"Autsome": Fostering an Autistic Identity in an Online Minecraft Community for Youth with Autism

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Abstract. Autism is a medical diagnosis that has attracted much attention in recent decades, particularly due to an increase in the numbers of children being diagnosed and the changing requirements for getting the diagnosis. In parallel online communities around autism—both those supporting individuals, families seeking treatment and those supporting embracing the autism identity—have grown. Previous literature has shown the positive impact support groups can have for those encountering hardship in their lives, such as depression. In this qualitative study of an online community for autistic children centered around a virtual world, I explore how the label "autism" can be not only a source of disenfranchisement, leading to harassment and violence—in both the virtual and physical world—but also a source of empowerment and identity. I illuminate the tension in claiming the autistic identity within this community—having a sense of identity in the community, but, in doing so, also "othering" those with autism further. The walls of the community work to keep community members safe, but also set them apart from others on the internet. I see that the Autcraft community goes beyond being a support group for victims of targeted violence, to one that redefines and helps community members embrace their own autistic identities.

Keywords: online community, autism, youth, disability, Minecraft, virtual worlds, identity.

1 Introduction

Autism has been the topic of much public concern in recent decades, especially since the sensationalized "autism epidemic" swept through the media [36]. As a medical diagnosis, autism focuses on challenges for individuals; such as whether they are verbal, make eye-contact, or are sensitive to change [1]. Often, as a label, autism is given to youth in order to gain accommodations in school, or for medical treatment. Therefore, autistic youth often experience various ways in which this label is used to disempower and disenfranchise them.

This is the case for many youth that are a part of an online community, "Autcraft," a community centered on a Minecraft virtual world for autistic youth. While those with autism are often the target of harassment and violence in online spaces, the Autcraft community has been actively engaged in making themselves a safe space for youth with

autism. Beyond simply keeping bullies out, however, the community has taken the label of "autism" and turned it into something positive—a label worth identifying with.

The rest of this paper is as follows: First, I discuss autism as a socially constructed identity. Next, I review related literature and the methods used in this work. Then, I describe the findings of this study, including examination of the autism label as a target and as a source of identity for community members. Finally, I conclude with a discussion of some of the implications for the use of the autism label in the Autcraft community, including how the Autcraft community moves beyond being a support group for victims of the autism label to one that reclaims and redefines the autism label, allowing members to embrace their own autistic identities.

2 The Social Construction of Autism

The analytical lens of this work primarily uses the social model of disability, which focuses on disability as a social construction. Society creates the barriers that make individuals, who may be differently abled, into "disabled" [12]. The medical model of disability is the clinical perspective of disability, wherein diagnosis (labeling), treatment, and cure of the individual is the directed course of action [11,38]. The medical model portrays disability as a flaw of the body that is "inherently abnormal and pathological" [12]. Historically, for cases such as mental illness, the diagnosis was created by the medical community to help categorize groups of symptoms.

For many who have been labeled with an autism diagnosis, from a medical perspective, their label will follow them for the rest of their lives. It is quite possible a person could have the label of autism from a very early age, whether they are aware or told about it or not, but only really begin to grapple with it as an identity later (*e.g.*, when they are preteens). However, whether an individual then decides to join a particular autistic community is their choice.

In concert with the social model of disability, I use intersectionality as a lens to understand the different facets of the Autcraft community members' identities. Intersectionality is the understanding that race, class, gender, sexuality, ethnicity, ability, and age are not mutually exclusive parts of one's identity [8,9]. The concept of intersectionality helps avoid reducing a person's identity to a single trait [9,13]. Intersectionality supports the understanding that individuals will often identify with multiple groups (*e.g.,* gender, race, class, dis/ability) [13,24,37]. These identities may or may not be distinct categories, but they flow between and influence one another. Intersectionality occurs across all ages, but preteens and teenagers may be especially impacted as they are working to solidify their identities [26]. This is especially salient as many of the Autcraft community members are youth looking to assert their own identities and understanding of the world.

3 Related Work

Research of social media and online communities has covered a wide range of issues that people face including eating disorders [23] or pregnancy loss [3]. Many of these

studies look at the effect of a specific social media platform, such as Facebook's impact on depression [25]. Research has found that these online support groups can have a positive impact on people [2,6,20].

