research can be fraught with bad science and allistic expert apologism, and I can only hope that I have properly recorded your experiences as they deserve to be presented: in the forefront, above the words of any allistic researcher, including myself (should I remain in that category), and in a way that can lend further credence to your experiences through the lens of academia. It is through your expertise and your knowledge that this work is possible, and I cannot begin to express the gratitude I feel to each of you.

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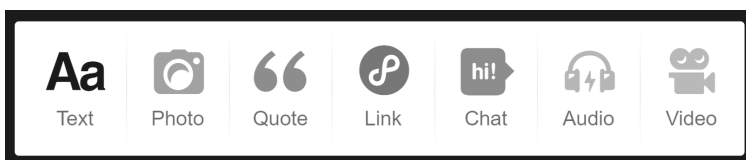
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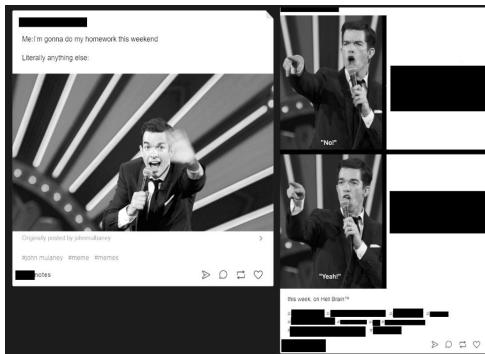
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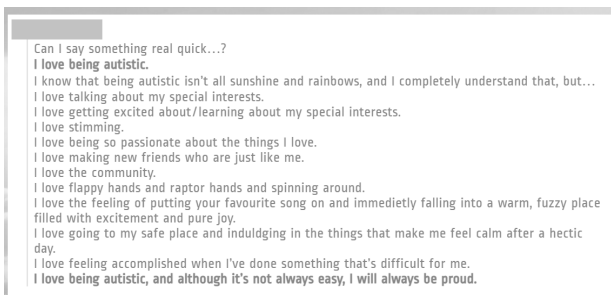
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I am Autistic, and Autism Speaks does not speak for me

I am not a burden.

I am not a mistake.

I am not missing a piece.

I am not a disease.

I am not something that needs to be cured.

I am not something that needs to be fixed.

I am not something that needs to be prevented.

I am autistic, and Autism Speaks does not speak for me.

Autism Speaks has SUPPORTED families of autistic people that have abused, and even *murdered*, their autistic child because they are "too much of a burden".

Autism Speaks is a board made ENTIRELY of neurotypicals - Autism "Speaks" does not speak for autistic people, they speak for themselves.

Autism Speaks is a hate group.

Autism Speaks tries to instill fear into the minds of others to try and target us as dangerous.

As tragic mistakes.

As something that can be prevented.

But do you know what?

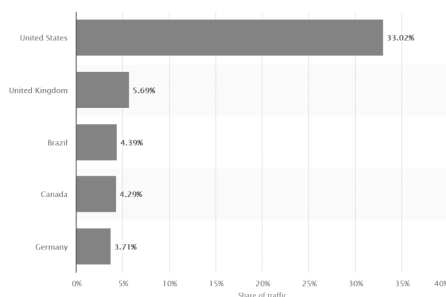
I am autistic, and I am perfect.

I am autistic, and I am **human**.

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INTRODUCTION

According to World Health Organisation estimates, globally 1 in 160 children are diagnosed as autistic (2017). This number is likely to increase, however, as healthcare professionals and families in more regions around the world become aware of autism, its diagnosis, and stigma surrounding the condition is reduced (2011). Until recently the anthropological literature on autism was limited, and existing literature on the subject was primarily concerned with either the biomedical realities of autism or the perspective of the parent who had to raise an autistic child. In recent years, however, autism studies have tended to align more closely with the goals and perspectives of the nascent autistic community, which argues for greater autistic agency and values neurodiversity (allowing for, accommodating, and celebrating a wide array of neurological conditions – a descriptive approach) rather than neurotypicality (the maintenance of a normative standard of thinking and being – a prescriptive approach) and argues for greater autistic agency.

While there have been many noteworthy academic works and influential publications aimed at a general audience (Subbaraman 2014, Grandin 2006, Higashida and Yoshida 2013, Sainsbury 2000) that are beginning to change public opinion about autism as a condition, the autistic community is primarily sited on the Internet. Virtual media on the Internet is well-suited to autistic users, since communication can be altered to provide as little or as much clarity and stimulus as the user requires or is able to endure, while not penalising the autistic person for exhibiting their autistic traits (Davidson 2008, Duncan 2017). Tumblr, a blogging platform, boasts 55 million users,

and while there are no definite statistics for the number of Tumblr blogs by autistic users, these users have formed an active community on the site (SimilarWeb, 2019). Tumblr, however, is a very popular site among youth more generally, and many of the jokes and much of the rhetoric shared by autistic users on the site make their way elsewhere, often among neurotypical circles. The process of community formation by autistic users on Tumblr has not been well delineated, and thus forms the focus of my research questions:

- Considering that Tumblr is a locus of autistic community, how did that community originate on Tumblr, and why did Tumblr become widely known for its autistic community?
- Given the popularity and influence of the site, how has autistic culture on Tumblr made its way into wider neurotypical society?
- What is the capacity for Tumblr to create positive change for autistic people?

Theory and Literature

There are influential works about autism online that inform this study. Joyce Davidson (2008) has done extensive work on autistic use of blogs and provides a comprehensive view of autistic culture online and the role of the Internet in the formation of autistic culture. Davidson's work also explores the effects of blogging on the quality of life of her participants, an integral part of my own study, and she documents the sense

of community and sociality felt online (2008). Davidson has also co-authored other pieces with Henderson, and yet other pieces with Henderson, Hemsworth and Edwards (2010, 2014), and other researchers have provided data supporting their findings (Nguyen et al. 2015). By probing the mechanisms behind forming and reforming the autistic community in the face of changes to the site and its demographic, we can better examine the role of the autistic community on Tumblr both in the lives of its members and in the wider public. While I am adopting a qualitative stance, works that provide quantitative data concerning autistic blog usage are vital in contextualising the data this study has generated (Jordan and Caldwell-Harris 2012, Nguyen et al. 2015). Works on life writing (Van Goidsenhoven 2017), combining humanity and technology (Henderson et al. 2014), confirming diversity within an autism diagnosis as well as within human populations more generally (Badone et al. 2016, Jackson Skirrow and Hare 2011, Solomon 2015), and research that focuses on presenting autistic narratives primarily (Badone et al. 2016) provide essential information portraying the lived experiences of autistic people. Works criticizing conventional portrayals of autism that do not include the perspective of autistic people (Crosman 2019, Bridge 2019) and works pointing out the potential shortcomings (Demo 2015: Rudacille 2011) or dangers (Millman 2019) of conventional treatments for autism provided essential background reading in order to help me understand the frustrations of the autistic community on Tumblr. More broadly, my project is situated in the context of research on blogs, blogging, and the maintenance and importance of Internet spaces. As such, works providing analytical counterpoints to humanity as a disembodied experience (Kenway 2009, Murthy 2008) have also been influential in my

analysis. In addition to full-length ethnographies of the Internet, such as Boellstorff's (2008), shorter works deal with the different roles of the writer and reader of blogs (Baumer, Sueyoshi and Tomlinson 2008, Lehdonvirta 2010) methods of community formation online (Bruenig 2013) or the role of personalised online spaces as sites of agency and autonomy (Hodkinson and Lincoln 2008). The latter is particularly significant since both agency and autonomy are often denied to autistic young adults.

CHAPTER 1: METHODOLOGY

The methodology for this research consisted of two parts. The first part was a series of online in-depth interviews or surveys. The second part involved an online ethnography of Tumblr. Both were undertaken using a purpose-built Tumblr blog, through which I was able to interface with participants and receive their informed consent to participation in the ethnographic component of the research. Twenty-six participants were recruited for this study. The initial recruitment process was performed using the #actuallyautistic, which tracks posts made by autistic people (and not by allistic people using the #autism to discuss what autism means to them). Later recruitment was achieved either through word of mouth, with some participants contacting me to be part of this study, and through snowball sampling by way of notes on popular posts with the #actuallyautistic (refer to Glossary or page 31 for relevant terminology). Both parts of the study were geared toward examining community formation through cultural production, either of digital artifacts or original discourse, and identifying the agency and subsequent influence of these cultural products. Evidence of this agency and influence was traced through important and/or common patterns of social interaction online, cross-platform influence, and instances of communication styles, topics, and/or structures unique to Tumblr. This split methodology allowed for the best data to be selected from each participant. As Badone et al. note, interviews themselves are biased towards coherency, with individual memories and stories coming to the fore (2016). Interviews are therefore an excellent way to probe participants' memories for specificities, but not as effective in parsing the day-to-day life and challenges of autistic people online and offline. Tumblr

blogs act as living repositories of content, so one can glean a reasonably comprehensive idea of how people are feeling at any given time from shared posts as well as from blog posts-as-journal entries. The dual investigative methodology employed for this study granted a far better idea of the generalities of participants' lives and experiences than either methodology could have provided if used separately.

Participants were given the option in the Letter of Information and Consent to have their real name used in the finished thesis or to be identified by a pseudonym. Those in the latter group had a pseudonym chosen for them. I created unique pseudonyms by both using popular username conventions on Tumblr as the structure for the pseudonym and by making a random number of abstractions away from the original username to come up with the pseudonym. Using my own personal blog, *clearskiesandsunrise*, as an example, I rolled a four-sided die to determine the number of abstractions I would make away from the original username to create the pseudonym. Assuming I rolled a three, I would take the idea of "clear skies and sunrise" and explore three tangentially related topics. Clear skies could be related to weather, which would make "weather" the first abstraction; "the weather" is the in-universe name for the musical segment in the "Welcome to Night Vale" podcast, meaning that podcast or podcasts in general would be the second abstraction; and "Welcome to Night Vale" contains references to angels, making angels and Heaven the concepts for the third abstraction, the one that will form the basis of the username. With that abstraction as the topic, I could pick any number of references to that topic, but remembering typical Tumblr usernames I would pick something like *flamingwheels-featheredwings**, marking it as a pseudonym by using an

asterisk. In addition to this, original posts and reblogged posts with under 15,000 notes (combined Likes and Reblogs, explained below, see page 26-27) are paraphrased here to conceal the identity of the original user and those who reblogged the post. In a system where one's username is one's name, the name that appears in the notes of a post when you reply, reblog, or like a post, I believe these precautions adequately protect the identity of participants. While Tumblr blogs are considered public access by Tumblr's privacy policy, respecting the conditional privacy of Tumblr (covered on page 20) and the autonomy of participants on their blogs and in interview was a high priority. Requiring participant assent was therefore essential.

Interviews

The process of recruitment and obtaining informed consent was conducted using Tumblr's built-in instant messenger service, as were the interviews for this study. In order to make participation in the study more accessible to the autistic community, interview questions were distributed through four fora, two of which more closely resembled a survey than an interview. Participants were given the option of answering interview questions either in a single session (Option 1) or over several sessions over a longer period of time (Option 2). Alternatively, participants could fill out a short survey provided online through LimeSurvey and then debrief with the investigator using Tumblr's instant messenger service (Option 3). The final option involved a single, longer survey which was provided to the participant through LimeSurvey with no need for any follow-up (Option 4). This four-fold approach was chosen to accommodate participants'

differing styles of communication. However, the metadata concerning which options participants selected will contribute to future research, in much the same way that feedback from Davidson's (2008) study has informed my methodology.

Questions were developed based on my prior experience both with Tumblr as a whole and with my interactions and experiences with the autistic community on Tumblr. Commonly discussed topics by autistic people online included Autism Pride, neurotypicals and varied experiences with them, the outside world and experiences with it, communication and autistic traits, and the specific culture of Tumblr. From these topics, I built questions based on salient experiences discussed by others in the autistic community. In question development, I kept the varied methods of interviewing in mind. For this reason, both a short list and a complete list of questions were developed. The former was created with the end goal of spurring discussion about experiences online and offline, and thus pairs of questions were designed to inspire comparison between these two contexts. For example, one pair of questions concerned a participant's interactions and experiences with neurotypicals, with one question covering offline experiences and the other relating to online experiences. The short list of questions went through two iterations before reaching the final version, changing once after my own secondary edit and once after discussion with a community self-advocate, who acted in an unofficial capacity as an advisor to my study and who has chosen to remain anonymous. In both instances I revised the lists after an extensive literature review to ensure the questions followed shared experiences, were clear, and specific. The complete list comprises the short list, as well as questions anticipating participant responses, and was only used in

Option 4 (the long survey) as that format would yield no follow-up questions. Most participants opted for Option 2, with an interview over instant messenger taking place sporadically over a period of days.

Literature used to evaluate my question list was selected based on salience to my research question. Thus, studies focused directly on autistic people online and studies that centred around autistic narratives or autistic autoethnographies were given priority. Studies were pulled from Primo, AnthroSource, and Google Scholar. Joyce Davidson in particular was influential in forming the content of my questions and provided the initial inspiration for the interview process I designed. The interview process was designed in order to allow for flexibility on the part of the participants depending on their comfort level. Using both my intuitive understanding of Tumblr as a site and Davidson (2008) in order to determine the initial medium in which the interviews would take place (i.e. the native chat function of Tumblr), I then built upon that initial basis using my understanding of some of the major issues in the community. Spoon theory - a metaphor for the limitations imposed upon a person by disability, illustrated by tasks taking a certain number of spoons from a total, coined by Miserandino in 2003 - is popular on Tumblr. For this reason, I wanted my approach to take a person's potential limited number of spoons into account in the research process. This in conjunction with the fact that IM conversations are not conducted in real time led to both the possibility of and the eventual implementation of the fragmented interview format, in which interview questions could be asked and answered over a period of days. Another interaction people mentioned as causing discomfort is answering questions at length in the chat, as the

expectation of immediate answers might interrupt their train of thought. Thus, the survey format was implemented in order to allow participants more comfort in the response process. Two survey processes were used: one using the full research question list, meaning participants could fill out the survey without any further interaction with the researcher; and one using a the shortlist of questions, meaning less time in the survey client but necessitating a short follow-up interview with the researcher, allowing the participant to expend fewer spoons in each portion in order to ask for clarification and elaboration on their answers, which may or may not be covered by the extended question list. Small technical failures led one participant who selected the survey process to leave the study, but this problem seemed to be idiosyncratic to their case, as others completed the survey without issue. However, further studies using this combined method should keep the stability of the survey provider in mind. The vast majority of participants opted for the synchronous and non-synchronous interview options, but enough participants selected the survey portion that I would recommend offering this option in further studies of this type. Quotations from interviews or survey responses are verbatim unless specified otherwise, retaining the source grammar.

