

Carrie Henley

27 April, 2023

The Able-Bodied Normal

In a time where representation in the media is so highly valued, we've missed a key minority group which makes up 15% of all people in the global population—Disabled people. (*Disability*). According to the United Nations, "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." As with all marginalization, disability is historically underrepresented in film and television, and is commonly misrepresented in the rare circumstances when it is present. This affects not only an audience of disabled people who lose the right to role models and fair work in the media, but parents of disabled children who build a parenting style upon false precepts, and the general public, as harmful and discriminatory thought patterns regarding disability are enforced and encouraged. (*Media Representation*).

In the past century, only 4.2% of films released have contained significant themes of disability, while 26% of all adults are disabled. Television has even less representation. Furthermore, viewers with disabilities are 52% more likely to describe depictions of disability in media as inaccurate. (*Bahr*). *Disability Planet UK* clarifies some of the common misconceptions found in media and how they can be harmful. These common misconceptions are: disability should be pitied, disability is something wrong that needs to be fixed at all costs, disability is evil, disability is a burden, disabled people cannot participate in life. Disabled stories often represent disabled people as a plot point for the other characters to respond to, instead of a viable

character to have their own storyline. These inconsistencies likely arise from the lack of disabled people having a say in the way they are represented in the media.

According to Disability Planet UK, 19% of the working population is disabled, while only 2.3% of the working population in the media industry is disabled—A percentage even smaller than the amount of disabled films produced in the past century. Media professionals are presenting an able-bodied view of disability, thereby depriving disabled people of the privilege to have normal role models. Disabled characters are often seen miraculously overcoming their disabilities in films, finding themselves only able to be happy once the impossible has been achieved, or finding themselves never able to be more than a victim to the hands of disability, such as with Tiny Tim in Charles Dickens' *A Christmas Carol*.

Otherwise, disabled characters are often given superhero qualities to compensate for their “lack,” such as in *Rain Man*, where the main character is autistic, but possesses savant abilities. Able-bodied people thereby justify the disability as no longer undesirable, because there is reasonable “compensation” for the inability. (*Media Representation*). Media professionals assume their audience is able-bodied, as the majority of the audience is, and find no need to provide genuine representation. Thereby, when the disabled characters are depicted as more human, the story tends to revolve around caretakers and the able-bodied view of life with disability.

This problematically fuels the friction against changing the way we view disability as a society because misconceptions are reinforced in the media. Parents of disabled children lack legitimate resources to better understand the disabled experience, and end up relying on the medical model of disability, the perception from doctors that disability is a mistake that must be

corrected in order for a human to be normal. Thereby, disabled kids are raised with the false understanding that they are a mistake that needs to be corrected.

However, when we take a look at positive examples of disability-centric art, such as proper representation or art made by disabled artists, art becomes a useful tool to promote understanding and unite people despite their differences. Disabled artists are given a chance to speak out about the marginalization they experience(d), and can contribute to the conversation of creating a more universal future. As told through art, the disabled community seems to be desiring humanity and de-stigmatization of disability. There's a push in disabled works of art to encourage people to simply see disabled people as people, but also not negate their disability. The 2020 Netflix Documentary *Crip Camp*, gives insight to the history of the disability rights movement. We're introduced to historical footage from Camp Jenet, a camp for disabled kids run by hippies, which took place from 1951-1976, and these disabled campers eventually become the pioneers of the 504 sit-ins¹ and the disability rights movement. In this time, many disabled kids were sent to understaffed institutions which failed to provide them with their basic needs. Things got so horrific that kids in these institutions were often only given 3 minutes to eat because the nurses didn't have time to feed everyone. The kids that were lucky enough to be raised in accommodating families would often be denied entry to schools or public spaces because their presence would "scare the other patrons," not to mention physical accessibility barriers like stairs. Judy Heumann, disabled rights activist and pioneer of the 504 act, cites being finally accepted to a special education program in public school, only to find that she was kept out of sight in the basement of the building and not usually permitted to intermingle with able-bodied children.

¹ A series of nearly month-long sit-ins in government buildings, staged by disabled individuals in 1977 in a successful effort to get the government to pass further regulations enforcing the 504 act.

Upon finding their way to Camp Jenet, the disabled campers were shocked to find that they were treated humanely and kindly. They were not seen as disabled people in a camp full of disabled people. They were just kids. This opportunity liberated them and gave them their humanity back. It was a moment of realization that the problem wasn't disability, it was society. From there, led by Judy Heumann, they held a nearly month-long sit-in in a government building to ensure the signing of the 504 plan.² They fought tirelessly for rights society told them they weren't entitled to because of how they were born. The right to be seen and treated as a human being.