When looking at autism specifically, researchers have found that autistic individuals have mixed experiences online. One study found that Facebook support groups fostered expression of positive emotions among users [39]. Autistic individuals may appreciate the mediation provided by social media platforms (*e.g.,* mitigating the need for eye-contact), but also struggle with navigating trust and privacy issues on various platforms [6]. However, despite these problems, finding socialization and support online is particularly salient for autistic individuals because of their discomfort in face-to-face interactions [33]. Scholars have proposed that this type of sociality mediated by online platforms is a space where autistic individuals are no longer disabled [28].

For any vulnerable population, navigating online spaces is fraught with challenges. Online harassment, bullying, and threats of violence are commonplace and often target marginalized groups (*e.g.,* people of color, LGBTQIA [18], women [35] and autism [32]). A solution to this has been to create private, policed spaces online that keep specific groups of marginalized people safe [21,32]. Previous research has found how these online spaces have been a source of social support for marginalized individuals as well [2,6,20]. In this paper, I build on this previous research by examining the tension that occurs because of these "safe spaces"—allowing for this safety but also increasing the likelihood of being targeted by those outside the community.

4 Methods

This paper reports on results from a qualitative digital study of an online community that has grown around a Minecraft server known as Autcraft [1]. I collected data through interviews with children and parents; participant observations; directed and non-directed forum discussions; chat logs; and digital artifacts.

4.1 Setting

The multiplayer virtual world in our study, Autcraft, is a semi-private server on Minecraft created for children with autism, their families, and allies. Anyone wishing to join must first complete an application. Only those on the "white list" of approved players can access the server. Autcraft currently has more than 7,000 white-listed members with a daily average of approximately 50 players in-world at peak hours of the day and approximately 1,200 individual players logging in each month. While there are no age-restrictions in the community, the content is aimed at members aged 8-12 years old.

Minecraft is an open-ended virtual world with no particular goals or play requirements [10,27]. Players can build and create new objects by manipulating blocks in the game. Autcraft is a version of Minecraft that includes modifications and add-ons to the

[1] http://Autcraft.com

software to allow for the safety of community members [32] and to enhance their socialization [31,33]. In addition to the Minecraft virtual world, the community uses in tandem including YouTube, Twitch, Twitter, Facebook, and a community-maintained website (including an administrator's blog, community forums, member profiles, and an in-browser web messenger).

4.2 Data Collection & Analysis

This work employs virtual ethnographic methods and techniques that have been developed in other studies of virtual world communities [4]. After receiving ethical approval, I gained access to Autcraft via permission of the server's creator for this study and used an avatar labeled as a researcher in-world. Both my presence and purpose were made clear to the community through the Autcraft web-based forum and the in-world chat. Parents were informed of my presence via a parent message board and the Facebook page of the community. Parents and children were encouraged to voice their concerns and ask questions about the research through all communication platforms used by the community.

From May 2014 to May 2017, I collected approximately 200 hours of immersive in-world observations, including participating in activities on the server, recording chat-based dialogue, and taking extensive field notes on everyday practices of community members and events as they occurred in the virtual world. I also participated in community activities outside the Minecraft world, including observing discussions in the forums and on the social networking sites. Digital artifacts from the various platforms used by the community were also included in the analysis. These data include approximately 5,000 forum threads and 150 blog posts created by players, parents, and administrators.

I used an iterative, inductive approach where emergent phenomena were identified, named, and categorized following techniques similar to those employed in grounded theory [7]. I used an inductive method of analysis to understand how participants engaged in social play through practice, rather than testing theoretical definitions found in the literature, because I was explicitly interested in understanding how the community views and experiences their autistic identity within the Autcraft community. This approach was iterative as is an established best practice for qualitative data analysis [7].

5 Results: Finding Autism in the Autcraft Community

As discussed above, the label of "autism" is one that is socially constructed—first being used as a medical label for those displaying specific symptoms that can be diagnosed as "autism." Below I describe how the label "autism" has morphed from a medical diagnosis to have different meanings for those interacting in online communities. Autism has become a point of harassment, a means of *targeting those with autism*. However, the Autcraft community has reclaimed the label of autism as their own, *redefining autism*.