Ethnography

Boellstorff (2008) was an instrumental work in terms of navigating the structure of the ethnographic process on Tumblr. While Second Life in Boellstorff's work is an interactive game-world and Tumblr as a site is a personalised media aggregation and social media site, Second Life as Boellstorff describes it is an aggregation of original and reused content centred around interaction between individuals (2008). While the

comparison between the three dimensional world of Second Life experienced in real time and the non-real-time social media structure of Tumblr without context would be reductive, in the context of designing ethnographic methodologies this comparison is useful. Interactions in public on Tumblr take place via reblogs, tags, and inbox messages rather than IMs (instant messages) in Second Life, and the methodology that suited the real-time interactions of Second Life needed to be adjusted to adapt to the non-real-time nature of Tumblr. However, that change allowed for a greater breadth and depth of ethnographic data. Ethnography on Tumblr presents both opportunities and problems. Tumblr is a static but constantly updating site, with new content being generated on a second-by-second basis since the site's inception in 2007. The ethnographic portion of this research is limited to the blogs of those people who participated in my study. Anecdotes about interactions with neurotypical people – on Tumblr and in the physical world – have been prioritised in my analysis, along with jokes and memes about being autistic and anecdotes about the individual's personal life. Tumblr essentially acts as an automatic archive of a person's life whether the content is original, since the act of liking or reblogging something without commentary implies the user's interest and tacit approval. As a result, the ethnographic component of this study involved navigating the archives of each participant using user-generated tags as well as investigator-inputted keywords. Throughout this ethnography, the purpose-built blog for the study "followed" all participants as well as an undisclosed number of non-participants in the autistic community on Tumblr by their Tumblr username rather than their real name, both to protect the anonymity of the user behind the username and because Tumblr usernames are

the most relevant signifiers within this online community. This also means that all the posts participants made during the data collection period were immediately visible, thus streamlining data collection.

Terminology and Labelling

In addition to the aspects of the research methodology described above, the terminology used both in the research process and in the writing of this thesis is integral to the ethos of the study, which seeks to respect neurodiversity and to treat individual members of the autistic community with respect. The most salient and least obvious of the choices I have made with respect to terminology and labelling is the avoidance of “functioning” labels such as “low-functioning” or “high-functioning.” While these terms are frequently used by biomedical practitioners dealing with autism, and by family members and caregivers of autistic people, members of the autistic community note many different issues with “functioning” labels, as seen in this paraphrased post:

Functioning labels are imposed on autistic people by allistic people. This is harmful to all of us, because:

1. Higher functioning autistic people will be treated like neurotypical people with quirks, steamrolling the problems they face, while lower functioning autistic people will be dehumanised and demeaned. It implies a dichotomy of “human” and “not human”
2. “Functioning” implies that one’s adaptation to neurotypical society is what determines their value. To be ‘low-functioning’ is to therefore be valueless in this oppressive system.

3. This method of labelling is reductive, as if autism is only one of three things. This is patently false.

The same post outlines an alternative labelling schema based on support labels, labels that indicate how much support an autistic person needs to navigate neurotypical society. For example, “low support” autistic people still require some support with specific tasks or processes (the example given in the post was help balancing finances) but can manage most other things on their own. “High support” autistic people meanwhile may be non-verbal and have more difficulties with fine motor skills, or any number of other difficulties that require a great deal of support to adapt to the neurotypical world. The difference between labels based on support and labels based on “functioning” is that the former do not hold any implications about the humanity or capacity for thought of the person in question, while the latter do entail such implications. The support-based labelling system also does not erase the needs of lower-support autistic people, and the system does not make assumptions about the kinds of support needed. For these reasons, and because this system tends to be popular in autistic circles on Tumblr, I use this terminology throughout this work.

Additionally, I must quickly comment on the lack of reference to DSM-5 in this thesis. I have chosen to use participant narratives and the anthropological literature to describe autism rather than the more rigid DSM-5 criteria throughout the thesis because I draw heavily on my participants' embodied experiences. To understand autism as a catalyst for the creation of an online community, and as a focus for navigating and creating meaningful cultural artifacts in that community, one must first look at the

individuals in that community. This approach is more complex than referring to the DSM-5 criteria for the diagnosis of autism. While the broad strokes of the DSM-5 description hold true (all participants noted some combination of stimming, special interests, sensory idiosyncrasy, and social difficulty or idiosyncrasy, and some participants noted other issues commonly associated with the DSM-5 description of autism), the minutiae of participants' profiles were varied. Moreover, there are some commonly experienced but uncommonly discussed aspects of autism that the DSM-5 does not include in its diagnostic criteria, which reduces the usefulness of the DSM-5 for exploring those experiences. Moreover, the purpose of this study is not to evaluate the legitimacy of participants' autism diagnoses. I will be discussing the varied attitudes toward formal diagnosis within the community later in the thesis. Finally, and most importantly, the DSM-5 has been criticized by autistic self-advocacy groups in the past, primarily for the strictness and rigidity of its autism diagnosis criteria (ASAN, 2012). Therefore, I do not refer to the DSM-5's autism diagnosis criteria in this work.

CHAPTER 2: BACKGROUND

In the following chapters I will be discussing both the confluence of Tumblr and autism and the two in isolation from each other. When discussing the autistic community on Tumblr, one must take into consideration the cultural processes that govern Tumblr as a whole, as the former is a subcommunity of the latter. Moreover, as we will discuss in greater depth, Tumblr's communities are governed not so much by physical or material borders, as on Tumblr those constructs rarely come into play. Membership in a community on Tumblr (and the definition of that community in the first place) is more a matter of interests and dialectics than anything else. As such, community borders are rarely well-defined, so understanding Tumblr on a macroscopic level is necessary for understanding the autistic community on Tumblr on a microscopic level. More noteworthy, however, is the inverse relationship: one must understand the autistic community on Tumblr in some capacity to gain a better understanding of Tumblr as a whole. Once one has a basic level of understanding of Tumblr as a whole, learning and understanding the cultural processes specific to or originating from the autistic community on Tumblr allows for greater insight into the cultural processes on Tumblr, for reasons that will become clearer as the discussion of this relationship moves forward. It is telling that most of my study participants have little difficulty communicating and expressing themselves online, or at least less trouble than in the physical world.

Tumblr was created by David Karp in 2007 but gained increasing popularity from 2009 through the early 2010's. As one can see in Figure 1, site usage has only increased

over time, but the initial spike happened in 2009, coincidentally, the year in which I made my first account.

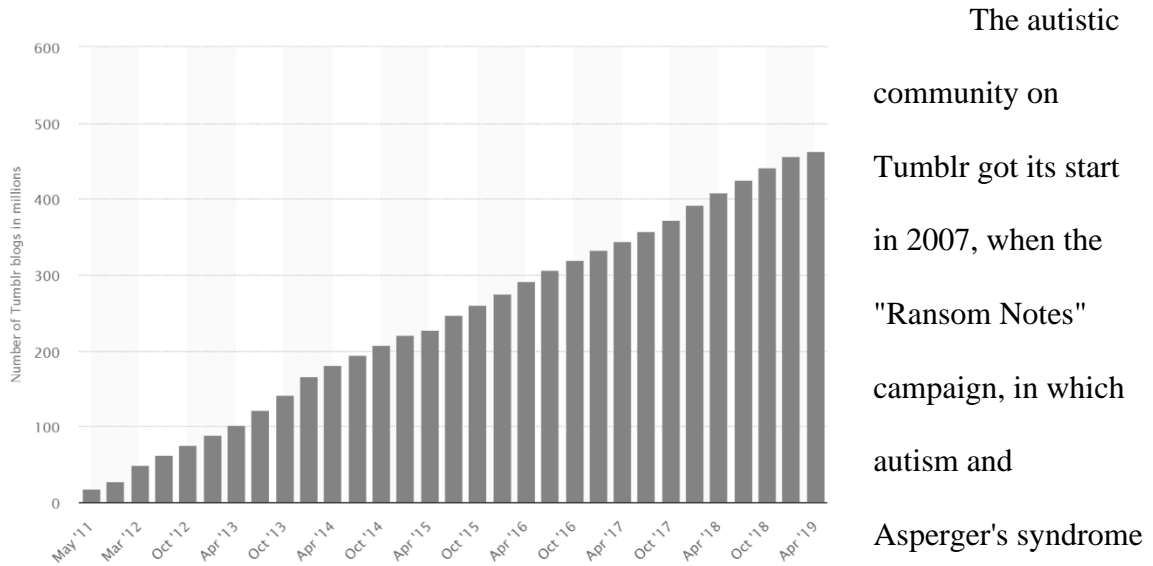


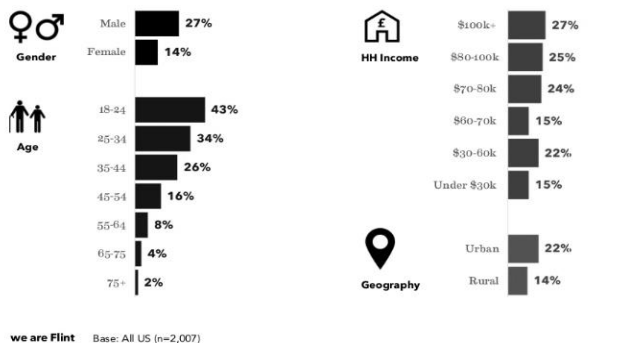
Figure 1: Tumblr usage over time. Statistics provided by SimilarWeb

were depicted as kidnappers stealing children's lives and livelihoods, was introduced by the U.S. based charitable organization, Autism Speaks. At this time, the Autistic Self-Advocacy Network (ASAN) was one year old. ASAN is a non-profit organization created and run by autistic people, with the mandate of ensuring that autistic people have the same rights and opportunities as other people in society and that autistic voices are included in public discussions about autism therapies and policy. The organization fought hard against the "Ransom Notes" campaign for months, creating petitions and garnering enough support that the initiative was abandoned by Autism Speaks in December of that year. The level of support attracted by ASAN and the controversy that stemmed from its relatively new stance promoting neurodiversity created a lot of debate

and discussion (Kras 2010). As Tumblr was coming into being at the same time and as its interface was well-suited to both discussion and simple venting, Tumblr became a friendly space for autistic people to engage in these debates about neurodiversity and autistic identity. Tumblr also attracted other categories of marginalised people who began to use the site as a space to spread information, express strong opinions, and network. However, as Davidson (2008) shows, blogging was particularly useful for autistic people.

Tumblr

Among online US adults aged 18+, the % who use Tumblr



Among online UK adults aged 18+, the % who use Tumblr

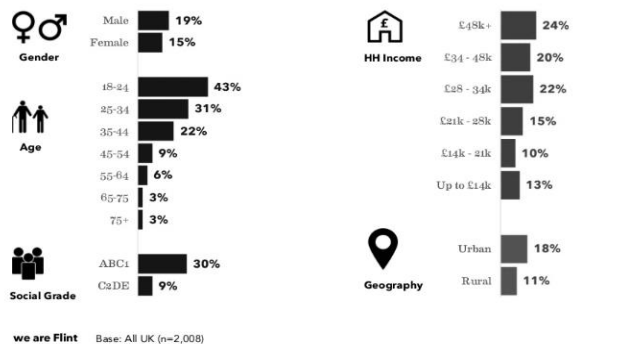


Figure 2: Tumblr demographics breakdown in U.S. and U.K. users. Statistic by We Are Flint, graphs and presentation by Tom Hashemi

demographic using Tumblr in the U.K. and the U.S. (the two biggest Tumblr users by

Tumblr can allow for great or

small amounts of data to be shared,

and the data shared by the user is

entirely voluntary. Once on Tumblr,

data is thereafter publicly accessible

by anyone. Yet users in their teens

and twenties – even those who share

their names, ages, locations, and other

identifying features – can reasonably

assume that their parents will not be

able to locate them online. One

possible reason for this level of

privacy is the age demographic of

Tumblr users. The biggest age

percentage at 5.69% and 33.02% respectively of 55 million total Tumblr users) is the combined is the 18-34 demographic, comprising 74% and 77% of all users from each country respectively (Hashemi 2018). Conversely, the generation of their parents (likely falling in either the 45-54 or 55-64 age categories) make up just 15% of the user demographic in the U.K. and 24% of the user demographic in the U.S. (Fig. 2), a relatively small share, especially considering the proportion of youth that use the site. This demographic difference combined with the curation of site content means that while any individual story may be seen by anyone who encounters a specific user's blog, the odds of that user's parents locating their child's blog is relatively small. To quote user *waken-thewind**, "it's a platform that allows my presence on it to be relatively hidden from my parents, which is weird because it is one of the less anonymous platforms out there, but circumstantially it worked."

There are no clear borders delineating the autistic community on Tumblr – or any other community on Tumblr – because of the presence of multiple themed blogs owned by the same person and the varied topics covered by personal blogs. Moreover, taking part in the community varies in terms of scale and activity. Some people are very active in the community, having different blogs for different purposes relating exclusively to autism, while some people "lurk," reblogging and liking posts while sharing little to no additional commentary. Moreover, the means of spreading the conversation are varied, with specific comments occasionally completely upturning the intended meaning of the post. Matt Bruenig (2013) wrote a piece describing Tumblr as a "dialectical community" in its truest form, citing differences between academic dialectics and the dialectics of

Tumblr. According to Bruenig, in academia, any sort of discussion has a base theory one works from, which is adapted as the discourse develops. Tumblr, conversely, adopts an approach somewhere between grounded theory and common law, in which there is rarely a single cohesive theory backing arguments. This absence allows those participating in Tumblr discussions to evaluate arguments and engage with them based on previous arguments made; hence, the comparison to the common law system (Bruenig, 2013).

