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Embodying a Disability

My time as a Gender Diversity Studies major at Slippery Rock has allowed me to challenge my own beliefs and understanding of disabilities and disorders. A variety of classes brought new literature to my attention that I may not have previously read or even understood. This led to me wanting to seek a deeper understanding of those who choose to embody their disorders and/or disabilities, including myself. In "20 Stories of Depression and Suicide and Living Our Lives" by Michael Blackmon, many of the individuals who wrote their stories described their depression or other diagnoses as part of who they are.

In order to explore my own position on "ownership" of one's disability, it is important to define the "disability." According to the Americans with Disabilities Act, a disability is any mental or physical impairment that restricts someone from completing a "major life activity" (What is the definition of disability under the ADA?). In mental health fields, mental illnesses are typically defined by the DSM-5 for diagnosis (Stein et al.). Moving away from a legal or medical paradigm, many with disabilities or mental illnesses integrate them into a sense of personal identity as a part of themselves. While this is a very complicated issue, for the sake of my argument, I focus on physical manifestations of a disorder where the person with the diagnosis claims an embodied form, including whether or not they use or reject person-first language. My primary interest is in analyzing which can be more beneficial mentally: embodying a disorder/disability or separating one's self from it, including the choice to use person-first language as a tool in order to diminish the stigmas and stereotypes that come along with a diagnosis.

These are concepts that I have come to struggle with myself. As a former Psychology major, I have been told that the person with the diagnosis that they were given is not the diagnosis but that the diagnosis is just one facet of who they are. To gain more perspective, I interviewed a graduate from Slippery Rock University with a Bachelor of Science degree in Psychology to gain her perspective solely from a psychological standpoint, starting with a kind of discursive perspective.

Q: As a psychology major, are you taught to use person-first language?

A: Yes, when talking to clients and when talking about clients with other colleagues. In discussion in classes, we were also encouraged to try our best to use it.

Q: Do you think using person-first language would be beneficial for the client?

A: I think that it would be because it doesn't sound degrading when you use person-first language. Saying it any other way implies a lot of negative connotations.

Q: What do you think about using "disabled person" over "person with a disability"?

A: The word "disability" seems negative altogether and shouldn't be used, in my opinion, because people automatically associate negative aspects with that individual. I like "person with a disability" better.

Q: So, if you believe that it is a negative word, what comes to mind when you think of someone with a disability?

A: I automatically think, "oh, they can't do things that other people can," which isn't true at all, but it's my first reaction and I think that would go for other people as well. The first reaction is often negative because we have a tendency to assimilate that into schemas that we learn at a very young age. Even if the disability is something that's small, I think that the word "disability" is negative because it takes away characteristics of a person without knowing that individual on a personal level.

Q: Do you think that if a disabled person identifies so closely with their disability or being disabled that they can take on those negative stigmas? Do you think that it can be empowering?

A: It could definitely be empowering when people say that they can't do something because of their disability and they overcome those stereotypes and stigmas. Even athletes who have paralysis win gold medals and overcome all of the people who said that they wouldn't be able to achieve something like that. I think that if they have a good support system and are in a supportive environment in general with resources and skills, then they are more likely to overcome a lot of stigma, even if it's internalized. If they don't have that type of support or environment of care, they could be consumed by the negative aspects and that would take a huge toll on their mental health.

This interview brings a lot of thoughts into perspective. The interviewee had no previous knowledge of Gender Studies or Disability Studies and was speaking solely from a psychological perspective. But her replies show how much stigma is placed on people who have any type of disability. Even as someone who is taught to separate person from mental diagnosis, she has trouble separating the person from disability as someone who lives in an ableist culture. When she speaks of schemas, she is referring to a cognitive process tied to how we store information. According to Ghosh and Gilboa, a schema is a mechanism that allows humans to file (or encode) and retrieve information (Ghosh and Gilboa). I have heard it compared in Psychology classes to a filing cabinet. When we are children and first see a dog, our brain makes a file for a dog. Then when we encounter other four-legged animals that are not dogs, we accommodate and make a new file. The interviewee suggests, based on this concept of schemas, that when we become aware of humans as small children, they are more than likely abled bodied, so that is the "file" we make for a "normal" person. This means when we see someone, for example, with a mobility disability, they do not fit into the schema we have for "normal people." While we could simply have schemas that we categorize as "different" without value attached, in an ableist society, we typically think of them as "non-normal" or "less than," however.