5.1 Targeting Autism

Concerns over safety of children is an ongoing concern for parents and other caregivers. This is particularly true of those with autistic children, as those with autism tend to be targeted both by their peers and by strangers [32]. Much like other marginalized groups, "autism" is used as a derogatory term. Further, threats of violence can be found across the internet, including in the comments section of YouTube videos, a site used by Autcraft community members. This is especially meaningful as other related work has shown the embodied experience in these online spaces can be as impactful as in physical spaces [29]. Unfortunately, these threats of violence can also result in actual physical harm.

Verbal harassment and attacks on autistic individuals can be found in many corners of the internet. One prime example is in the comments on YouTube videos. This bullying and harassment of autistic players is troubling for parents who allow their children to participate in the Autcraft community, but then must make decisions about what other websites and applications their children are permitted to use.

YouTube comments reveal some of this bias as commenters refer to Minecraft as a game solely for autistic people. In one YouTube comment, a non-Autcraft member wrote, *"i feel like the game itself is dedicated to autistic people."* The implication is that Minecraft only attracts players that have autism—or at least exhibit behavior that others might construe as autistic. Having the Autcraft space labeled for autistic members also means that they can potentially be targeted more easily, as one YouTube commenter put it, *"All the autistics in one place. Sounds like a trolling paradise XD."* Among a subset of internet users, autism is a reason to troll, or harass or bully, an individual.

In his TEDx talk, the founder of Autcraft describes how autistic children have been told by strangers on the internet that they should kill themselves. In the comments of that video, one respondent wrote:

> *Probably the wrong place to say it, but autist people should not live. What people call love and humanity are just really intricate instincts and neuro-connections, but still, they are sentient and for some reason i am happy that they can get help like this...*

Comments such as the above are common enough to not be surprising, but, fortunately, are outnumbered by positive comments (in the above post, for example, there were five negative comments out of 80 overall). This is not the only Autcraft video on YouTube. Many of Autcraft's younger members create YouTube content as well—sharing their own experiences with autism and anti-bullying messages [30]. By creating the Autcraft community and having a social divide between community members and others, there runs the risk of affirming the otherness of community members.

Harassment, threats of violence, and comments about autistic people killing themselves can have a large impact on those targeted, such as additional stress and other psychological harm [22]. The harm, however, does not stop with verbal and written threats. Like other marginalized communities, those with autism face the very real threat of violence against them [14,15].

Figure 1. Colorful sheep wander through the rows of names in a memorial to those with disabilities as victims of filicide.

To exemplify and remind us of this violence, an adult Autcraft community member built a secret chamber to memorialize victims of filicide. The builder has recorded the names of approximately 420 victims from 1980 to May 2016 (the date of the interview). When asked about where he obtained the list of names from he answered, *"I was a chapter [coordinator] for the autistic self advocacy network and they sent it to me."* The Autism Self Advocacy Network (ASAN) provides an Anti-Filicide Toolkit[2] on their website that coordinates with the Disability Day of Mourning[3].

The memorial contains light glass walls and signs with names, ages, and dates of victims. The chamber itself has cathedral ceilings and colorful sheep wander through the rows of names, giving the place a light, open feeling despite the sad nature of the motivation for the space (See Figure 1). The father explained to me in the interview that he does not allow the children to enter this space, because of the content, saying, *"I don't really talk [to] any of the [players] about this because there are young kids who might get upset. I try to keep it age appropriate. If anyone asks me I just tell them it's a memorial for disabled people and leave it at that."* But despite the fact he does not invite young children to see the space and that building the memorial *"took a lot out of [him] to do this*," he still felt the need to create it. Because Disability Day of Mourning is a day set aside by many advocacy groups (*e.g.,* ASAN), this seems to have translated into sites of mourning not only in the physical world, but also in the virtual.

While this site can be seen as a place of sadness and mourning, there is also a sense of pride. Pride in the beauty of the architecture, which this parent designed and built single-handedly. But also pride in the sense of belonging to the Autcraft community. Much of the Autcraft community strives for members to accept and be accepted as someone with autism, but this memorial chamber invokes a sense that while others may hurt them (be it physically or emotionally), they are not forgotten, and they have a safe place to belong—albeit virtually.