Bruenig's blog post dates from 2013, but the content still applies to Tumblr today.

Moreover, as a long-time user of the site, I have seen how the dialectics of Tumblr shape the communities that form on the site, the overall site discourse, and my own opinions on salient topics as a user. Certain topics are still hotly debated. Bruenig's example, which involved accusations of the appropriation of transgender culture by the online "otherkin" subculture and the rebuttal of these accusations, is still an ongoing discussion in some circles. The presence of Trans-Exclusive Radical Feminists (shortened to TERFs) on Tumblr tends to result in arguments between this group and transgender people. Many times the discourse on Tumblr can be on the cutting edge of sociological relevance, and sometimes it seems people have to explain the basics of a given social issue to those who would like to argue against them. Judging from my own blog, the blogs of those I have followed personally, and testimony from participants in my study, there is a gradual evolution of ideas on the site resembling the classic Hegelian dialectic. One idea gains prominence and is argued against by its detractors and from this discussion, another idea is formed, taking the criticisms of the detractors into account. The resulting new idea may or may not gain prominence in the mainstream but definitely gains prominence in

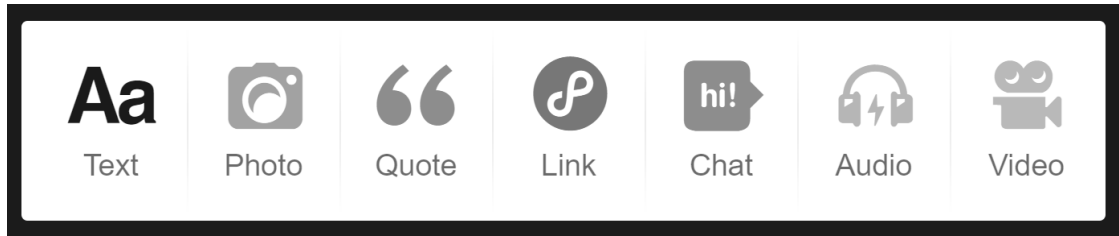


Figure 3: The new post menu on Tumblr. The icons from left to right are black, red, orange, green, blue, purple, and pink

some communities on Tumblr, inasmuch as these communities can be separated. It is important to examine more closely the ways information is transmitted on Tumblr, in terms of both native mechanisms (e.g. reblogging, liking, commenting) and their philosophical implications (i.e. the inherent dialectic of Tumblr) before we delve into the characteristics of the autistic community on Tumblr. Figure 3 depicts the New Post menu on Tumblr, located at the top and centre of a user's home screen, also known as a Dashboard. The option to create a new post is always at the top of the screen, with each post type having different formatting, though some formats are used more often than others. Among autistic and allistic (non-autistic) Tumblr users, text and photo posts are far more popular than link or chat posts. There is often some overlap with other formats.



Figure 4: sample image post

Photo posts, for example, prioritise the image or images while allowing for some commentary, though the image in

question may be something that could be easily replicated in text (Fig. 4). Text posts, on the other hand, prioritise a given text, however much or little of it there may be and however interspersed with embedded images the text may be.

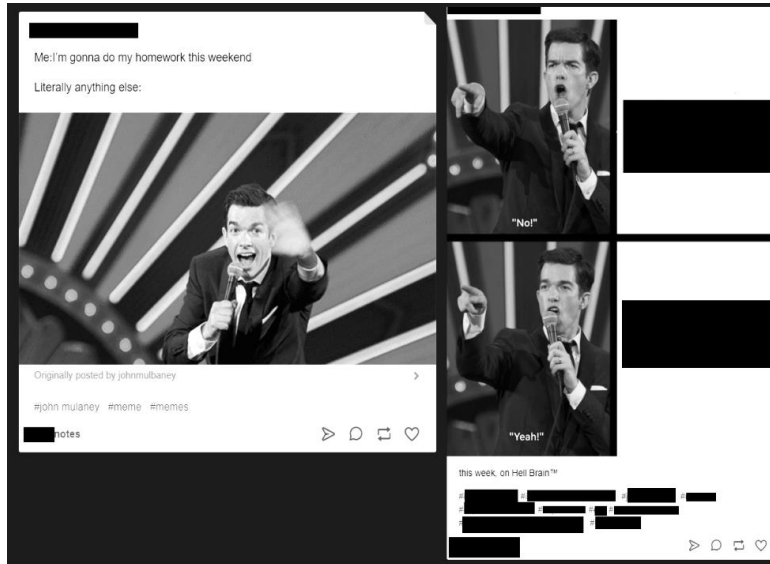


Figure 5: The difference in format between a text post with embedded images (left) and an image post with commentary (right)

There is, however, a key contextual difference between the two types of posts in terms of their usage. In Figure 5 we can see the subtle differences between using a text post and an image post to communicate

similar messages. The text post is an explicit statement followed by a reaction, and therefore the image is embedded in the text post. The format is implicit, and the content of the image can vary depending on the circumstance, with reaction images being taken from potentially any number of sources. There are still soft rules to its usage – for example not having a title, keeping the initial statement short, and tagging relevant subject matter – but these are general suggestions at best, and subject to plasticity. The image post is an editable meme - the image itself is the content, and it contains the meaning while the text comment contextualises the meme. The format is explicit and somewhat formal, comparatively, with a set of rules governing the meme's usage, though

these rules are mutable and are entirely formed by the historical usage of similar memes as well as the consensus of Tumblr users. In short, the text post with embedded image is an implied dialogue with soft rules dictating formatting, while the image post is a cultural product in and of itself. This difference is important to consider when looking at posts made by Tumblr users, as it demonstrates that not only do Tumblr users have an implicit understanding of the social rules of Tumblr, but that they can also identify when these rules are being broken. This type of competence also underlies the recent trend of corporations using memes like the ones on Tumblr to advertise to younger demographics. The ads that work are the ones that adhere most closely to Tumblr's social rules. For example a Denny's Restaurant Tumblr account straddled the line between advertisement and genuine Tumblr meme entity because it followed the rules more often than many of its contemporaries, and as a result, it became viral for a time.

Although Tumblr is ostensibly an informal setting in terms of language, there is a notable difference between formal and informal text posts. Formal text posts tend to be



Figure 6: A sample text meme, comprising of a title and nothing else. Frustratingly to its creator, this received few notes.

long and involve titles or headlines that draw attention, while shorter posts will either be written as a title without text or as a text without a title (Fig. 6). Nonetheless, a great deal of effort may be put into informal posts. Many posts that adopt a more informal style and grammatical structure of writing can still include factual information and/or a complete

argument that may have taken a great deal of time to research, but certainly a great deal of time to write in comparison to shorter posts. The informal style of writing on Tumblr has great plasticity, but the co-existence of title, text, and grammatical correctness (i.e. following the rules of Standard American English) tend to connote formality. Moreover, one can set up what may seem like the beginning of a formal post, but end informally, for subversive or comedic effect. For example, a title reading "For your consideration" might be followed by text consisting solely of the word "gun," throwing the reader off for a laugh.

As discussed previously, discourse can occur through the reblogging of posts and the responses that are subsequently made to the original post. It is interesting to note that for certain posts, particularly the ones that are already viral, there are certain responses that are implicitly allowed and others that are not allowed. On a very old viral post (ca. 2012 or older), commenting on the age of the post is allowable, but rarely is any other addition acceptable. Conversely, on a post that is meant to encourage discourse, additions that add to or rebut the original post are allowable; minor additions like "^this" indicating the user agrees with the most recent content on the post are occasionally allowable though occasionally mocked for not adding anything; and irrelevant discussion is otherwise forbidden. Tagging, however, is always allowable, as the tags do not appear on an individual's blog unless another user records them to add to the post later. It is also always allowable because the initial purpose of tagging (or "hashtagging" elsewhere on the internet) was so that the user could organise the posts they make or reblog thematically. As with many other aspects of Tumblr, however, continued usage transformed the

organisational tool into another way to communicate with people, with many people providing their own commentary on the original post only in the tags they provide. Because this was originally an organisational tool, tags only persist on the user's own reblog of the post, and so they add no length to the original post while reblogging with an addition does. Therefore, tagging can be an excellent way to respond with irrelevant, tangential, or minor information, and one will occasionally see people criticizing other people for not putting their response in the tags but rather as a comment in a reblog. This may seem arcane to those who are not privy to the culture of Tumblr, and this is not lost

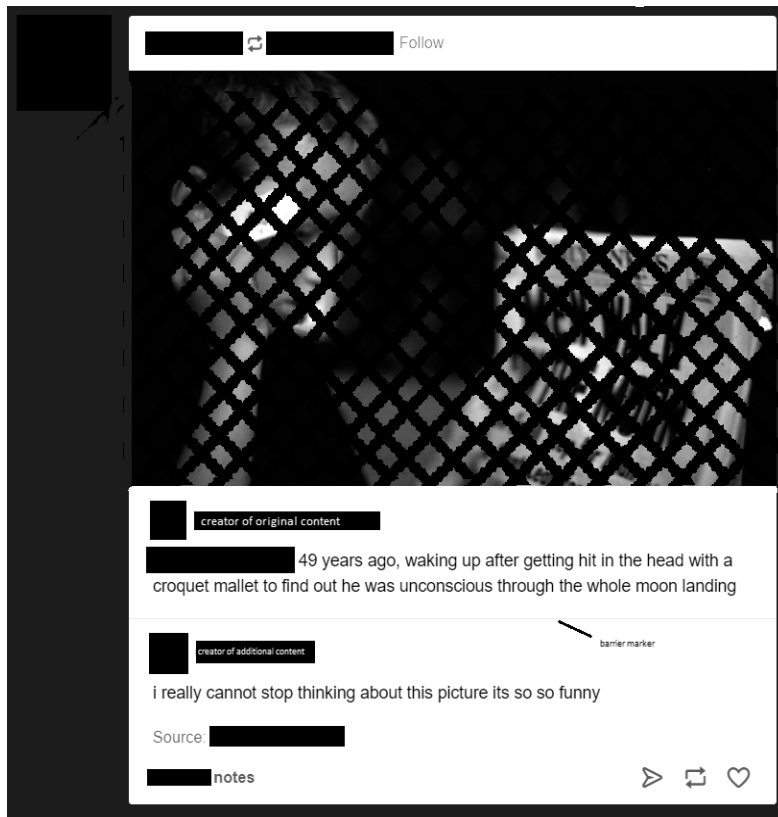


Figure 7: sample reblog structure

on some of the users of the site. To quote *aap-autistic**, "... it also takes time to learn those rules. so I feel like I made some 'mistakes' early on that I've now got better at. (this is a fairly common experience for autistic people, I suspect!)”

Stepping back for a moment, the reason Tumblr is able to be a source of discourse and constant content is its reblog function, which allows other users to directly react to an initial post or simply share tacit agreement with the post outside of liking it with the native "Like" function. Reblogging allows posts that resonate with a specific user to be part of their own aggregated content, to which all their followers are privy. Further, other users can then reblog and comment on that content, and so on (Fig.7). The popularity of a given post can be ascertained from the notes, which are the sum of all likes and reblogs accumulated by a given iteration of a post. There are some posts on Tumblr that have reblog chains extending for the equivalent of pages of content, in which two or more users are discussing a specific post and its implications, and there are some posts on Tumblr that have gone so viral that the notes are not listed, each having easily over ten million notes. As posts become more popular via reblogging, the chance of them being reblogged again increases, which in turn increases the odds that someone will comment in their reblogs. In some of the older posts, the comments can be as simple as "Oh look, it's this post again," but in more contentious or controversial posts the odds are good that someone will respond to the post with a rebuttal, ranging from simple dismissal to paragraphs debunking the initial post. From this point onwards, that reblogged version may become more widely shared than the original, as the culture accepts the new information, including users who previously reblogged (and thus tacitly agreed with) the original post. Further, other users can join the conversation, bolstering one side, finding a compromise, or putting forward an entirely new position.

As these discussions continue, Tumblr's aggregate opinions change through time. Since I first joined Tumblr in 2010 the discourse surrounding, for example, popular media depictions of LGBTQ+ content has changed dramatically, in reaction to both real-life events and online discourse shifting – just as described in Bruenig's blog post (2013). The point-counterpoint style of argument leading to a new consensus almost perfectly and completely accidentally follows Hegelian dialectic, which Bruenig describes here:

What I find so interesting about this community is that it is a dialectical community in the purest sense. All thought and theorizing is ultimately dialectical, but usually the dialectic happens between or among basically complete theories of, for instance, justice... But the Tumblr arguments are purely dialectical in the sense that there never really seems to be an effort at putting together anything resembling a full theory. They seem to reject working within or towards complete theories.

It therefore resembles something much more like common law evolution. In common law, judges make up the law piece by piece as issues present themselves. They don't try to legislate an entire set of rules all at once. And this is basically what you see in the tumblr set. While more typical political thinking tries to start general or at least become general, the tumblr set seems totally content in starting hyper-specific and remaining there. And not for bad reasons either. There is a developed meta-theory that explains why broad theories are bad: they necessarily miss and distort things, they enable domination, and they elevate the principle over the personal, among other things. One of the interesting consequences of this piecemeal approach to theorizing is that it provides a rich set of discrete ideas and arguments that can be assembled together in different and new ways (Bruenig 2013)

While Bruenig's blog post is far older than the current discourse on Tumblr, the pattern of argumentation he observed in site discourse holds true at the time of this writing, both more generally on Tumblr and in its autistic community. Generally the

autistic community is much like other communities on Tumblr, in that its borders are fairly loosely defined, if they are defined at all. The autistic community on Tumblr as a concept is a collection of individuals potentially maintaining blogs relating specifically to autism. These autism-focused blogs may be the basis of the individual's own blog, part of an aggregate of content with other topics, or simply a small facet of the individual's own personality that factors into their interests online. In the latter case, Tumblr users often look at and/or passively reblog information relating to autism without necessarily taking part in discussions. Tumblr user *crusaderman*, for example, tends to reblog some autism-related content, but mostly reblogs things related to the fandoms he participates in. *crusaderman* and I spent a great deal of time between interviews and afterwards discussing fan-created content for Dungeons and Dragons. He describes himself as a "lurker", liking and reblogging without adding much to the conversation in the autistic community. His presence in the community, however, is no less significant because of this passive stance, in his view. In interviews, *crusaderman* shared how he feels like a part of the community not necessarily because of what he adds to the conversation, but because of the presence of other people whose contributions he agrees with. Moreover, he understates his own presence; as previously discussed, reblogging content increases its distribution, even without any other interaction with or comment on that content. Reblogging without additions is understood to mean tacit approval of the content of the post. In addition, someone following *crusaderman* for his fandom content may be exposed to autism content incidentally. The fact that autistic Tumblr users do not necessarily blog exclusively about autism highlights an important feature of the

community: it is not a place in which people are marginalised by their identity, at least in the same way that they can be in the physical world. Furthermore, people are not marginalised by the content and/or theme of their blogs, nor by any lack of cohesion in the content of their blog. We will discuss later how the autistic community on Tumblr (and Tumblr more widely) polices its communities, but for now it is important to recognise that the content and structure of a blog and the amount of original content in it have little effect on that blog and its owner in terms of their membership in the community.

