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Autism and Youtube:

Communication vs. Commodification

“For many of the humanitarian and human rights workers I interviewed... storytelling is the very nature of the work. Many... [humanitarian] organizations... do so in large part by using language.” (Dawes 1). This quote from the introduction of James Dawes’ *That the World May Know* demonstrates the inherent link between language, communication, and voice to the effort of maintaining the human rights of people all over the globe. As technology has grown and advanced, so too have our methods of communicating with others and our reach in the fight for human rights. However, communication is a two way street, and with the advent of modern technology it’s become even more confusing to tell which voices we should be listening to. In particular, the video sharing website Youtube has been used to amplify the voices of many, leaving it to the viewer to discern which ones they should heed. This confusion is seen with clarity within the autism community, and on the other side, the Autism Parent community.

Historically, those diagnosed with the neurodevelopmental disorder of autism have had their voices dismissed. Autism as a term was first coined in 1908 by Eugen Bleuler. Over the last century the diagnosis has evolved, as well as the recommended treatments. Today a large portion of the scientific community recommends applied behavior analysis therapy, developed by Ole

Ivar Lovass, which is designed to teach autistic people how to act like they are allistic (def. Not autistic). Along the same vein, because many autistic people are semi- or non-verbal, for most of history their voices have been translated by and filtered through their allistic caregivers.

This translation as communication tradition has been continued in modern times by Youtube channels like Autism Family, where a married couple records the lives of their three autistic sons. In the video “Autism Meltdown at the Mall Updated”, their autistic son is shown screaming, crying, and crumbling to the floor in a public place while a parent picks him up both by his arm and a harness (0:00- 0:28.) This video is an updated version of another called “Autism Meltdown and Tantrum at the Mall.” Most notable in the case of these videos is the use of the word “tantrum”. A tantrum is colloquially known as when a child screams and cries in an effort to achieve an objective, like getting ice cream, for example. Autism meltdowns differ in that they’re completely involuntary, and result most often from sensory overload, when the person becomes overwhelmed by the noises, smells, etc. of their surroundings.

Primarily this video frames the meltdown as a tantrum, placing blame on the child and redirecting sympathy to the caretakers, rather than the boy who is in significant emotional distress. Furthermore, being shown in such an emotionally vulnerable state, then recorded and posted online for thousands of people to see (the video has 106,897 views at the time of writing, since its posting on May 18th, 2019) is a breach of the privacy of the autistic person. Finally, the video has been generating income for the parents, an act of commodification that will be addressed further.

Another video on the channel, named “Autism Haircuts Revisited”, shows footage of the two boys calmly getting haircuts. At the end it contrasts to the last haircut attempt, where the

boy is seen screaming, crying, and trying to escape the electric razor (3:41-end). Again, it must be emphasized that this isn't a case of a child just not wanting a haircut. For many on the autism spectrum, sounds like the buzzing of the razor, the feeling of the razor on their skin, and the texture of the trash bag they were using to cover their clothes are intensely uncomfortable and even painful sensations. By recording and uploading the scene they are commodifying their sons' discomfort. Both videos identify autistic behaviors as wrong and abnormal, encouraging the same behaviors as ABA therapy would. Known as "masking" in the autism community, it is the active suppression of autistic traits in order to blend into allistic society, which has been known to decrease the overall mental health of the person. These types of videos not only function as a breach of privacy, as mentioned above, but also as an act of humiliation, an assault upon the dignity of the person. This is most clearly seen in the video "Autism Potty Training Troubles", which shows one of the sons learning to use the toilet.

Finally, the act of uploading videos to Youtube is an act of commodification. Views on Youtube generated revenue for the channel owner, so by uploading videos depicting meltdowns and toilet training to Youtube, the parents of the autistic boys are commodifying their suffering and humiliation while reinforcing the shameful stereotype that surrounds autistic people, identifying them as abnormal and in need of correction, therapy, and masking. In addition, the channel also has a video called "Autism Family on Patreon", which links to a donation website. This is a more direct act of commodification in which the caregivers ask their allistic audience for money in exchange for their sons' lives as entertainment.