The label of "autism" has become a widespread target for harassment, bullying, and even physical violence. The example above from anonymous, harassing comments on YouTube to reminders of physical-world violence are just part of the larger cultural story about violence against autistic people. The toxic culture, as found in some online game cultures [15,35], goes beyond targeting those in the Autcraft community. In some

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2 http://autisticadvocacy.org/projects/community/disability-community-day-of-mourning/anti-filicide/

3 http://disability-memorial.org/

ways, Autcraft is this community's answer to how to deal with this wider culture of hate against those who are different.

5.2 Redefining Autism

Where the terms of disability may be used to flatten and marginalize individuals, they can also be a source of empowerment and strength [19]. Those who join the Autcraft community are connected to autism in some way—they may or may not have a formal diagnosis or they may have a close loved one who is autistic. There is evidence throughout the Autcraft community of those who are expressing this facet of their identity. As many members are still coming to understand their autism, there is also teaching and learning that occurs in this space. Autcraft community members may be learning to understand and accept themselves or their child as an autistic individual, but they are also learning to deal with challenges found outside the Autcraft community where they may not find themselves accepted and face opposition.

Adopting "autism" and various forms of the word—as seen in the name of the community "*Aut*craft"—lends to a sense of identity with others who have the same or similar medical diagnosis. Aside from using "aut" or "autistic" in their user names (*i.e.,* the names that are displayed with their avatars and forum posts, rather than a real-world name), the Autcraft community displays this acceptance through the creation of autism-centric words, such as "autsome." According to a community post, "autsome" means, *"Having autism and being extremely impressive or daunting"* and *"extremely good; excellent."* Disability Studies scholars have described how those with disability are often held to a higher standard and those who are "extreme" tend to be held up as inspirational [17,34]. This type of "inspiration" frames disability as something to be overcome, while achieving difficult objectives [17]. However, I argue that having language such as "autsome" is meant to be inspirational not for others looking in to the Autcraft community, but for the autistic children who are otherwise dealing with a barrage of negative language about autism. This is a reframing of the autism label as an identity that is worth *embracing*, rather than *overcoming*.

Autcraft community members also engage in learning and educating about autism. They write educational pieces and essays and post them in the Autcraft community forums. Their research projects and essays about autism are also often presented to their classes at school, with the student reporting back to the Autcraft forums with the results. These acts of learning and educating about autism help solidify what it means to be autistic as part of the Autcraft community. This identity may be different from how an autistic identity is performed in school or at the doctor's office—given the varying expectations of others in these spaces. In Autcraft, community members engage in an education process that ultimately defines what it means in be autistic in the space of the Autcraft community. And this form of education process spills out into other spaces

Figure 2. A statue at the head of a classroom labeled with a sign "Professor Enderman."

when community members work to educate those outside of the Autcraft community, such as when they create YouTube videos.

Parents also educate each other on their children's autism through a forum dedicated specifically to parents, as well as through other social media. Here they swap information on how to deal with "meltdowns" or how to get their children's needs met at school. There is a mix among the parents of those who have their own diagnosis of autism and those who are considered neurotypical. The parenting board on the forum also includes autistic adults who often give advice to neurotypical parents about why their children may be acting in specific ways. These parents end up, through the Autcraft community, aligning themselves in some ways with the autism community while looking for ways to support their children.

For example, in the Autcraft virtual world, one father built an entire school campus where other Autcraft community members could visit and learn about autism. Some of the classrooms even have golems walking through them and statues set up to be professors at the head of the class (See Figure 2). The building has many classrooms, with informational and inspirational signs posted throughout. In one, the material reads as follows:

> *What's the problem with body listening? Eye contact can be physically painful for some. You don't have to look to be good at listening. Your ears can do their job all by themselves. Sometimes verbal stims help to process. And that's ok if making sounds helps you listen and learn. Flappy hands happy hands. … Your boundaries are just as important as anyone elses. Your brain is always thinking even when others don't understand. You are 'aut'some just the way you are. Your heart is caring about others & you deserve the same.*

This posting educates autistic members about some of the ways they may process information differently. This gives the members a way to speak about their own needs and communicate these needs to others. The end of the post reinforces that being different and being autistic is okay, showing again the inclusive nature of the autism community as found within the Autcraft community. Beyond inclusion, the naming and describing of symptoms in a positive light reshapes the discourse about autism as an

identity. While symptoms are typically seen as a deficit they are reframed by the Autcraft community into positive identity markers.