There is, however, a note I would like to make on the borders of community on Tumblr. Bruenig observes that the borders of a community on Tumblr are nebulously defined, and difficult to parse (2013). This is true, but only if you consider individual blogs to be unified in terms of purpose and ideology. While this unity may hold true for themed blogs, whose expressed purpose is dedication to a subject, this type of coherence does not adequately describe most participants I interviewed, whose blogs are far more personal and far less thematically unified. The end result of this fluidity is that membership in communities on Tumblr cannot necessarily be determined on the level of individual blogs. Rather, it is the type of post that is made and the frequency of posting original material or reblogging salient content that determine one's membership in a community on Tumblr. This metric is inclusive of "lurkers" who do not produce their own original content but may reblog the content of other people, as well as those who produce original content, and it is inclusive of people whose blog content and themes may have shifted, focused, or diversified over time. As user *thehappy-landfill* exemplifies, one

can change their blog content drastically over time, becoming prominent in one community after leaving another. My definition of community inclusion does not measure the popularity or influence of specific users in a given community. Examining these factors more closely is not in the purview of this study, but my informal observations suggest that amount of original content and popularity/influence are correlated. An easy way to evaluate this metric for individual users would be to examine the user's archived posts for salient content. One can evaluate the reach of a given post by the notes, seeing who liked a given post, who reblogged it and who added commentary. In future studies on the demographics of Tumblr communities, this approach might be a good way to find participants in specific communities. This was a technique I used after the initial wave of recruitment during my snowball sampling phase, leading to the bulk of my participants being recruited at this stage, though whether this was partially due to the burgeoning influence of my purpose-built blog and the degree of my influence on the site is difficult to ascertain. Regardless, my success finding study participants using this method is evidence of both the efficacy of the sampling method and the validity of the metric.

CHAPTER 3: ETHNOGRAPHIC DATA

“I started using tumblr when I was 15 and spending the week at a creative writing summer camp. I had made a friend there who told me I seemed "very tumblr.””

- *gothtistic-stims*, 2018

Throughout my study, one common theme expressed by participants was that their autistic traits were often perceived negatively or had a negative impact on their life outside of Tumblr. In addition, participants frequently mentioned that this negative impact of autism on their life was greater prior to their time on Tumblr. As an example of the former, *speak-autism-without-speaks** is both an autistic person and a professional who provides services to autistic people. *speak-autism-without-speaks** noted that their experiences as an autistic person were discounted unless those experiences were spoken in the context of their role as a leader in their profession. Tumblr user *ladyautie* shared her account of being passed over for a position for which she was more than qualified because she could not maintain attention on the words of the interviewer and restrict her “stims” or self-stimulating actions which help reduce anxiety for her, at the same time. (See below page 33 for a more complete discussion of stimming). As I will discuss in a later chapter, the type of difficulty experienced by *ladyautie* in her job interview is evidence less of the inability of autistic people to interact with neurotypical society than it is evidence for the failure of neurotypical society to accommodate autistic people's needs. In any case, participants in my study did also note instances of positive or neutral interactions with the neurotypical world outside Tumblr, but overall my data suggest that

autistic people's interactions in the physical world offline tend to be more negative than positive.

This is not to say that participants perceived their way of being as negative. Part of the ongoing discourse of Tumblr is actively framing as positive autistic traits that are often framed as negative by neurotypical people and/or people subscribing to the medical model of autism. When asked, participants were with few exceptions able to cite many ways their own autistic traits were beneficial to them. Tumblr users *junimo-forest** and *ladyautie* described how enhanced emotions, a trait of autism usually associated with negative emotions and their resulting behaviours, enabled feeling happiness more intensely. Tumblr user *jugemusans-anime-hut** described how their hyperfocus allowed them to be deeply immersed in their special interests, leading to a high level of proficiency in that area and related areas. Hyperfocus is a trait shared by Attention Deficit Hyperactivity Disorder (ADHD), which is part of the reason ADHD and autism are often either co-diagnosed with or misdiagnosed as each other. One study by Polderman et al. (2014) suggests the 28%-42% of autistic people with a co-diagnosis of inattentive ADHD exhibit a genetic component to this relationship. Many of my participants disclosed a co-diagnosis of ADHD consistent with these findings, sharing that their hyperfocus (whether from autism or ADHD) allowed them to learn about topics of interest quickly. Returning to my conversations with *jugemusans-anime-hut**, we discussed many of their special interests at length, and their high level of proficiency in those areas was demonstrated in these conversations, as *jugemusans-anime-hut**, shared a lot of technical and historical information in its proper context. This proficiency was matched only by their passion for

the subjects and enthusiasm in sharing information about them with me. As I will discuss later, this enthusiasm for sharing information about special interest areas is a key feature of the autistic community on Tumblr. Tumblr itself allows for and encourages this kind of mutual education online, so much so that many of my participants create and run blogs specifically for the purposes of educating others.

Moreover, while the positive aspects of autistic traits seemed to be emphasized online, the traits that seemed most problematic for participants in the physical world were often nullified online through any number of factors, consistent with the findings of Davidson (2008) and Bagatell (2011). For example, *speak-autism-without-speaks** is able to share expertise and experience far more easily online, when she does not have to watch her actions and take in all the stimuli of the physical world at once. This observation is applicable to most if not all participants. Removing sensory and social barriers from the context of communication allows the participation of people unable to participate in other social situations. Nowhere was this removal of barriers more apparent than in the case of *autistic-avengers*, who was able to effectively and eloquently describe details about his life through instant messaging, but self-identified in an interview as non-verbal in the physical world. Other advantages commonly shared included the aforementioned cases of hyperfocus, but also the ability to recall information and identify patterns, as *sbroxman-autisticquestions* describes in interview:

I also like how it helps me spot things most people may not notice... Things like patterns, details on people and objects that would normally not be obvious to others. Being able to memorize a lot of things about my special interests is also a great advantage :)

Other participants noted similarly that the facets of their autism manifest differently online. Tumblr user *calictii* describes his experiences in daily life being occasionally frustrating because of the social barriers his autism presents. *calictii* requires an iPad to speak (the voice he chooses is that of a gruff Southern man). He cites the many miscommunications that can happen in real-time conversations. On Tumblr, however, *calictii* can ask for clarification, read over what other people say carefully before responding, and interact through words, internet memes, or GIF files, so the social barriers he faces break down online.

Stimming is verbal short form for self-stimulatory behaviour. Common stims include rocking back and forth, flapping arms, vocalising in any number of ways, biting one's nails, and fidgeting, though this list is by no means exhaustive (Rudy 2019). The action has a calming effect on the actor, especially when the actor is feeling overstimulated. While stimming is not unique to autism, as people with ADHD and various anxiety disorders also stim, stimming is almost universal among autistic people. Stimming is a mostly harmless aspect of autism (though certain stims can be harmful to the actor and/or their surroundings) and can help reduce overstimulation-associated stress. Many people in the autistic community on Tumblr, however, report that stimming tends to be one of the behaviours most often suppressed by allistic medical practitioners. The repression of these behaviours, either through ABA, parenting, or the influence of friends and coworkers later on in life are part of the autistic experience in the physical world, in part because neurotypical people tend to regard stimming as a highly visible marker of “difference”. The autistic community on Tumblr, conversely, not only refuses to shame

stimming behaviours but actively champions them. The hashtag #stimpide often accompanies #actuallyautistic among the most common tags applied to autistic Tumblr posts. These tags are applied to videos, images, and/or descriptions of positive experiences of stimming. Flapping arms is often described as "happy flapping" and is well known as one of the more common stims, but less common stims are talked about and shared with the community online as well.

One of the key tenets in autistic advocacy generally and the autistic community on Tumblr more specifically is that Applied Behavioural Analysis or ABA, one of the most widely accepted forms of therapy for autistic children advocated by neurotypical practitioners and the biomedical community, is inherently abusive. Many autistic people liken ABA to torture. Different practitioners of ABA incorporate different specific tactics in their practice, but the objective of the process is the same, which is to train autistic people to suppress their autistic traits in public. This goal is intended to make the person undergoing ABA better able to interact with the mainstream social world, as they would be able to "pass" as neurotypical. Statistics demonstrate that ABA is considered one of the more effective "treatments" for autism (McDonald et al. 2012). This assessment of effectiveness is, however, made from the perspective of the families of and professionals working on (I hesitate to say "with") autistic people. Autistic people themselves can speak to the experience of being subjected to ABA, and their stories do not paint it in a positive light. As made clear by Tumblr's autistic community and as noted in Kirkham (2016), ABA is problematic in terms of both its methodology and goal. Methodologically, ABA has a history of using pain as an aversive, using gummy candies or similar treats as

positive reinforcement for good behaviour and electric shocks to punish "bad" autistic behaviour (Kirkham 2016; Millman 2019). This practice alone is worth condemning, in my opinion and in the eyes of the autistic community, but the results can also be problematic. If the behaviour being selected against is a stim, ABA is being used to punish a behaviour that alleviates stress. As such, not only is the therapy punishing self-consoling behaviour, ABA ties a stress-reaction to the action whose function is to alleviate stress, permanently inhibiting that stim's ability to calm the individual because of that association. Another example of "problematic" behaviour that requires correction according to ABA theory is avoiding eye contact, which is a common (though not universal) autistic trait. A recent study investigated the effects of eye contact in autistic people and found that the subcortical system was activated more intensely in autistic people when subjected to eye contact regardless of the emotion on the other person's face, indicating a stress response (Hadjikhani et al. 2017). Training autistic people (primarily children) to maintain eye contact when they are not naturally inclined to do so causes autistic children to experience stress, once again creating a no-win situation in which the stress of eye contact and the stress of the trauma associated with the ABA consequence for avoiding eye contact are directly at odds. The methodology behind ABA has often been likened by practitioners, proponents, and critics to dog training. Proponents use this comparison to explain the principles of behaviourism that underlie the method (Dorsey et al. 2019). Carol Millman, a professional dog trainer, weighs in on the differences between ABA for autistic people and behaviourism in dog training:

Dog trainers understand that dogs need to chew and bark and dig, but ABA therapists don't understand that autistic children need to repeat words and sentences, flap their hands, and sit quietly rocking in a corner when things get too much.

ABA assumes that the key to happiness is changing their behaviour to be more in line with non-autistic children.

It focuses on training children by holding their sources of happiness hostage and using them as blackmail to get the children to meet goals which are not necessarily in the best interest of their emotional health.

And like I said...

I wouldn't treat a dog that way. (Millman, 2019)

Even if the methodology behind ABA was entirely sound, however, the goals of the process are still diametrically opposed to the goals of the neurodiversity movement. Simply put, the goal of ABA is to effectively "cure" autism by forcing the suppression of autistic behaviours and thought patterns and affirming neurotypical behaviours and thought patterns. The goal of the neurodiversity movement is to demonstrate that neurodivergent thought patterns and behaviours are not harmful or destructive inherently, and that divergent thinking can be advantageous, is something that exists regardless of visibility, and should not exclude people from the respect of others.

One oft-cited part of the conversation about autism in the allistic world was unsurprisingly uncommon in the autistic community on Tumblr: the supposed link between autism and vaccination. Only two participants mentioned the debate, and even then, only tangentially and with derision. Tumblr user *ladyautie* mentioned that many

people in the country where she lives strongly believe in the link between autism and vaccines despite the lack of evidence, and user *jugemusans-anime-hut** mentioned that her mother is an “anti-vaxxer” among other things. The fact that my participants did not refer to the vaccine theory as a cause for autism, combined with the frequent posts made by autistic users critiquing Wakeman (the scientist whose research purported to show a link between autism and vaccination which was later retracted due to false data) suggests that the autistic community on Tumblr rejects the alleged connection between vaccination and autism. Here the community is in agreement with biomedical research which confirms that there is no causal relationship between the onset of the practice of early vaccination and the exponential increase in autism diagnoses (Modabbernia Velthorst and Reichenberg 2017). As McDonald et al. (2012) note, however, many parents of autistic children (who grow up to be autistic young adults) are attracted by untested and/or pseudoscientific explanations, treatments and “cures” for autism, which range in efficacy from being a waste of time and resources to being actively harmful to the recipient. While the parents of an autistic child may be led to any number of treatments or explanatory theories for autism, the autistic children who are subject to these treatments and theories grow up to recognise their ineffectiveness and invalidity.

