

Disability Experience: Deconstructing People's Misconception about Disability

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Over the past couple of decades, our society's understanding of what disability is evolved greatly. It has evolved from seeing disability as an impairment that needs to be fixed, to one that understands disability as purely a "social construct", a construct that can be addressed through inclusion and adequate participation in their community, ensuring that the approach that we use in understanding a person with disability is holistic and focuses on the person's self-determination has become the focus in today's society. In this paper, I will discuss the two models of disability, the social model and the medical model in relationship to Chris and Amiee. I will discuss the effect of labels in relationship to Chris and Amiee's experiences. I will examine the views of Amiee and Chris in relationship to their disability. I will talk in details about why the perception of others can have a lasting effect on a person with disability. Finally, I will relate their experiences to my understanding of some major concept around the inclusion of individuals with disabilities in society.

In the article, *Resistance and Resilience in a Life Full of Professionals and Labels: Narrative Snapshots of Chris*, they discuss in great detail the effect of the medical model of disability. When Chris was first released from an institution, we see the effect of the medical model of disability in her life. She was isolated for several years and they took her kids away. As a result, she was quite psychologically unstable. As was noted by a disability writer, Mason (200), "segregation holds out a model of punishment, devaluing and isolation as society's response to... disability". In addition, Chris herself testifies to this fact when she said: "... If they lock you up in a psychiatric institution, you might go through hell without good support." (Van Hove, 2012 p. 427) When people with

disability are excluded from doing the things that we take for granted like washing their own clothes or helping in preparing their own meals, they often go through a stage internalized development of anger and frustration, they feel useless. As a result, this anger can lead to long term depression. This illustrates the importance of inclusion for people with disability. To be equal and appreciated for her diversity is Chris' dream. Furthermore, we see that as a result of the impact of the labels that were associated with Chris' disability, she was segregated right from the early stage of her life, she was sent to a segregated school, she was not allowed to take medications for her supposed "illness" and consequently, she became a victim of a system that view her as incapable. (Van Hove, 2012)

Johnstone (2001) tells us that "it is society that perpetuates the oppression and exclusion of disabled people... the onus of responsibility is shifted from the individual with an impairment or disability to the restrictions imposed by the construction of the social and physical environment and the attitudes of institutions and organizations. Conversely, when Chris started working with Geert, we saw the positive side of Chris, we started to see the many different roles that she wanted to fill in her life. She showed us that she has ambitions just like everyone else, she has goals just like everyone else. We see this when she took on the role of a woman with sexual needs, a mother, a grandmother, a friend and a public speaker. By taking on these roles, she was able to demonstrate that she is worth respecting, she was able to show that she wanted to be self-determined and more importantly that she is a human being, not an object that needs to be locked up and put away to be fixed. Claiming that sense of her own direction in life was absolutely critical in understanding Chris' experience. Being self-

determined is another stereotype that she wanted to counter. She wanted to show that just because she was labelled as being disabled, does not mean that she can't break that construct put on her by society. We see this when they said: "Chris fluidly negotiated between a disabled identity given to her by professionals.... and the other roles she had to fulfill." (Van Hove, 2012 p. 430) Another major challenge that Chris went through towards the end of her life is poverty. This was expressed in the article when they said: "At the end of her life, too, when her physical dependence forced her to leave her apartment and move to a home for the elderly, this feeling became more marked". (Van Hove, 2012 p. 432-433) Because she was heavily dependant on the government to pay her rent and feed her, she was forced to be economically deprived. She wanted to ensure that others don't take the burden of taking care of her funeral, hence she was saving up. Everything is always about prioritizing when you have very little. Economic marginalization is a real issue for many people with disabilities in our society. When a person isn't seen as being capable to work, they go through a cycle of poverty. The very little that she might have been given had to be prioritized. Therefore, when she was forced to wear a second hand clothes because she was saving up, when she was forced to move out of her apartment, this demonstrates the negative effect of that cycle. The stigmatization associated with people not being able to buy new clothes, people not being able pay for their own accomodation is often a reality for many people with disability. Empowerment of people with disabilities is very critical if we are to see a change in society's attitude and ultimately laws that will give people with disabilities greater control over their lives. We saw that she felt like a second class citizen, which is often a reality for many people with disability. From Geert's perspective, Chris is a

person of worth, a friend, and someone that he has grown to respect greatly. When he was going through some personal issues, he went to Chris. He did not think that she had nothing to offer, but thought of her as a friend that he could lean on. In most situations though, people with disabilities were not considered to be worthy. No one else in the halfway house respected her the way he did. While her experience was certainly mostly negative, there are others fighting to combat societal stereotypes about people with disabilities.

From Amiee Mullin's perspective, her disability was not as a result of her impairment, it was a direct result of the labels that people associated with it. She believes that by changing people's attitudes, we can effectively create a world that is more inclusive and promotes tolerance. She believes that when we have a positive attitude towards the challenges that we face, when we realize that our disability is not a burden but something that we can be proud of, we create an environment that promotes inclusion. Therefore when she said: "There is an important difference and distinction between the objective medical fact of my being an amputee and the subjective societal opinion of whether or not I'm disabled." (Mullins, 2010) In this quotation, she is suggesting that there is no direct linkage between the fact that she has an amputation, an impairment, and the way society chooses to see her. This is a more social model of disability. The social model of disability seeks to separate the disability from the impairment. She suggests that society's response to the impairment is what causes her to be secluded from society. As a result, when people use words like mangled, done up, useless to describe her disability, that's what creates separation and denies people with disability opportunities. The power of those words is what creates barriers for people

with disability. This was evident when she further said: "Truthfully, the only real and consistent disability I've had to confront is the world that I think could be described by those words" (Mullins, 2010) She chooses not to let people define her.

Growing up, she always wanted to be just like everyone else, she always wanted to be "normal", but as she grows and realizes the amazing opportunities that come out of having a disability, her understanding of what it means to be a disabled person changed. She realizes that her experience, being a disabled person, has brought her opportunities that might not have a rise without her disability. This relates greatly to the idea of self-determination. When people are given opportunities to actualize their potentials, they are more than likely going to become a productive member of the society. Whereas, if doors are not open, they will never really enjoy that ability to develop the different roles they have in society. It is through those roles that we develop lasting relationships and ultimately it leads to a better quality of life. When we focus on the individual, rather than the limitations the person might have, we can ensure that the person is maximizing their true potentials; we can create a conducive environment that allows the person to be self-directed. We talked about how some people might not be able to communicate, yet there are ways that we can use to support them to make sure that they are directing their own life. Furthermore, she talked about her experience in therapy and how much she hated it. As a result of Dr. P transforming that experience into something positive, something "strong" and "power" she was able to see the potential in her ability. This goes back to the idea of the strength of the words we use and how it can strongly impact on the way a person views themselves. As a society, we have a responsibility to help in creating that environment that will motivate change in attitude

and change in thought process. Through her experience, Amie should us that we can see disability as an opportunity to grow and learn in a unique way, she taught us that we all have a disability and that the extent we let it impact us is dependent on the environment we live in.

While it is clear that the experiences of these two individuals differs significantly, I will argue that there is some common trend. The goal of moving towards a more citizenship understanding of disability can only be realized when people with a disability stand up for their rights. Amie as shown us that through advocacy, inclusion of people with disability can be a reality. The challenges that Chris faced under the medical model of disability is less visible under the social model of inclusion that Amie's experience present. As a result, we are moving towards a more citizenship understanding of disability that Duffy talked about.

Reference Page

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