On the other hand, modern technology has also vastly improved how autistic people are able to communicate. Whether through simple sign language, text to speech devices, or online

blogs, technology has helped to boost the voices of autistic people across the globe. The advent of the Internet has led to a growing autism positivity movement, where people on the autism spectrum advocate for themselves and reveal the trauma that is caused by things like ABA therapy. Youtube is not exempt from this, housing channels such as The Aspie World. This channel is run by an autistic man and contains videos such as “Aspergers Meltdowns: What You Need to Know About Overload” where he teaches people what meltdowns are, why they happen, and how to help from the point of view of an autistic person. He also has videos addressed to raising positivity and lessening stereotypes around autism, such as the video “How I Use My Autistic Traits In My Career.”

Another channel, Willow Hope, contains a video called “An Adult Meltdown (Autism Spectrum) where she shows footage of herself having a meltdown. This video fulfills the same role as the “Autism Meltdown at the Mall” video from above, but from the autistic person’s perspective, providing information and awareness about meltdowns without framing the autistic person as abnormal or shameful. Both channels are run by adults with autism, which in the very act of existing counters the public perception of autism as a “childhood condition” as well as the stereotype that autistic people are never able to become independent or speak for themselves. Using Youtube and other technology, autistic people are able to make their own, authentic voices heard, rather than having to be filtered through an allistic caregiver or organizations such as Autism Speaks, who though claim to advocate for autistic people, still research cures and promote ABA therapy. In the contrast between Willow Hope’s meltdown video and that of Autism Family, we see another core tenet of human rights storytelling revealed: consent and control.

In *That the World May Know*, Dawes discusses the inherent paradoxes of humanitarian work, one of which is the fine balance between sharing someone's story as an act of healing, and exposing someone's hurts as an act of retraumatization. In the book he notes how many victims giving their statements express their wishes not to be turned into novels or characters. Some authors disregard this and take these people's suffering to fuel their own writing, using the veneer of human rights to sell more copies or fuel a more "impactful" plotline (Dawes 164-233). The same is occurring on Youtube between autism "parent" channels and those run by actual autistic people. The Autism Family channel uses their sons' diagnosis to garner sympathy and money from an allistic audience, which gains no deeper understanding or empathy for the autistic members of the family. By contrast, those channels run by autistic people amplify the voices of actual autistic people, promoting acceptance, educating the audience, and in some cases, willingly show vulnerable parts of themselves in an act of sharing, education, and healing.

In this example of Youtube and the autism community is exemplified how modern technology, as well as forms of artistic expression that have emerged from it, can be a double edged sword in the sphere of human rights. In more cases than just that of autism Youtube has been used to spread awareness, explain complicated situations, and provide insight into another person's perspective, all of which are integral to the work of human rights. But, like many other forms of expression, it has also been used to perpetuate stereotypes and harmful practices, as well as smother the voices that need to be heard. As well as mediums such as film, photography, journalism, and the novel, Youtube walks a fine line between garnering communication between people and commodifying their existence. In journalism one asks if they have the right to tell the story they're telling, and wonder if their positions of privilege can warp the narrative or be used

for their own gain. Photographers beholding human rights abuses and brutal treatment wonder whether the very presence of the camera is exacerbating the problem. Novelists question how best to integrate a true experience into a character without bastardizing the narrative in the act. These types of questions are the ones that must be considered by those using video as a form of expression-- modern technology and mediums are not exempt from the questions and paradoxes of the old.

However, as deep as the problems lie, Youtube and other modern expressions have also been vital in granting a voice to a population which until now had very little. Autistic people finally have the means to project their voice beyond the constraints of an allistic translation or censor, and now have the opportunity to show the rest of the world what their lives are like. To reveal what things have harmed them, which stereotypes are wrong, and to provide comfort for other autistics who may not have had it before. It will be instrumental in showing allistic society what needs to be done for them to flourish in it.

Hopefully, you'll listen.

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