Several participants in my study were self-diagnosed rather than professionally diagnosed as autistic. Others were initially self-diagnosed before receiving a professional diagnosis, and still others were professionally diagnosed before they were aware of their own diagnosis. Given the steep costs, both economic and social, of getting a professional diagnosis in many parts of the world, I made the decision at the beginning of the study to

include self-diagnosed autistic people on Tumblr within my study. This turned out to be an excellent methodological choice, as it vastly increased the number of potential participants and the enthusiasm of many of the participants I recruited. Anecdotally, my results showed little to no difference between professionally diagnosed and self-diagnosed autistic people in terms of prevalence and intensity of autistic traits, social experiences, and interactions online versus offline. Determining the degree of quantitative difference between the accounts of self-diagnosed and professionally diagnosed autistic participants is beyond the scope of this research. Moreover, in my view, this approach would be counterproductive, since the goal of the study is to describe the autistic community as it is found on Tumblr. In addition, by distinguishing between self-diagnosed and professionally diagnosed autistic people, I would be implying that the former lacked self-knowledge and self-awareness of their condition. In fact, the differences between the experiences recounted to me by professionally diagnosed and self-diagnosed autistic people were no greater than the differences in the experiences recounted to me by different professionally-diagnosed autistic people. There is, however, some debate in autistic Tumblr circles about the validity of self-diagnosed autism. While none of my participants clearly expressed any denial of the validity of a self-diagnosis for autism, participant interviews and portions of posts indicate a belief on Tumblr, within and outside of autistic circles, that only a doctor or psychiatrist can objectively determine whether a given individual is autistic. Based on the discourse I studied, there is apparently a consensus among critics of self-diagnosed autism that people who self-diagnose are simply quirky or eccentric and are claiming the status of being mentally ill without

justification. In a sense, these critics seem to view those who self-diagnose as appropriating the culture of autism without having to face the associated difficulties of actually being autistic. While I acknowledge that these critiques may be valid, and that evaluating their validity is outside the scope of this work, I find the arguments in favour of self-diagnosis more convincing. Participants shared, both in interviews and in posts made independently of the interviews, reasons why one might not pursue a professional diagnosis, and their views about the benefits of self-diagnosis. Moreover, the main criticism of self-diagnosis – that it is either inaccurate or disingenuous – is often logically disproved on Tumblr. The rebuttal to this criticism is that autistic people know their minds and bodies, and that the Tumblr community provides the information necessary for self-diagnosis. Moreover, access to professional diagnosis can be expensive, especially for autistic adults who are often left behind in health systems that prioritise early intervention (Autism Ontario 2008). An autism diagnosis for adults can be expensive, with the Autism Society of British Columbia estimating between two thousand and four thousand Canadian dollars (Digital, 2019). Ontario also has out-of-pocket costs for adult autism diagnoses, and these may not be eligible for Ontario Health Insurance Program coverage (Redpath Centre 2019). An adult wishing to avoid the financial costs and the lost time required to get a professional diagnosis might choose to self-diagnose, trusting their self-knowledge and research to validate their diagnosis and relying on other resources that might help meet their needs. The previously cited Redpath Centre in Toronto states “No, a formal diagnosis is not required in order to receive services from

our mental health organization”, another validation of self-diagnosis as a technique (Redpath Centre 2019).

People who self-diagnose as autistic are able to access the resources of the autistic community on Tumblr and be treated like a peer in a community of other people with the same condition. Self-diagnosis also means that one can control who knows about one's autism diagnosis in the offline world, meaning that some of the more deleterious effects of ableism against autistic people can be de-emphasized. People with official diagnoses of autism must still "come out" to their employers in order to receive workplace accommodations, which can mean receiving the full brunt of ableist practices on the job (Davidson and Henderson 2010). Self-diagnosing is also free, which cannot be said for professional diagnosis. Despite these drawbacks, most of my participants expressed the view that a professional diagnosis is preferable to self-diagnosis because of the resources available to professionally diagnosed autistic people. However, it is interesting to note that the autistic community on Tumblr does not entirely reject self-diagnosed autistic people. Moreover, self-diagnosis entails some difficulties. Tumblr user *ladyautie* shared that because she was self-diagnosed she was unable to access accommodations in her job that would have made it far more bearable. Receiving a professional diagnosis and “coming out” to her boss, however, would have put her career in jeopardy. Additionally, there are people within the autistic community on Tumblr, as previously mentioned, who reject the accuracy of the claim that you are autistic based on your own self-diagnosis rather than a professional one, which may hamper acceptance in the community.

Some of the participants in my study had been diagnosed with Asperger's Syndrome or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), diagnostic categories that were folded into the autism spectrum diagnosis in the DSM-5 under the label "Social Communication Disorder" (American Psychiatric Association 2013). Asperger's Syndrome was previously considered a different diagnosis from a low-support autism diagnosis due to the scarcity and/or absence of language impairments and intellectual impairments in the former (APA 2013). While the diagnostic label of Asperger's Syndrome for low-support autistic people was removed from the DSM-5 and has mostly fallen out of favour on Tumblr, some people still use and identify with that label, either because they were diagnosed earlier when the label was still in current usage, or because of a belief that Asperger's Syndrome is fundamentally different from autism. People diagnosed with Asperger's Syndrome or low-support autism frequently refer to themselves, and are referred to by others, as "Aspies." Unfortunately, on Tumblr and in the offline world, an ideology of "Aspie supremacy" has developed among some people. Aspie supremacy involves the view that "aspies" are superior to other autistic people. This ideology is mentioned in posts and notes on Tumblr and was touched on briefly by some participants in interviews. Critics of this ideology compare it to simple ableism and/or see it as part and parcel thereof, as the ideology prioritises those autistic people who are more able to function as part of neurotypical society. Several of my participants noted that there are people on Tumblr who uphold aspie supremacist ideology. Aspie supremacists are a conditional ally for some autistic people and a more virulent ableist to others, depending on their support level.

One way to describe the aggregate experience of being autistic on Tumblr – taking part in the autistic community and participating in its discourse – is that the autistic community on Tumblr reframes the condition that connects all of its members. The Tumblr discourse does not universally frame the condition as positive, however. As demonstrated in interviews and posts from participants, both the positive and negative facets of autism are discussed and put forward in the collective conversation. However, except in the case of Aspie supremacists who are relatively rare, even the negative aspects of autism are not framed in terms of an issue of inherent personal worth. Rather, the problems associated with being autistic are understood as resulting from the inability of neurotypical society to accommodate the needs of autistic people and other neurodiverse groups. The framing of autism and autistic people is meant to run counter to the mainstream narrative perpetuated by society. I use the word "society" in the general rather than the specific sense because my participants were located in a number of different countries in Europe and North America, including Canada, Germany, the United Kingdom, and the United States. While posts from specific participants provided information about or referred to specific national health care systems, many of the struggles participants experienced were the same whether they were located in Canada, Germany, the United Kingdom, or the United States. The narratives were, with minor differences in intensity, much the same. Tumblr, however, is a community space shared by many people across the globe, including autistic people who are now free to explore and communicate without the same sensory and societal barriers they experience in the physical world. It makes sense, then, that the autistic community on Tumblr would

reframe autism as a condition that is not inherently advantageous or disadvantageous, but rather just different – markedly less negative than mainstream narratives make it out to be.

CHAPTER 4: COMMUNITY

“it's like i finally found a community where everyone waddles like me”

- *sin-cordura*, 2018

Participants reported many different reasons for their initial decision to join Tumblr. As a microblogging platform, Tumblr is home to many other communities of interest outside of autism and is populated by people of any and all political alignments and demographics. We can see this diversity in my participants' responses. While some users created a Tumblr account explicitly to take part in the Tumblr autistic community, the majority joined Tumblr for another reason and stumbled upon the autistic community through following popular users and/or autism-related hashtags. Tumblr user *junimo-forest* describes joining Tumblr initially to write and share original poetry, but that initial purpose was quickly put aside as he "got swept up in other topics once I started to get exposed to more and more bloggers/the website as a whole." From there *junimo-forest* describes rapidly becoming involved in the site's political discourses, particularly surrounding LGBTQ+ issues and disability/mental illness. He discovered the autistic community through the latter. While *junimo-forest* joined Tumblr as an outlet for writing poetry, Tumblr user *fascistsrbad* joined "because of those 'best of Tumblr' Facebook pages. They post screenshots of Tumblr threads that I found to be pretty funny." As previously alluded to, Tumblr has a reputation outside of its userbase, though the substance of that reputation tends to vary based on context and community. Tumblr occupies an interesting space, simultaneously reputed to being overly serious and

reactive, and being shown to be a powerhouse of content generation in terms of both sharing information and creating funny situations and scenarios. These humorous blogs are then saved as screenshots and distributed to other communities, and in turn other communities have screenshots that are shared on Tumblr and elsewhere. User *fascistsrbad* specifically noted seeing out of date Tumblr posts, resulting in his impression of Tumblr from 2013 (the year when the posts in question emerged) being inconsistent with the culture of Tumblr at the time he joined the site in 2015. Despite the differences in their reasons for joining, both *fascistsrbad* and *junimo-forest** encountered the autistic community in the same way: through taking part in site discourse and finding users from the autistic community who are active on the site. User *jugemusans-anime-hut** described joining because their friends were all on Tumblr upon its launch when they were in middle school. This user cites the progression of their blog as: "homestuck => kpop => whatever it is now but not kpop. when i started falling out of love with kpop i made several sideblogs to organize my other interests." At the time of the interview *jugemusans-anime-hut* had nine blogs in total, including three explicitly autism-themed blogs and one devoted to detailed logging of the specific experiences associated with one trait linked to autism and other conditions. This example illustrates one way that users can curate their online experience. They are not simply curating what they experience through following specific users and/or tags, but by curating the content of specific themed blogs.

Other users, as previously stated, did join Tumblr explicitly to take part in its autism community. Tumblr user *aspieman* describes his initial blog creation as the result

of "searching the Web for information related to autism and Asperger's" two or three years prior to our interview. His explicit goal was to share his experiences with autism in order to validate and educate others. Tumblr user *speak-autism-without-speaks* joined for the same reason, and with the same motivation, stating that "I joined Tumblr looking for an autistic community to belong to. I also was looking to find acceptance within myself." Their blog's theme evolved over the years: from educating autistic people and disabled people on ways to adapt to an unfriendly world initially, *speak-autism-without-speaks* branched out to discuss uncommonly discussed topics and how various other identities intersect with autism. According to this user, this process is facilitated by Tumblr's generally intersectionality-friendly discourse. Of course, with the existence of sideblogs and the reputation that Tumblr has attained across the Internet, it is not surprising that some users choose to join Tumblr both to take part in an autistic community and to take part in other communities on the site. Tumblr user *aap-autistic** describes how she made a main blog for venting her frustrations about navigating the neurotypical world and a side blog where she can take part in fandom. The key thing she mentioned about both blogs was that she feels less safe talking about these topics in the physical world, and much more safe talking about them on Tumblr.

By far the most relevant factor influencing these people to join the community was exposure to the experiences of other autistic people. We will discuss later the ramifications of this exposure, but for now we will discuss the specific details of inroads to the community. Many users interviewed stated that seeing the different posts from users in the community gave them insight into that community and into the condition of

autism itself. These posts vary in type, of course, but there are a few notable types of passive interaction one can have with users in the community. The absence of any expectation of formality in writing (without discouraging the use of formal writing) and the potential for varied creative forms of expression online (with specific rules governing behaviour stated explicitly rather than being merely implicit) not only leads to and maintains the type of language idiosyncratic to Tumblr, but also allows autistic people who use the site to express themselves online in their own preferred fashion.

Mechanically speaking, this lack of formality and potential for creativity contributed to empowering autistic people to use Tumblr as a platform for sharing their experiences and interests. More organically, however, there were a large number of autistic people who came to Tumblr in its initial inception. As discussed in Davidson (2008) and alluded to in Hodkinson (2008), online spaces can be places where people can assert a sense of autonomy without the same sort of physical, social, or sensory barriers experienced in the physical world. As a result, early blogging platforms like Blogspot, Livejournal, and later Tumblr came to be welcoming places for people who know they are autistic as well as for people who may not know they are autistic but who experience similar barriers in the physical world to a professionally diagnosed autistic person. As previously discussed, the autistic community on Tumblr is an excellent resource for those looking for information on a possible autism diagnosis, professional or otherwise, and the format of the platform attracts people who might have traits congruent with an autism diagnosis. Tumblr's format does seem tailored to the specific needs of autistic people, though there is no evidence to suggest that Karp was taking autistic people specifically into account

when designing the site. Part of the explanation for this openness of the site to autistic users might be that Tumblr, since its outset, was focused around the utility and accessibility of its features, which were its main selling features in the site's early days (Carr 2013). The focus on the mechanics and optics of Tumblr's feature set as intuitive and accessible as well as powerful may be the key to Tumblr's ease of use by its entire user base, including the autistic community. These characteristics of Tumblr have been influential, both in the intended usage of the site and in the co-opting of site mechanics to create site-specific cultural artifacts. That is not to say there are no issues with Tumblr's formatting and site design philosophy – after all, many site users refer to Tumblr half-jokingly as a "hellsite" because of some aspects of its culture and design – but rather that through design and cultural development, the site has become accessible to autistic users.

Owing to Tumblr's broad appeal to users, both autistic and non-autistic, who appreciate its accessibility and intuitive character, it can be hard to parse what content is specifically generated by and for autistic people in the autistic community on Tumblr. There is a great breadth of content that could be classified as generated by the autism community on Tumblr. The archetypal and perhaps most recognisable type of autism content shared online would be autism pride posts like the following:

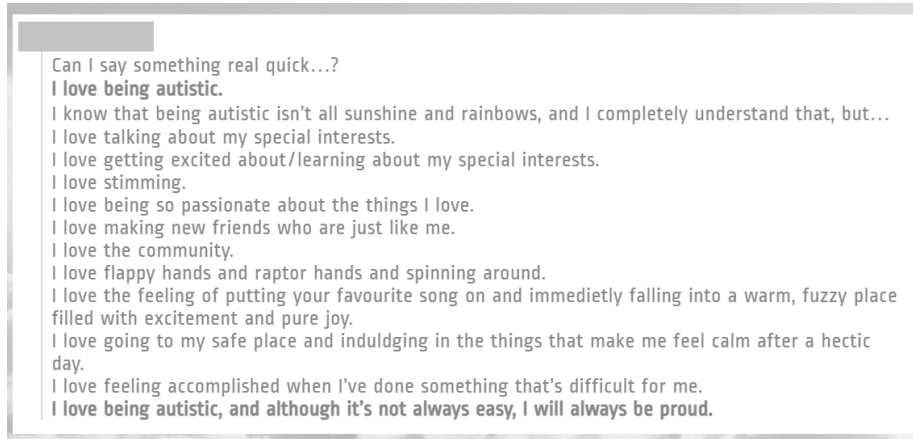


Figure 8: a sample autism pride post

Posts

like this are a
deliberate move
toward
correcting an
unjust narrative
about autistic

people in the neurotypical world by creating and perpetuating a more positive counternarrative. This counternarrative is built on posts like these that affirm the value of being autistic, and posts that criticise the mainstream narrative that influences allistic perceptions of autistic people. The latter category could include posts by an autistic person venting about their treatment at the hands of an allistic person, posts about the struggles of navigating the allistic world as an autistic person, or posts sharing reasons to dislike problematic autism charities. The advocacy organization Autism Speaks faces particularly harsh criticism from the neurodiversity movement in general and the autistic community on Tumblr more specifically.