While this point of view has made sense to me since being taught the concept starting with my first year of college, I had not thoroughly considered another side to this debate. In one essay we read in a class on Disability Studies, author Rachel Reed

states that she does not identify as "someone with Autism" but as "an Autistic person." Her argument is that identifying as "an Autistic person" implies that she cannot and will not separate herself from her disability because it is so much a part of who she is and her everyday life, that being separate from it would not be an option nor would she want to be separate from her disability. In contrast, the phrase "someone with a disability" literally separates the person from the disability and thereby reinforces ableist biases by suggesting that a disability is so bad that we need to separate it from the person. I thought that this was a profound choice for not only her, but everyone who would choose to "claim" disability despite (or because of) the stigma attached to it by other people. According to a study done by Cuttler and Ryckman, when not using person-first language the noun (or diagnosis) has a negative connotation that suggests that the stigmas that come with the disorder are also associated with the person who has the disorder (Cuttler and Ryckman). A year ago, I would have assumed that without using person-first language, someone with a mental illness or disability would end up feeling attacked or lesser than because they are not being looked at as a whole human being. Many people that suffer from mental illness express that, while it was difficult to overcome at times, their disorder had empowered them and ultimately crafted them into the stronger person that they are now. They do not separate themselves from their diagnosis because it played a vital role in "becoming themselves."

While I was fascinated with the radical implications of rejecting person-first language and "claiming" one's disability in positive and anti-ablest ways, I struggle between choosing a side in this debate for multiple reasons. On the one hand, I do believe that it is important for someone with a mental illness to know that they are not only a diagnosis and not only the negatively stigmatized ideas that come with being diagnosed, and person-first language can help achieve this. On the other hand, I can see that it is beneficial for some people to embrace a disorder and/or disability rather than separating themselves from it. According to Patrick Corrigan, person-first language can often be mistaken for pity as well as implying that the person with the diagnosis is nothing more than a victim of their mental illness or disability, so that, ironically, using person-first language could place the person with the disability in the victim position. He also states that it is a common and almost automatic reaction for people to feel pity for those who are sick or appear to be sick. Since disabled individuals are often thought to be less than "normal" because of their disability, they will unfortunately be met with pity more often than not in a society that sees disability as "less than." If this is the case, person-first language can amplify ableist bias.

Given this, I can see that possibly embodying a disorder or disability can allow someone to have power over it and determine how much significance it can have over their own identity. Jillian Weise, a disabled author and performing artist, describes her disability as a part of her identity and not a separate object with which she is in a relationship. Weise frames her choice as a political and ideological one that is necessary to fight against ableism.

However, the argument for using person-first language rather than embodying a mental illness becomes clearer for me when I substitute an eating disorder rather than just saying a disability. While embodying a disability, whether it be visible or invisible, can come with more benefits, I would like to argue that embodying a disorder may have opposite if not harmful effects based on my own experience with a disorder.

When I was a freshman in high school, I was diagnosed with Anorexia Binge/Purge type. In some ways, I believe that if I looked at this disorder as "who I was" or "part of myself," it would have been harmful. In other words, if I chose to embody this disorder it could have been even more detrimental to my health because I would have, in a sense, become the physical representation of this diagnosis. However, even eight years later, I would still not say that my eating disorder was/is part of who I am. I spent years separating myself from my body; my body was not part of me, my "self." If I embodied my disorder, that implied that my "self" was as ailing as my body was. I, as an individual, was not anorexic, but my body was. My body was the physical representation of this illness, but since I had separated self and body, I was not anorexic; I was a person with anorexia. If anorexia was part of who I was as a human being, that meant that I had immense control while restricting my eating but very little control while bingeing, which stereotyped me as erratic. My eating disorder also taught me to be secretive and to lie not only to other people, but also to myself. These are not traits that I would never wish to embody. Arguably, when I first developed this disorder, I very much wanted to embody the diagnosis. I say this because at first, I did not look at the diagnosis as something to be "treated" or "fixed". If I was anorexic, that meant that I was (at least in other people's eyes) skinny. So, if being anorexic meant being skinny, then that's what I would embody. Looking back, this may be because I was under the impression that it was "fashionable" and normative, even ideal, to have an eating disorder or that I would eventually be prettier and skinnier if I was anorexic. I also embodied the slang terms; words like ana, thinspo, ed-nos, plan a (another "name" for anorexia), stgw (short-term goal weight), and school diet can all be learned and embedded into someone's life style via the help of pro-anorexia websites. "Pro-anorexia" websites are popular and easy to access, and they worked to "normalize" my disorder, even to frame it as a good thing. Too many people are not aware that "pro-ana" websites even exist, let alone are accessible. When I was younger and seeking out these websites, there were fewer restrictions placed on what could be posted on the internet. They were even, at most times, disguised as websites that claimed to have "dieting tips." This also became one of the "secrets" I kept from family and friends. Though they are harder to find now, when I was younger it was as easy as typing it into a search engine, and doing so invited me into a community of others who celebrated and embraced being anorexic.

Embodying the disorder in the early stages of my diagnosis arguably enabled me, maybe encouraged me, to continue it. But when I compare it to other diagnoses that come with similar stigmas, I find it hard in hindsight to understand why one might prefer to embody their disorder or disability rather than keeping it separate from themselves, even if it has shaped them into becoming a stronger person. In my case, identifying with anorexia ultimately was damaging.