The film itself is structured in a way that particularly pushes this message and permits the viewer to enter into the normality found within the disabled experience. As with any documentary, we're presented with a versatile array of footage, from old news reports to home movie footage to professionally shot interviews, making the disability rights movement more accessible by presenting the history of those involved in an organic way. We walk with the people featured in the film, seeing the archival footage from the camp, and how much of it was just kids being kids. When presented with an environment where disability wasn't a barrier, a bunch of kids were able to just have fun at camp, laughing about the drama of who liked who and complaining about the possibility of lasagna for dinner. But then, as they age out of camp and head back into society, we hear their first person accounts of how they were treated differently. We see archival footage of horrific happenings in institutions and politicians and the public denying a problem, and we begin to understand firsthand that we are denying life, liberty and the pursuit of happiness to human beings who we have just seen a half an hour earlier in an

² The 504 plan refers to Section 504 of the Rehabilitation Act, passed in 1973. Section 504 prohibited the discrimination or exclusion of individuals with disabilities from activities. "Essentially it said no program receiving federal funds could discriminate against a person with a disability" (*Disability Rights Education*). However, before the 504 sit-ins, there were no regulations to enforce the act or define who qualified for protection under it.

environment where their concerns were the same as everyone else's. Without this film, we wouldn't be able to see that at their core, even the activists who started the disability rights movement are, and have always been, human just like everyone else.

As with *Crip Camp*, I find the message of a stolen humanity to be very prominent in Heidi Latsky's short dance film "Solo Flight ADA30." The film, made during quarantine for the COVID-19 pandemic, features disabled people alone, in their homes and in empty public spaces, performing dance solos. The solos are elaborately different from person to person, each dancer exploring their own message and individuality, but one commonality stands out above all else: Humanity. These are people asking us to see them as exactly that—people. To be human means to be different and real and imperfect, and everyone in this video invites us into their imperfections in their own unique way. Through appreciation of beautiful shapes made by twisting wrists and legless movement, we are appreciating a visual display of the human experience. A woman without legs lifts her body from the ground, then pulls up into a handstand, moving with precise control and patience. She suspends us from reality as we breathlessly anticipate the stunt without regard to her missing legs—We are no longer watching a disabled woman dance, we are simply watching another human perform a defiance of gravity that many of us have personally struggled with.

Everyone carries a unique burden, and "Solo Flight" unites us in that knowledge. We are asked to look at disabled individuals as people with their own strengths and weaknesses, just like everyone else, even though their weaknesses may be more on display at times. But even further, the challenge of seeing the struggle itself as the strength is one illuminated in Latsky's piece. Through each remarkable feat (such as the earlier referenced handstand) we watch the dancer overcome a physical battle to find the strength needed to turn any momentary struggle into a

fluid and captivating movement. Weakness in the form of physical disability permits the real struggle in one's soul to become embodied in dance: a perfect harmony of beauty and pain. The disability is the thing that makes the movement so real—That the very thing that is supposed to be the pain and hindrance, becomes the heart of beauty and meaning itself, uniting us as humans despite our differences.

Last Fall, I had the privilege of seeing Martyna Majok's play, *Cost of Living*, make its off-broadway debut. The play, which won the 2018 Pulitzer Prize, features two disabled people and their caretakers, in two vastly different dynamics. The intent of the piece is to humanize disabled people, in a real and raw representation of the interference disability can have in the way we connect with other people. The characters are rough around the edges at times, but they don't let disability stop them from living the lives they want to live, and they don't succumb to societal or interpersonal pity. The characters are very much real and multidimensional humans, capable of wrongdoing and enjoying life without being cured. They are complete in themselves and not depicted as an angelic representation of misfortune.

However, despite the rave reviews for depicting disability in a human manner, the show still retains a critique from disabled activist Regan Linton, that, as the caretakers are more prominently followed, it continues to revolve around on able-bodied perspectives. The show seems to present a correct representation of the way we should approach disabled people as a society, and the struggles that able-bodied caretakers may face, but continues to be centered around able-bodied people and their lives around disability. I believe this comes from the fact that, from what I've seen in my research, Majok herself is not disabled. In an interview with Public Books, she states that her experience with disability revolves around having worked as a caretaker for a man with CP, and she intended for the play to be less specifically about disability,

and more so about class differences across physical ability. The piece lacks the firsthand experience of what it is to really be disabled, which is something we need. So, while *Cost of Living* presents a valuable piece of the puzzle with an accurate, able-bodied view of disability, pieces like *Crip Camp* and “Solo Flight” are what we desperately need more of—pieces about disability from those who live with it. We need to listen to the disabled themselves about what they experience, as their voices have been historically repressed, and allow them to provide an insight into the disabled experience that no able-bodied person could recreate.

If the goal is to create a more universally understanding society, we need to provide a voice to those who have lived through the problem at its deepest depths. That is where we find the learning and understanding that allows secondary sources to provide an honest and equal opinion on their side of the matter. That said, I don’t mean to imply that able-bodied people shouldn’t be free to include accurate depictions of disability in their works. In fact, I highly encourage everyone to use disabled characters in any manner of representation that is not promoting the dehumanizing standard. We simply have a long way to go as a society, and accurate able-bodied sources come as a secondary source of understanding what a disabled person lived first hand. It is good to gain insights from those who have lived the experience in addition to those who have witnessed it, but we are currently in a state of valuing the latter over the former.