I am Autistic, and Autism Speaks does not speak for me

I am not a burden.

I am not a mistake.

I am not missing a piece.

I am not a disease.

I am not something that needs to be cured.

I am not something that needs to be fixed.

I am not something that needs to be prevented.

I am autistic, and Autism Speaks does not speak for me.

Autism Speaks has SUPPORTED families of autistic people that have abused, and even *murdered*, their autistic child because they are "too much of a burden".

Autism Speaks is a board made ENTIRELY of neurotypicals - Autism "Speaks" does not speak for autistic people, they speak for themselves.

Autism Speaks is a hate group.

Autism Speaks tries to instill fear into the minds of others to try and target us as dangerous.

As tragic mistakes.

As something that can be prevented.

But do you know what?

I am autistic, and I am perfect.

I am autistic, and I am **human**.

Figure 9: A sample post describing the unanimous opinion of the autistic community on Tumblr regarding Autism Speaks

For people in the autism community on Tumblr, the main complaint about Autism Speaks is that its presence harms rather than helps autistic people. From the perspective of the autistic community on Tumblr, the goals and ideology of Autism Speaks are antithetical to neurodiversity since the organization sponsors research and fundraising to find a "cure" for autism on a neurological level and through treatments like ABA (see also Fig. 9). As noted earlier, the autistic community on Tumblr

came into prominence at around the same time as the neurodiversity

movement started, and indeed the existence of Tumblr probably facilitated the growth of

the movement. This coincidence underlies the vitriol expressed toward Autism Speaks on Tumblr. As the memes shown above in Figures 9 and 10 illustrate, autistic Tumblr users are strongly critical of Autism Speaks. Most



Figure 10: A sample relatable meme. One might find similar memes with different text in other communities, but in this community Autism Speaks is salient. This is also another example of how Autism Speaks is viewed in the community.

autistic Tumblr users recognise that it is organisations like Autism Speaks and media depictions of autism that have in the past influenced allistic perceptions of autism as a negative condition. The resulting counternarrative therefore must be thorough, affirming the value of autistic people while also disproving and/or discrediting negative depictions and narratives. The content generated by the autistic community on Tumblr is not limited to these posts critical of Autism Speaks, however. Many posts about autism more generally would be familiar in form to any Tumblr user, but are tailored to an autistic audience (Fig.10). The content of these more general posts is, much like the content of posts critical of Autism Speaks and ABA, frequently tailored to facilitate the acceptance of autistic and other neurodivergent people and the perpetuation of a positive autistic counternarrative using the affirmative model of disability, according to which the

negatives of autism are erased entirely, instead examining and celebrating the positive aspects of the condition (French and Swain 2000).

As an example of the community's ability to disseminate information, we can turn to the collective understanding and identification of the models of disability that affect public perception of autistic people. The consensus of the autistic community on Tumblr goes against the medical model of disability, a model in which the individual, not society, is the locus of disability, and problems arise because the individual has an issue that needs to be solved or “cured” (Brisenden, 2007). This view is almost universally reviled by the autistic community on Tumblr, for its own demerits and also because it is a prerequisite for the tragedy model of disability, which considers the disabled person a sufferer of their condition, their diagnosis and the accompanying social and developmental difficulties a tragedy for the family to overcome or succumb to (Brisenden 2007, Woods 2017). Most people in the autistic community on Tumblr subscribe to the social model of disability in which the locus of disability is not the neurodivergent and/or physically disabled individual, but rather society's failure to provide space and resources that enable the individual to function (Woods 2017). Posts shared by participants in my study indicated that most of them were thoroughly familiar with the concepts of the medical, tragedy, and social models of disability. The social model of disability is a useful prerequisite for what Swain and French (2000) term the "affirmative model of disability," in which the individual's condition is not a problem. It should be noted that all participants in this study were able to identify good things about their individual autistic traits, and most could provide a long list of positive features of autism. Participants tended to hold both

the affirmative model and the social model of disability, as exemplified by *ladyautie* in the following quote:

I guess my autism makes me more open-minded. I'm not the kind to judge people based on a first impression or how they look or how they behave. People appreciate this and it allows me to meet great people that I probably wouldn't have interacted with, if I paid attention to how they look.

Also, I like the fact that it makes my emotions very intense. I mean, yeah, my negative emotions, but my positive too. When I'm happy, I'm very, very, very happy, even for the little things. So it's kinda cool.

One can see parallels between *ladieautie* and disabled participants cited in Swain and French (2000):

I just can't imagine becoming hearing, I'd need a psychiatrist, I'd need a speech therapist, I'd need some new friends, I'd lose all my old friends, I'd lose my job. I wouldn't be here lecturing. It really hits hearing people that a deaf person doesn't want to become hearing. I am what I am! (Shakespeare et al. 1996: 184 cited in Swain and French 2000: 576).

We are who we are as people with impairments, and might actually feel comfortable with our lives if it wasn't for all those interfering busybodies who feel that it is their responsibility to feel sorry for us, or to find cures for us, or to manage our lives for us, or to harry us in order to make us something we are not, i.e. 'normal'. (Tyneside Disability Arts 1999:35 cited in Swain and French 2000: 577).

The neurodiversity movement embraces the social model of disability, but autistic Tumblr users reframe their condition not simply as “not-negative,” but as positive in its own terms. It is important to note, however, that this discourse of affirmation is made possible – or, at least, made far easier and much more accessible – via Tumblr.

It is important, however, to recognize that the autistic community on Tumblr is not homogeneous. Tumblr is known throughout the Internet as a locus of social and environmental justice and activism, but it is also known as a place where a lot of arguments over the finer points of these causes can occur. Lack of consensus in the autistic community on Tumblr was discussed previously in the context of the Aspie supremacy movement on Tumblr and the controversy that it generated. Differences of opinion also exist more generally on topics connected to, intersecting with, or unrelated to autism. Interestingly, these intersecting and unrelated issues can have a greater effect on one's influence, popularity, and interaction with the autistic community on Tumblr than issues directly concerning autism itself. My study indicates that there is a relatively high degree of consensus among autistic Tumblr users with respect to autism. Regardless of their opinions on other topics, most autistic people on Tumblr and certainly all participants I interviewed agreed that neurodiversity as a concept is good, Autism Speaks and the medicalisation of autism is bad, and that autistic people should have more rights. That said, the amount of social awareness present on Tumblr can mean that people whose opinions on one issue align well may still get into arguments because their opinions regarding another social issue differ. Tumblr user *autisticrevolution* exemplifies this division perfectly. He is rejected by some users for his anti-feminist approach to politics

and activism (an unpopular view on Tumblr) and often gets into conflict with other users about feminist issues. However, many people still respect his autism advocacy work, and his posts get thousands of notes. He cites his political beliefs as the impetus for many arguments and some of his posts provide evidence for this, with some reblog chains extending well over a page in length. While his controversial opinions are not necessarily a limit to his popularity in the autistic community on Tumblr – as mentioned previously, reblogs spread the message of both the initial post and any replies to it – these opinions may affect how other members of the community view him. The example of *autisticrevolution* also attests to the diversity of thought within the autistic community on Tumblr, and shows how the borders of this community are nebulous and delineated not by identity but are constituted by a dialectical process of discussion, as mentioned earlier.

Tumblr user *thehappylandfill* provides another example of the diversity in the autistic community on Tumblr, though their account is evidence of one of Tumblr's more toxic tendencies. Their blog started off centred around sexual content but moved toward activism early on. The following quote from *thehappylandfill* describes how their story then took a turn for the worse based on that initial history:

about three years ago, an abusive ex lied to people and started telling everyone i was a child molester

so for about a year someone started (and is still running) a “callout” blog that essentially keeps spreading harmful lies like that and harassing people who befriend me.

back in december, i stayed with a friend for two weeks and when i came home, they stopped talking to me and i found out they’d been posting on here and saying that i’d

assaulted them in their sleep. so i ended up losing almost every friend i actually had in [location redacted], as well as having lost countless others purely due to the existence of that single blog and their relentlessness.

it's definitely affected too many of my relationships.

Because an individual user can have a great deal of reach, one person can very quickly spread a rumour about another person before the target has the time to address it. If the campaign is forceful enough, it can lead to wholesale exclusion from certain parts of the community. The curious thing about this case is that the end result of this campaign against *thehappylandfill* is that they became more reliant on Tumblr, not less:

considering i'd lost all of my local friends, i still had people on here i could talk to, even if i didn't know them just by posting something like "hey does anyone wanna chat?) and i'd usually get a handful of responses.

i struggle with making friends offline (unless they're old ladies at bus stops for some reason), so having tumblr honestly has made a difference in that regard

plus i get a lot of messages from people thanking me for helping them, thanking me for sharing knowledgeable posts, and helping them understand certain issues more. so i really think this platform is definitely useful to more than just myself, and if i help even one person then it's worth all the trouble.

After understanding how Tumblr as a community functions as a community, the logic of *thehappylandfill*'s situation is intuitive: despite losing friends in one corner of the site, there are enough people online that some will listen to you and remain friends. There is certainly group cohesion within communities and a measure of hostility based on

ideological differences between communities, but there is enough cohesion and diversity of opinion within and between individuals that anyone can find a place in any given community on Tumblr, including in the autistic community. *thehappylandfill* also describes their experiences here explicitly as part of the autistic community on Tumblr. Sharing their experiences allowed them to make the friends and receive positive feedback from the people they helped. This example enables us to begin to see more clearly how divisions and tensions on Tumblr take form, how they manifest, and how they can be either overcome or ignored in order to maintain one's place online. Most other users did mention, at least in passing, some form of conflict or troubles. For example, *junimoforest** mentioned having occasional issues with people sending hateful messages anonymously over Tumblr's native ask function (*anon hate* in the online vernacular), Tumblr user *calictii* mentioned seeing screenshots and reblog chains featuring intense fights and arguments, and user *deliciousbiscuits** mentioned getting caught up in an argument on Tumblr over the existence of intersex people. As much as Tumblr as a site can harbour community and maintain cohesion within communities, the site atmosphere can be combative, especially for those not used to it. Tumblr user *fascistsrbad* explains:

I'm always worried that I'm going to say something problematic, not like the whole walking on eggshells thing but something that actually is problematic and I have an actual problem with saying the wrong thing, it's actually caused problems irl [In Real Life] for me as well. It's never happened to me, but I've seen it people who mean well taking flak for something like a comment that seems harmless to me but apparently is problematic and I can't help but worry about how easy it would be for me to make the same mistake.

In spite of this potential for contestation, the autistic community on Tumblr seems to have an overall positive impact on its members, according to participants in this study. The opinions were not homogenous and sometimes varied even within individual accounts. As with any community, conflict and tension are unavoidable. However, all participants directly reported a neutral to positive opinion about their experiences on Tumblr, and moreover were able to share information about their experiences, both positive and negative, that substantiated these opinions.

Throughout my time interviewing participants and examining posts on Tumblr, and Hodgkinson and Lincoln's idea that online spaces are like virtual bedrooms – places where users could exercise limited autonomy – was applicable to many posts on the site (2008). Bedrooms are places where, growing up, children with little space for autonomy can exercise limited autonomy. In their bedrooms, children can paint the walls, close themselves off from the outside world, and stack the room with their own possessions. The bedroom provides the space in which the child has the closest experience to autonomy. The child still cannot tear down the walls. Moreover, the barrier between them and the outside world is not impermeable, and the privacy experienced by the child depends on parents' respect for that privacy. However, the bedroom is a place in which some measure of autonomy can be afforded. Participants in my study universally discussed feeling marginalised to some degree, with many of them implying or stating outright that they feel infantilised by significant people in their lives and feel that they lack autonomy. Their autism was not the cause of this lack of autonomy, as many people in the study were employed, in relationships, and/or living on their own, all the usual

markers of adult status and success in society. While some of their autistic traits were considered by participants themselves to be objective hindrances, the vast majority of traits were considered negative based on interactions with the public. Thus, it was the social perception of the traits, and the people who exhibit them, and not the traits *a priori* that constituted the impairment. As a result, the people in my study who were feeling marginalised everywhere in society could find solace in their own living space if they had one, but many could not and/or did not have such a “home” for various reasons. Every participant in this study did, however, have Tumblr. In this respect, Hodkinson and Lincoln’s (2008) analysis is accurate. The online space is a virtual bedroom, a place to

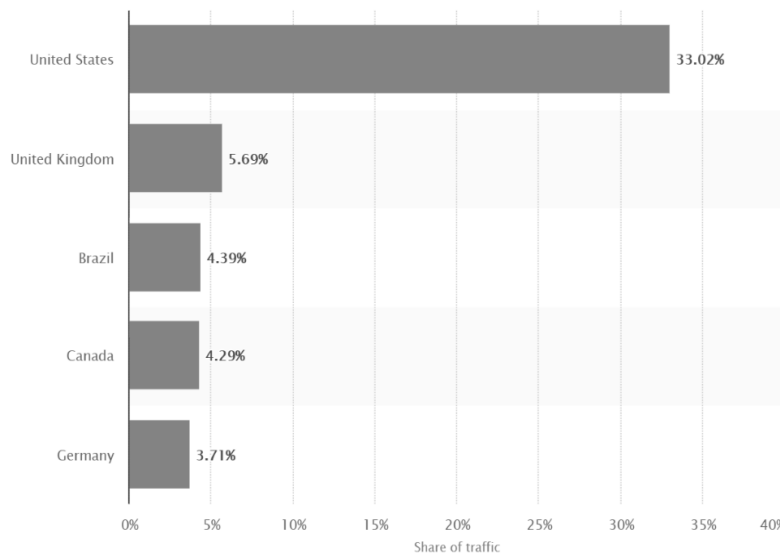


Figure 11: The top five countries that Tumblr users come from, ranked by percentage. Statistic provided by SimilarWeb.

exercise agency and autonomy with a reasonable expectation of having both respected. Tumblr is, essentially, one giant interconnected

bedroom space - not

quite one giant bedroom, but rather a dormitory style apartment. Each person has their own semi-autonomous space that they can customize to their own specifications as well as a shared experience via the dashboard. Curated though it may be, the experience of navigating the dashboard is universal. One can visit other “bedrooms” regardless of physical space, and there is a perceived barrier between this space and the physical world.