One can argue that embodying anorexia is my best choice since I will never get rid of it or recover wholly from it – the idea that I am always “recovering” from anorexia. Although having a mobility disability is not that similar to eating disorders, the same concept of never being able to “get rid of it” can also apply. The definition of recovery is “A return to a normal state of health, mind, or strength” (“Recovery” 2018). In an earlier draft of this paper, I stated that I was “in recovery,” and while this is a popular term for people who have overcome a disorder (i.e. recovering alcoholic or recovering drug addict), the word and definition of “recovery” in a general sense is problematic in itself. It creates a narrative in people with disorders that equates “recovery” with health or being able-bodied. Thus, for a disabled person, a recovery paradigm can reinforce a cultural narrative that they need to get rid of their disability and “get better” in order to be in recovery. My own position is that someone with a disorder that has permanently affected their strength, health, or mind can never be considered to be fully “recovered.”

In my own case, I have had a nutritionist for multiple years and attended therapy as needed. I took all of the proper and healthy steps that are supposed to be taken. However, I contend that most people diagnosed with eating disorders would concur that specific triggers exist that will affect them throughout their lives. This reflects back to the “mind” not being able to “return to normal.” These thought processes – triggers I have to engage, impulses I have to negotiate, a history which is always part of my “now” -- have become my normal. Now, I have coping skills to handle those triggers, but the concept of “recovery” suggests an all-or-nothing which oversimplifies my situation. Some side-effects from the anorexia still impact my life almost daily. My teeth are very sensitive from purging, my stomach is sensitive to an array of foods or medications, and my joints can get incredibly sore. Those are symptoms that I will carry throughout my life. But I believe – have decided – that the symptoms are part of who I am and how I live my life and that the diagnosis of anorexia is not.

Some disabled people might argue that I can't compare anorexia with a “real” disability because eating disorders are a “choice” while having a disability or being born with a disability is not. Though I reject the claim that having an eating disorder is a choice, it is a common misconception made by those who do not fully understand the diagnosis. This can also apply to many other mental health illnesses and addictions. With eating disorders, there are certain risk factors that make some people more prone than others to develop them. For example, females who are in the age range of 15-19 are more prone than other females to develop anorexia nervosa

(Smink et al.). If having an eating disorder or partaking in disordered eating was a choice, there would likely be no correlation between gender, age, and susceptibility. Quite clearly, having an eating disorder is no walk in the park. The health risks, the mental (as well as physical and emotional) strain are not things that someone would willingly choose. Even if someone was not aware of the risks when they "chose" to have an eating disorder, once these risks become evident, it's hard to imagine that someone would "choose" to continue having an eating disorder. But I do think that I have had some agency in deciding how to understand and experience my anorexia.

Although I would never think of myself and my disorder as one, I would say that it has played a vital role in the person I have become. And with saying that, I believe that might be why people tend to associate with and embody their disorders. Maybe it is not the disorder themselves, but perhaps what it has taught you or turned you into that is worth embodying. The disorder itself may not be worth embodying, but the person someone becomes because of living with a disability may be. As I've said, I would not look at my disorder as part of who I am, but I am stronger because of it. I learned to become angry with my disorder. Because I was once so close with it, it became embedded in my everyday life and to counteract that, the only other option I could see was to reject the identification I once embraced. It was such a part of who I was that for me, the only other choice was to be completely separate from it. I can say that now I have a healthier relationship with my diagnosis, but even so, being labeled "an anorexic" comes with more negativity than being labeled "someone with anorexia." Even though I am comfortable talking about it and disclosing it to anyone who may ask, I still find myself hesitant to bring it up in classes or bring it up at all unless someone asks about it first. This may be because of the misconception I discuss above that having eating disorders are considered by some to be a choice; it also reflects my point that we tend to internalize the stigmas associated with disorders and disabilities. Even though I am very much aware that having an eating disorder was far beyond something that I would ever "choose" to have or partake in, I still internalize that common stereotype. The possibility of being reduced to disorder causes this hesitation because, as human beings, we have a strong tendency to automatically stereotype people, including ourselves in a process of internalization. This stereotyping and labeling is going to happen even when someone embodies their mental illness or disability, and while I admire those who actively resist this stereotyping by claiming their disability or diagnosis, it's not a choice I want to make.

Maybe the solution to this tension is that of a happy medium: not to fully embody a diagnosis or disability, not to make it all that you are as a person, but also not to completely disassociate yourself with it. Another solution could be to simply let the person who has the disorder or disability choose how they would like to identify. For example, even though most disabilities come with stigma and stereotypes that can be internalized, having an in-group in which there are people with that same diagnosis fosters disability pride and acts as a sort of barrier, at times, to those stigmas (Bogart et al.). The happy medium, possibly the healthiest and most beneficial, might be to acknowledge the diagnosis or disability that you have, know that it has made an

impact on your life and maybe the person you are, but also to have some parts of your identity that are not fully associated with it at all times.

I was a person who was once diagnosed with Anorexia Binge/Purge type, but I was also once someone who did not have this disorder. Even now, without the diagnosis, I am still a whole person without embodying it.

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