However, when done correctly, I find disability-centric pieces from able-bodied artists can be quite beautiful. My favorite example of this is a famous painting from 1949, that currently lives in the MoMA— “Christina’s World” by Andrew Wyeth. You might not know that Christina is disabled. The painting depicts a younger version of Wyeth’s neighbor, Christina, a mobility impaired woman, crawling through a field towards a distant farmhouse. Christina refused to use

a wheelchair, instead electing to crawl wherever she pleased. She made her own freedom where society told her she couldn't. Wyeth commented on the painting: "The challenge to me was to do justice to her extraordinary conquest of a life which most people would consider hopeless."

Wyeth used Christina in most of his paintings, as he was inspired by her unique movement patterns. He never painted out features of her disability, and in "Christina's World" we see the full impairments of Christina's limbs. Doctors who have analyzed this painting used to believe that Christina had polio, but led by new examination from Dr. Marc Patterson at Mayo Clinic, there is now widespread belief that Christina likely had Charcot Marie Tooth Disease, a form of Muscular Dystrophy primarily affecting the ankles and wrists. (*MailOnline*). I have this condition. So personally, I resonate with this piece. It's representation, and there's nothing that beats the ability to look at history and say "I was there." To see Christina depicted by Wyeth in a way that is not lesser but not glorified, is vindicating. Even if Wyeth wasn't disabled, his public recognition of a disabled woman as an equal and a human is an important part of the conversation. He used his voice to speak up about the truth he saw when others couldn't, and he thereby helped open the door towards a greater understanding. We need to take the step into that door now and listen to the disabled voices themselves, and not just the external advocates.

As Christina stares off at the farmhouse, it feels like someone sees the distance there is between society and disability. Christina has a long way to go to reach the farmhouse, but she will get there. There is no disability in the way she sees the world. There is no hindrance in her ability to arrive at her destination, only a plan that works for her. This is what society needs to see. We are our own people with our own plans and goals to work towards, and disability is only as much of a burden as society makes it. As a disabled woman, I know there are many things I

will never be able to do no matter how hard I try. But I also know that there are so many things I *can* do as soon as we venture away from the able-bodied “normal.”

Works Cited

Bahr, Sarah. "Study Shows Disability Representation Onscreen Is Increasing, but Still Falls Short." *The New York Times*, The New York Times, 26 July 2022, <https://www.nytimes.com/2022/07/26/arts/television/disability-representation-tv-movies-study.html>.

"Disability and the Media Enable." *United Nations*, United Nations, <https://www.un.org/development/desa/disabilities/resources/disability-and-the-media.html>.

Media Representation of Disabled People, <http://www.disabilityplanet.co.uk/index.html>.

Artincontext. "'Christina's World' by Andrew Wyeth - an in-Depth Analysis." *Artincontext.org*, 29 July 2022, <https://artincontext.org/christinas-world-by-andrew-wyeth/>.

"Andrew Wyeth. Christina's World. 1948: Moma." *The Museum of Modern Art*, <https://www.moma.org/collection/works/78455>.

Hoptman, Laura J., 1962-. *Wyeth : Christina's World. New York : London :Museum of Modern Art ; Thames & Hudson [distributor], 2012.*

Lebrecht, James and Nicole Newnham, directors. *Crip Camp*. Netflix, 2020.

Phillips, Maya. "'Cost of Living' Review: Worth Its Weight in Gold." *The New York Times*, The New York Times, 4 Oct. 2022, <https://www.nytimes.com/2022/10/03/theater/cost-of-living-review.html>.

Latsky, Heidi, director. *Solo Flight ADA30*. *YouTube*, YouTube, 21 July 2020, <https://www.youtube.com/watch?v=vxri-YZkO04&t=2s>. Accessed 25 Apr. 2023.

Majok, Martyna. "Cost of Living." 2022.

"Short History of the 504 Sit In." *Disability Rights Education & Defense Fund*, 23 Mar. 2022, dredf.org/504-sit-in-20th-anniversary/short-history-of-the-504-sit-in/.

MailOnline, Madlen Davies for. "Mystery of Disease behind Andrew Wyeth's Christina's World Is Solved." *Daily Mail Online*, 6 May 2016, www.dailymail.co.uk/health/article-3576812/Mystery-disease-one-world-s-famous-paintings-solved-Crawling-woman-Christina-s-World-rare-nerve-condition-expert-claimS.html.

Rodman, Melissa. "Staging Disability: An Interview with Martyna Majok." *Public Books*, 17 June 2020, www.publicbooks.org/staging-disability-an-interview-with-martyna-majok/#:~:text=From%20the%20Williamstown%20production%20to,know%20exactly%20what%20that%20means.