Tumblr is its own cultural space, and while people from many physically heterogenous locations may take part in the cultural processes on the site, the process itself (keeping in mind the site demographics in the physical world) is able to function as its own cultural entity, with its own traditions, rules, and artifacts.

CHAPTER 5: QUALITY OF LIFE

“I'd say it [Tumblr] helped me to feel better in public places, for example. When I feel anxious, I know I can take my laptop and go on Tumblr to find comfort and to stop thinking about the noise around me and stuff like that.”

- *ladyautie*, 2018

Before we can properly evaluate Tumblr's effect on its users' quality of life, we need to draw a comparison between those users' time on the site and their time in the physical world. In this chapter, I focus on the impact that participating in the autistic community on Tumblr has had on the quality of life of participants. I assess quality of life both in terms of life in the virtual community on Tumblr and through comparison between life on Tumblr and in the physical world. One noteworthy finding of my study is that most participants, regardless of their geographical location in the real world, faced similar social and economic struggles. While this finding is not surprising considering the relative similarities between participant locations and diagnoses, it is noteworthy that these issues persist despite the differences in legislation and public policy relating to disability that impact autistic people in different areas (The ESH Team 2014, Parkin 2016). More importantly, however, the similarities in social and economic experiences shared by people in the autistic community on Tumblr suggest that people from all over the world can discuss their experiences with autism online and these experiences will be recognisable to other autistic people. Therefore, the existence of an explicitly autistic community on Tumblr, where other autistic people and their stories are made accessible

and community engagement can be performed with a few keystrokes, can be an important factor in the life and well being of users. In my interviews and in blogs, participants discussed interactions with allistic and neurotypical people both online and offline. All participants had experienced some level of discrimination on the basis of their autism in the physical world, with many sharing their own individual narratives that demonstrate an overall pattern. Tumblr user *sbroxman-autisticquestions* described his interactions with neurotypicals in the physical world in the following way:

Usually it's stuff like people not understanding when I'm feeling overloaded. Like me needing to leave social situations has been interpreted as being "rude" before and such when I had no intention of it being.

One common challenge is facial expressions. Like often, someone will say something, and I'll understand exactly what they said, but I won't know what the appropriate response would be. Apparently I make an "I don't understand / I feel lost" face because a lot of the time, the person assumes I didn't understand and will proceed to say they were just kidding or something

There's also the chance of them either overestimating or underestimating what I can do. Some will either just assume I don't have autism "that bad", and a few, the moment they hear I'm autistic, will start baby-talking me, or treating me like a child that can't do much

User *aspieman* discussed similar points:

I don't talk about my autism outside of my blog with others who are "normal." Because of how I am as a person it is obvious to others that I am different, but I do not try to express my beliefs or my feelings to others because I have found that some of them

exploit that and exploit me for their own gains and that they don't really understand what it is like to be me. I have learned how to exist in a world where I am the alien observer

The problems that I have now are different then the problems that I had growing up because I have learned many ways to compensate and I have learned what these other people want from me in terms of responses to some of the standard forms of communication. Questions that are asked like how are you. They don't really want to know how I am and so I just say fine. No matter how I feel the correct response is fine

This gives me a sense that I am hiding information or lying and we all know that lying is not generally a good thing although there are times when one must lie to protect others

Or one self

But I have learned to live with that and many other things that are generally standard forms of communication for neurotypicals

I have not yet learned how to have patience with people who excel at chit chat or small talk

I try to move on and leave the area Because those people seem to get easily offended if you do not engage with them in that inane practice

But I have learned to be a good chameleon

And that ability has meant that unlike some on the spectrum that I've learned about on Tumblr, I have been able to maintain a job for long periods of time.

I have also learned that it's only a matter of time and not a matter of if Neurotypical's grow tired / frustrated with me (due to a lack of social graces), my way of thinking and my approach.

I try to understand when it is time to move on to something new Although that is very stressful and very painful at times it is less painful then staying and dealing with neurotypical anger, frustration, and ...can't seem to find words to finish the sentence
ridicule. That's the word. Group ridicule and disrespect

I have always experienced that. When neurotypicals perceive that you are different And that you are unable to conform to their world view of how you should behave, they tend to identify and group together with other neurotypicals and to uhhh express ridicule about your stupidity, or dim wittedness"

These two quotations are representative of the experiences of most participants. While some of my participants reported only certain of the issues mentioned above in their lives, all participants offered accounts similar to those of *sbroxman-autisticquestions* and *aspieman*. In encounters with neurotypical people, the experiences of being ridiculed, met with frustration, or the inability of neurotypicals to grasp what the participant was trying to communicate seem to be common factors in the lives of the autistic people interviewed.

By contrast, while Tumblr certainly is not free from conflict, negative interactions with neurotypical people are far fewer and the stakes are lower online. Participants discussed feeling more free to be themselves online without the sort of risks associated with doing so in the physical world. Moreover, allistic and/or neurotypical people online

are more likely to respond with curiosity rather than apathy or antipathy toward autism and autistic traits. Tumblr user *the-happylandfill* discusses this greater level of tolerance here:

online i've gotten people telling me that my openness about stimming and posting stimming gifs has actually helped them feel more comfortable about their own stimming, whether in public or not!

i haven't really gotten anything like that from people who've just observed me in the street haha

so it seems offline, people are more passive about it, when online it can end up being very important to others

people are definitely more comfortable asking questions about autism on here than they are in person.

There are other ways that being online facilitates communication between neurotypical and autistic people. Many of the problems cited in the previous quotations from *sbroxman-autisticquestions* and *aspieman* are mitigated or non-existent in online interactions. Most participants explained that the ability to plan out what they were going to say in text, rather than having to react to people in real time as one does in conversation, has facilitated better communication online. Moreover, sensory barriers that exist in the physical world – including but not limited to sensory overloads, persistent distractions, needing to stim but being unable to – exist online to a far lesser extent, and the autistic person has the ultimate control over the stimuli they experience online. This experience is not universal, of course, as no autistic person has the same specific traits as

any other. For example, user *aap-autistic** mentions that she finds deciphering tone a little harder online than in offline interactions, as body language can help her parse the meaning of a statement. However, removing the immediacy of response allows for a greater degree of control over one's response, so one could choose to ask for clarification or think their way through their conversation partner's intentions in more time than a split second, without worrying about their own body language. Once again, the metaphor of internet spaces as online bedrooms applies here: unsurprisingly, while total autonomy and perfect communication may be impossible, the comfort of being in a space one can control makes communication easier and more comfortable in and of itself (Hodkinson and Lincoln 2008).

While Tumblr has broadly the same benefits for all participants in terms of interacting with neurotypical and allistic strangers online as compared to offline, the effects the site has on interactions with current friends and family members are far more varied. Family situations for participants were diverse with some having entirely supportive families, others having unsupportive or abusive families, and others having some family members that were supportive or families that were supportive only situationally. Still participants had families that were only supportive after much effort on the part of the participant. Tumblr was most useful for the latter groups, those with mixed or situational support and those whose family members required education in order to be more supportive. The website, as previously discussed, hosts many types of content from simple memes to complex explanations of lived experiences. Participants whose families offered mixed or situational support and those whose families needed education

reported marked improvements in their living situation after showing their families posts from the autistic community on Tumblr community. Tumblr user *junimo-forest**, for example, mentions "There are so many great posts here with resources that have helped family members be more understanding of me. And I can back up some of my own experiences by saying, look at all these people who feel the same way." Other participants noted a lack of support from their parents. For example, Tumblr user *papertiger94* noted the following:

they [my parents]'re not exactly wild about the whole autism thing, especially when it was my special interest for awhile and i wouldn't shut up about it

My parents have always thought I was just a little odd, and I was never assessed for autism as a child, and they still don't agree with my self diagnosis. We clash a lot because they don't know what it's like to live in this brain. (I have a feeling my dad is undiagnosed autistic too and he's less negative about it than my mom).

This user also points out that she is out as gay to all of her friends but not to her parents, and that she is "at [her] gayest on Tumblr." Apart from ableism, homophobia on the part of family members was the most commonly cited complaint from participants who self-identified as part of the LGBTQ+ community. This issue is noteworthy considering both the disproportionate number of autistic people who identify as LGBTQ+ as compared to the neurotypical population (Freed 2018, Rudacille 2016), and the fact that Tumblr has a disproportionately high percentage of LGBTQA+ users (Hanckel et al. 2019). In the absence of family support, Tumblr can act as a surrogate for family,

providing the support and positive feedback to the oppressed person that would in ideal circumstances be granted to them by their family.

Most participants reported that their presence on Tumblr had no real positive or negative effect on existing friendships in the physical world. Some participants reported sharing site content for fun with friends in the physical world. Participants did, however, report that the site was excellent for making new friends, with some online friendships carrying over into the offline world. While I can personally validate these characteristics of Tumblr from my own experience, it is telling that the friendship-forming capacity of Tumblr, especially between autistic people, is something that every participant mentioned in interviews. Tumblr user *overexplainingautistic* provides a particularly noteworthy account, since this user admits to having difficulty knowing at what point one becomes a friend, but can still clearly identify how the site has allowed them to expand their social circle:

I've always been bad at knowing when someone is a friend or not, but I'mma [I'm going to] treat this question like one of a continuous scale of friendship, where the point of unambiguous friendship is some definite point on there, but that I just don't know where it is.

I became vaguely friendly with various other autism tumblr users (people who blog mainly about autism) to varying degrees.

No negative impacts to report, and no examples come to mind for old friends made more actively to be friends again.

For new friends, I also formed an autism discord built largely from people in my autismtumblrsphere. There, more clear friends were made, though where on the friend scale I can't stay for sure."

While other accounts accurately describe the experiences of making friends online, *overexplainingautistic* here provides a comprehensive summary of how, where, and through what channels these friendships can grow and be maintained. This process is made more efficient through the curation of one's content. While friendship formation can happen accidentally or incidentally through random chance, it is more likely on Tumblr that people become friends when they like enough of the same content that they keep seeing each other's usernames on posts reblogged by people they already follow. Not only are there no sensory or social barriers to interaction on Tumblr, but users who see each other via shared posts are already inclined to have at least one thing in common. Sometimes this evolves into a friendship immediately, sometimes each person follows the other's blog for a while before a friendship forms, leaving comments here and there, and sometimes both follow each other's blogs but a friendship never forms. When one can follow as many blogs as there are blogs on the site, there is hypothetically no limit to the number of friends one can make through Tumblr.

Friendship, and the wider feeling of community on Tumblr, has a secondary benefit outside of the usual benefits friendship and other relationships can confer. As noted previously, the neurodiversity movement crystallised online at around the same time Tumblr became a convenient place to hold and share opinions valuing neurodiversity, and Tumblr itself is uniquely designed to be intuitive and accessible.

Therefore, it makes sense that autistic people on Tumblr can find some catharsis on the site. The stories that are shared and the information given freely by other users serve two benefits for the autistic Tumblr user: they provide examples for what to do in situations outside Tumblr, and they allow autistic people to express themselves comfortably. Each of these benefits is noteworthy for different reasons. In the first place, some posts on the site are explicit guides for navigating life in the physical world, describing differences between the behaviour of neurotypical and autistic people for purposes of education, entertainment, or both. This type of post has a dual purpose. It informs autistic people about neurotypical behaviour, but equally importantly it also informs neurotypical and questioning people about autistic behaviour. Autistic people benefit by being better able to understand the neurotypical world without feeling the pressure to mask their autism, as so often happens with other autism resources and initiatives. Neurotypical people benefit by being better able to understand their autistic friends, colleagues, and friends and colleagues-to-be; and people questioning their own behaviour – wondering if they are autistic or otherwise neurodivergent – can find genuine accounts and comparisons with which to evaluate themselves. The latter case is especially noteworthy, since self-diagnosed autistic people are, as previously mentioned, mostly welcome in the community. Participants like *papertiger94* share their experiences of taking part in an explicitly autistic space as a self-diagnosed autistic person, accessing resources and validation of their traits that would be denied elsewhere. Others, like *junimo-forest**, describe how their experiences led to self-diagnosis, which in turn led to receiving a professional diagnosis. Both participants, and many others, mention that regardless of

their professional diagnosis, they suddenly had access through Tumblr to resources with which they could educate their allistic friends and family. Judging from these experiences, not only are the stories and descriptions on Tumblr providing education, entertainment, and catharsis for autistic people, they are also educating the neurotypical people that the autistic community interacts with and reducing, even if only slightly, the likelihood of negative interactions in the future.

CHAPTER 6: DISCUSSION

"people of my generation [millennials and late millennials] or younger all seem to understand me very easily... it's like we're all a little autistic because of the internet everyone had to think like me :)".