Learning and educating others about autism is a way for Autcraft community members to align themselves with the autism community and to empower themselves as informed autistic individuals. These practices also allow for the Autcraft community members to shape their own version of autism community, one that is inclusive and understanding of children and their neurotypical (*i.e.,* those who do not have autism or are "typical") family members.

6 Discussion & Conclusion

Being able to explore and express their identities is important for all youth [16], but it is especially salient for the autistic youth of Autcraft. The Autcraft community has a variety of social media that support expression of these identities. As Autcraft is a community that supports autistic children as part of their mission statement, having the freedom to be able to play with and perform autistic identities is important to members. Engaging in activities such as self-labeling and education helps to both assert membership into the autism community as well as reshape the autism identity of the Autcraft community to meet the overall goals of inclusion.

Members of Autcraft do not necessarily have a medical diagnosis of autism—membership requires only that they *identify* as autistic or with autism—but they have still opted into the Autcraft community, which is first and foremost a community for children with autism. Many community members in the Autcraft are grappling with a variety of social and medical autistic identities at once or, at the very least, dealing with each in the various contexts of their lives. Members may have other therapies, school, or a home life that entertains a more medical model approach to autism in addition to the more accepting, social model of the Autcraft community. As with other disability identities, individuals need to find a balance, dependent on the current context, that allows them to get the services they need as well as the desired social outcomes.

Autcraft community members actively work to reshape the mainstream dialog about autism. First and foremost, members try to lead by example, following a set of tenets set out by community founders that encourage and promote pro-social behavior. Community members also engage in outreach to both educate others and to make their own expressions of their autistic identities more visible to others. Members of the Autcraft community engage in activities—much like creating memorials for victims of violence—that purposefully shed light on the hardships they have faced. These efforts are examples of how those with marginalized identities fight back against oppression. As scholars, by listening to these community members and understanding their activities, we can begin to elevate the voices of those who have long been silenced.

The Autcraft community engages in gatekeeping practices to maintain exclusive membership. Community members must have a connection to autism, if they do not themselves have autism. These gatekeeping practices are meant to keep people out who mean to do community members harm (*i.e.,* the bullies and trolls). However, this works both ways. This gatekeeping also works to keep community members *in*. Choosing to

be a part of this separate non-normative identity and space has the effect of "othering" community members. Othering is when a group of people are classified as "other," which becomes a way to reify the self (*e.g.,* in-group or the self and the out-group or the other) [5]. For members of the Autcraft community, their othering began long before joining Autcraft (in fact, for many, this ostracization is the reason for joining).

The consequences of othering in the case of children with autism are alienation and bullying. The Autcraft community creates a space that feels safe for the members, but there is a balance that must be struck between keeping members safe and alienating them from larger society. Especially as children grow up and age out of the community, there is currently little support in place for community members who feel they are too old for Autcraft. Some of these members may "age out" of Minecraft altogether, but more are simply looking for a less restrictive server. More work needs to be done to understand how the transition for autistic youth can be supported as they spend more time in other communities, beyond Autcraft—especially as these children become young adults.

The data in this paper is largely from the perspective of older caregivers in the Autcraft community, many of whom identify as autistic (See related work for more from the children's perspective [29–33]). These caregivers are in the difficult position of creating a safe space that allows younger children to play with fear, but simultaneously needing to prepare them to be in the (sometimes harsh) outside world. At the same time, these parents and caregivers also need the social support found within the Autcraft community, as they (and their families) are also targets as part of this community.

The Autcraft community acts as a support group for its members—creating a sense of community for those who have faced similar hardship. The group is critical for its members to come to as a community and a place to learn about a facet of their autistic identity. The emphasis, for Autcraft community members, is rather than *overcoming* autism as a medical problem, they *embrace* autism as their identity. And despite the label "autism" being a target for harassment and violence, the Autcraft community is about identity support, rather than victim support. Threats of violence permeate through many spaces and contexts in the lives of autistic individuals. These children face these threats in the physical and virtual world. As the memorial to victims of filicide reminds us, these threats have very real consequences. The Autcraft community strives to create a haven for those who need respite from bullying and harassment in other online communities. In creating a safe haven, however, they have moved beyond being a support group for victims to reclaim and embrace their own autistic identities.

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