- sin-cordura, 2018

Tumblr is a site that hosts many different communities based largely around interests, politics, and identity. In the same way that one can find an autistic community on the site, one can find communities for borderline personality disorder, cartoons, leftist politics in varying degrees of specificity, right-wing politics in varying levels of specificity, animals and biology, studying, and so forth. The autistic community on Tumblr, however, specifically fits Rabinow's (1996) conceptualisation of biosociality – communities established around specific diagnoses or more general notions of biological divergence (e.g. autism; neurodivergence). The autistic community on Tumblr is a noteworthy example of a biosocial community due to its size, relative popularity, and integration into the site's mainstream. It must be noted, however, that it is ultimately one large biosocial community among many on the site, all of which are in constant interaction and dialogue with each other. Many participants noted other conditions, physical or psychological, with which they identified, in addition to autism, and/or whose communities they have championed alongside their own. While these interactions may not always be positive, one could argue either that the communities themselves are all loosely allied to each other – though the extent of the differences between individual perceptions of each condition can cause tension – or that each biosocial group is itself part of the broader biosocial label

of neurodiversity or even the broader label of “disability activist”. One could consider the autistic community on Tumblr a comparative organisation to the "autistic liberation front" cited in Hacking's work, and to a degree this comparison fits. There are two issues with this comparison, however, first of which being Hacking specifically describes lower-support autistic people as the frontrunners of the front, which does not accurately reflect the inclusion of higher-support autistic people and their narratives being shared on Tumblr. Moreover, and perhaps more importantly, these people are being considered the new experts on autism, factoring autistic people of all support levels into this online activism. Tumblr's autistic community is therefore not solely an “engine of resistance” (Hacking, 2007:311), but rather an “engine of normalisation” as Hacking phrases it, (2007:311) in and of itself, as well as a space where that new normal can be practiced. The autistic people in this setting are not merely the people, their condition not merely the classification, but rather they have become the experts that self-analyse and provide insight and expertise. In addition, in many cases, physicians will not be able and/or willing to provide this insight and expertise. The community on Tumblr becomes an institution therefore, the place where these autistic experts convene, share and debate knowledge and experiences, and absorb the cultural experience of being on the site. Following Hacking, it is possible to conclude that, in contrast to earlier eras, in the contemporary world, “it is possible to be a person, to experience oneself, to live in society” as an autistic individual, and Tumblr is one of the technological factors that have facilitated the advent and reinvention of this “kind of people” (Hacking 2007:303).

To draw on a precedent set by Boellstorff (2008) and Murthy (2008) among others, it would not be incorrect to describe Tumblr as a place of culture because it is a place where human beings interact. Tumblr is not a culture-neutral field site – the site shapes these interactions, and the shared experiences of old users who have experienced the history of the site and new users who bring in new ideas and interpretations of content generate recognisable cultural processes on Tumblr. This process is relevant for other sites than Tumblr – common knowledge suggests that different patterns of behaviour are to be expected on different websites, and this knowledge is exemplified in a Tumblr post describing the difference between Tumblr and Facebook:

Facebook: You know my name, not my story.
Tumblr: You know my story, not my name.

Figure 12: A concise statement comparing the site cultures of Facebook and Tumblr

Broadly speaking, cultural trends on Tumblr can be considered static over long periods of time, with new innovations in form being accepted or rejected as time passes and technology improves or declines. Adding the instant messenger (IM) on the site as a native feature rather than an optional third-party add-on in 2015, for example, instantly improved the one-to-one communication between people, making long chains of individual messages sent back and forth and the accompanying limitation of ask limits – the number of times per hour one could send a message to another user's inbox – obsolete. The more specific facets of Tumblr, however, are hard to pin down. The content of those asks or IM messages will vary with the individual, and any posts shared made in any time period may be difficult to parse depending on how new or how frequent the user is. While new content formats are typically made using the dialectic of new content and

old formatting, the content in question can be generated and changed daily. One meme that became very popular on the site - the word "BODE" superimposed onto pictures of fat cats - came from a user who made a post describing a dream they had in which that meme existed. The post that created the "BODE" meme, however, was made in the style that informal text posts are made on Tumblr, with little punctuation, no title, and a short post, and it spread through the native reblogging feature of the site. While the content and zeitgeist on Tumblr may change far more quickly than in the physical world, the rules about posting, from syntax to context, remain fairly static, if loose, and the wider site community tends to immediately recognise those who do not follow the site's cultural processes.

The implications of this level of regularity are twofold. First, it corroborates the assertion that online spaces are places of culture. The rules are idiosyncratic to the site, and while they may or may not be recognisable to people outside Tumblr, the implicit rules for site usage and posting are generally adhered to. More salient, and much more important, is that autistic people generally follow the social rules laid out on Tumblr implicitly. The implicit rules of Tumblr are akin to online social conventions, not so much explicit rules as expectations and conventions for interaction on the site. Despite many autistic people having difficulty with social interactions in the physical world and most participants disclosing some level of discomfort with neurotypical social norms in the physical world, most of the participants in my study are able to follow the rules of Tumblr and make posts that naturally follow those rules. Most participants expressed some form of freedom to communicate on the site, and posts from their blogs indicate the inherent

ability to follow the rules of Tumblr communication, as previously discussed. This ease of communication can be directly contrasted with their accounts of difficulty interacting in the physical world. Whether this difficulty comes from overstimulation in the physical world, not understanding the social norms, an inability to maintain focussed attention on social interaction, or any other reason, this complaint was a common one among participants. The implicit rules of Tumblr were not necessarily entirely grasped by all participants, but most of them exhibited in interviews and in their posts the ability to follow these norms. Why are autistic people able more easily to adapt to the norms of Tumblr than to those of real-world communication? There are numerous potential answers to this question, and I will discuss them here.

Tumblr is a website full of different people with different interests, and one of these communities of interest on Tumblr is a populous linguistics community. People with an interest in linguistics as a subject of study, for example, would be considered a community on Tumblr in much the same way the autistic community would be considered one, in that the borders are nebulous and hard to define but noticeable in the right circles. From this linguistics community come posts explaining in explicit detail the specific idiosyncrasies of Tumblr's language and the practice of posting, including how specific intonation is signified online in different contexts (e.g. hyperbolic versus ironic sarcasm). In this way, not only can users already familiar with the site's linguistic idiosyncrasies recognize their usage, but people who may have difficulty learning implicit social norms are able to learn them from these more explicit sources. While this source of information about Tumblr social norms is likely to be a relevant factor considering the

number of similar posts explicitly made by and for autistic people, in many interviews (and conversations) participants never really deviated from their established writing pattern, suggesting that it was not explicitly learned but rather intuitively incorporated. Therefore, one cannot conclusively say that this single factor – the presence of explicit commentaries about linguistic practices – explains the easy way autistic people fit into Tumblr's culture. Another potential explanation is the enhanced capacity that Tumblr provides to form and maintain friendships and have online interactions. The more one takes part in a given culture, the more one can adjust to its social norms. Yet this answer is also unsatisfactory alone or in combination with the previous one, as the evidence for this sort of acculturation is plentiful in individual cases but does not necessarily exist across users. Moreover, there are many users who have not adapted to the norms of Tumblr, no matter how long they have been on the site, and others still cite stumbling blocks for themselves in terms of understanding intention online. Perhaps the most interesting idea proffered by some participants, directly or indirectly, is that the autistic community on Tumblr helped create the norms that we see on Tumblr today.

Participation on Tumblr corroborates Damian Milton's conclusion (2014) that autistic people do like and require social interaction as much as any other people - i.e. variably depending on their personality. This observation was directly stated by user *speak-autism-without-speaks** when she said "I have to explain to a lot of neurotypicals that we understand each other just fine. We just don't understand them." The most noteworthy implication of that statement becomes apparent when paired with user *sin-cordura*'s insight that the Internet as an invention – and perhaps Tumblr as an entity

specifically, as it was a site more geared to autistic users than most – has made everyone who grew up with it think in ways that resemble autistic thought patterns, as she describes in detail here:

people my generation or younger all seem to understand me very easily

young gen x/xennials/millennials and anyone younger, it's like we're all a little autistic because of the internet

everyone had to think like me :)

so think about everyone who grew up online or who is

comfortable/enough/ with it to 'meme' or be on tumblr, basically

How do we talk online:straight to the point in the length of a text.Facebook updates about cancer or money going out to 500 of our closest friends.

Links and history available for the low low price of scrolling back

No small talk.No "NT" filters on communication.

Computers themselves are highly literal.The culture around computers devalues emotional communication (look how long it took emojis to be implemented vs email)

Reading people's faces is a SKILL no one my generation or younger got much real practice in

I'm just old enough to remember what it used to be like

I read recently 96% of people 35 and younger sleep with their phones within arm's length

that degree of attachment to an inanimate object in an adult seems super autistic to me

googling during conversations

totally resistant to phone calls

irrational hatred of forced interactions, in other words.

Sites like Tumblr bridge the gap between autistic and allistic users by providing an environment where people can communicate freely as they require in any medium they prefer. Requiring everyone on the site regardless of neurodiversity to use the same site functions: like, reblog, ask message, instant message, and media: video, audio recordings, links, images, and exclusively text, brings allistic users mentally closer to autistic users. At the same time, use of these common functions and media by both autistic and allistic users allows autistic users, in most cases, to communicate effectively and more specifically to enable greater understanding of them by allistic users.

CONCLUSION

This study had no conflicts of interest, though it was always my intent to produce a document that could aid in autistic self-advocacy online or offline. Although this study has produced useful results, it is somewhat limited in size and scope. There were only 25 research participants and were it not for the autoethnographic aspect of being on Tumblr, the ethnographic portion of the work, totalling six months, would not be nearly enough to form conclusions about the cultural processes on Tumblr. Participants who may not have positive views of Tumblr may be underrepresented in this study, especially since deleting one's own blog is, in essence, a way for the user to have a way to control the types of interactions they have on the site, and how many they have. People cannot interact with a dead blog, and as a researcher, I could not reach people who have chosen to delete their blogs. While I did strive to include blogs that were more active in the community as well as those that were more passive, the limited time available in which to do the study made it impossible for me to access both the most popular blogs and the most isolated ones. The former were difficult to reach because they are inundated with messages and requests as well as their own interactions on the site, meaning any correspondence with the study's blog would be quickly buried in their other correspondences without greater site presence. The more isolated blogs are difficult to interact with because they are isolated, and therefore easy to overlook. More time would have allowed for a more thorough sweep of autistic Tumblr users. Use of #actuallyautistic to find participants, while effective, worsens this problem since Tumblr's algorithm shows the more popular blogs that use the hashtag, overshadowing smaller users and doing nothing to make communication with

more popular users easier. Snowball sampling through Notes was an effective way of mitigating this issue and I would recommend that future researchers spend time developing a site presence and a robust list of potential participants with varying numbers of followers in order to increase the relevance of the data. Some users expressed interest in taking part in the study but had to be turned down for reasons of age, lack of time remaining to complete the study, or the absence of reliable wifi on their end. Autistic people who cannot afford to have a computer at home are not represented in this study despite having access to Tumblr in public spaces (and often being prominent participants in the Tumblr autistic community despite the monetary limitation) because this lack of reliable communication made communication prior to the consent process difficult. Future researchers should look into the possibility of a fully-online, browser-based consent/assent form in order to make the consent process more accessible.

Tumblr and the neurodiversity movement have been closely linked since the site's initial surge in popularity thanks to the explosion of social media outrage over the previously mentioned "Ransom Notes" campaign by Autism Speaks. This campaign and the reaction to it soured further an already tense relationship between the organisation and autistic people and set the tone for their interactions on Tumblr. Tumblr acts as a journal, image sharing space, and content creation platform all in one for the people who use the site, and these site features allow neurotypicals to better understand autistic people and autistic people to communicate more freely. Although some autistic Tumblr users have suggested that online communication is hampered by the lack of access to body language to parse meaning, with the advent of emojis and the Tumblr English dialect using specific

fonts for different tones and sarcasm, this difficulty can be mitigated. The combination of the initial use of the site by the neurodiversity movement and the inherent features and layout of the site enabled autistic people to join the movement either by vocally taking part in activism, passively reblogging autism-friendly posts, or "coming out" as autistic on Tumblr as a form of resistance (Davidson and Henderson 2010). From this position, the autistic community on Tumblr has had a fairly subtle influence on the world from its members' own perspective. But while few participants could quantify what parts of autistic Tumblr culture made its way into the mainstream world both on and offline, the evidence suggests that neurodiversity as a movement came into the mainstream due to the combined efforts of hardworking activists and autistic people on Tumblr empowered to come out as autistic to friends and family, not to mention to themselves. From this increased visibility came a language with which to describe themselves. For example, "stimming" becoming common parlance instead of simply a medical term, and "samefood" developed currency to describe the preference of many autistic people to eat the same food over and over again. Tumblr provided a platform through which to make friends and plan events, as evidenced by the instances of Autism Pride events across the world. While the neurodiversity movement and organisations such as the Autism Self-Advocacy Network and the Autistic Women and Non-Binary Association deserve credit for pushing the objectives of equality for and acceptance of autistic people in society at large, Tumblr as a site has been an excellent platform for disseminating these ideas, as well as other social justice issues. As previously mentioned, the neurodiversity movement online has led to a number of real-life events throughout the United Kingdom. When

asked about the influence the Tumblr community has had on the outside world directly, user *sbroxman-autisticquestions* responded, "It's hard to say. But whenever I've been to autism pride events, a lot of the stuff people spoke there sounded a lot like what the Tumblr autistic community talk about (fighting ableism, being proud of being autistic etc)." Whether or not these ideas came from the offline neurodiversity movement or from the Tumblr autistic community is irrelevant. The lens through which *sbroxman-autisticquestions* recognized the language at the event is the now-popularised language of Tumblr's autistic community. It would be presumptuous to assume the extent of the offline impact of the autistic community on Tumblr from a single account, but the collective experiences and direct testimonies of this study's participants demonstrate that the autistic community on Tumblr has at least the capacity to affect the quality of life of users on an individual level. The experiences shared with me about offline interactions lend credence to the idea that this site's community could embolden and allow for the mobilisation of the autistic community offline, and the site certainly streamlines the process of finding organisations by and for autistic rather than allistic people. There are limiting factors to this success, however, as community disagreements and the site's combative culture regarding political positions can and does cause divisions in the autistic community online. Despite these issues, however, I would conclude that through the normalisation of autism-related terms and the ease of networking and information sharing that Tumblr permits, the autistic community on Tumblr has already had an extensive impact in promoting the neurodiversity movement, and will continue to do so as long as the site continues to exist.

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