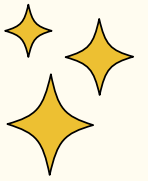


# Why do stories matter for Disability Justice?



Factsheet by Tosh Sherkat

Stories matter for disability justice because they have the power to create a world where every body's needs are met.

**nothing  
about us  
without us**

Stories reflect the human desire to transform the world through human action, to make it more adaptable to human needs and to create a place for ourselves in the world where everyone can fully participate in decisions that affect them.

## LET'S ZOOM OUT: WHY DO STORIES MATTER?

Stories have everything to do with what society perceives as "good" and "bad" and how we are supposed to act towards each other. Stories tell us how to make sense of things we don't understand, and stories show us through transformation what is possible and what we can believe about ourselves.

## ALRIGHT...SO WHAT IS A STORY?

In the West, what's known as the three act structure is the predominant mode of storytelling. It's found in most fairy tales. The structure features a *problem* that gets the story going, and requires the protagonist to go on a *quest* to fix it. Once the protagonist *returns* from their quest and has fixed the problem (or not), they live happily ever after (or unhappily, and not for long).

- Let's say a child is born with a cyst in her brain. Doctors use computerized tomography (CT) scans to find out that there is a cyst and then they perform surgery to remove the cyst. Now there is no cyst in the child's brain and she leaves the hospital with her family.

Stories are deeply connected to the context of the world we are in. Let's look at that example again:

- If you live in a world where there isn't the technology to have a CT scan, the "problem," "quest," and "return" are entirely different. What we identify as the "problem" entirely changes what our "quest" is and what we bring back with us when we "return."

## HOW DO STORIES OPERATE IN OUR WORLD?

Stories are tied up with power. In our world, stories tell us what is "good" and what is "bad" but they also tell us what is "normal" and what is "other." Let's use Donald Trump, for example:

- Trump tells stories that pack fear and prejudice into tight narratives that (falsely) explain the world.
- These stories champion individual triumph instead of changing the world so that everyone can win.
- Individual triumph requires that someone else loses, that someone succeeds at the expense of "others."
- Who are these "others?"
- These people Trump refers to as "others" are people who are already disenfranchised, and Trump associates them with "disease" and "disability," as something to be avoided, something to fear being associated with.
- Trump's stories work to further disenfranchise those already disenfranchised, thereby increasing the continued success of a particular few.

## DISABILITY

Stories have real consequences for people's lives. Prior to the understanding or language of "disability," people into the 19th century believed that if their child ever showed signs of what we would now know as cerebral palsy or autism it was because their child had been replaced by a fairy child—a story that made sense of the world around them. People would leave children outside to freeze to death just because they were different. How many lives have been smothered or disappeared or haven't been allowed to flourish because of the stories we tell?

## WHAT ARE OUR STORIES ABOUT DISABILITIES TELLING US?

The **social model** of disability begins its story by questioning what "disability" means.

Disability, as defined by the World Health Organization, is an umbrella term that describes impairments, activity limitations, and participation restrictions.

- Impairment is a problem in body function or structure
- Activity limitation is a difficulty encountered by an individual in executing a task or action
- Participation restriction is a problem experienced by an individual in involvement in life situations

The social model of disability is telling us a story where disability isn't just a health problem, it is an interaction between the features of a person's body and the features of a society. Disability of individuals is maintained by systemic barriers—the "features of a society." It is disabling environments that produce disabilities in bodies and require interventions at the level of social justice. The *problem* in the social model is the systemic barriers that make society inaccessible.

## WHAT ARE OUR STORIES ABOUT DISABILITIES TELLING US?

The **medical model** of disability creates a story where disability is wrong. "The child with a cyst in her brain shouldn't have been born with a cyst in her brain." It tells a story where "disability" means that there is something wrong with the body, and that thing, once it's been figured out (read: *quest*) can be "fixed" by medical intervention. In this model, the *problem* isn't the inaccessible features of society, but the features of the body. It desires to "fix" disabled people by returning them to a state of able-bodiedness by finding a "cure" for them.

There are extensions of the medical model called the **charity model** and the **psychological illness model**.

The **psychological illness model** of disability tells us a story where disabled people are disabled because they have unwittingly done something to cause their illness and therefore deserve it. This story tells us that disability is the *problem* of the individual, and that disability is something that can be overcome if one is "strong enough." It tells a story where "strong disabled people" overcome their illness, and therefore that it is "weak" disabled people who do not overcome their illness. This story creates a world where the only disability is a bad attitude.

The **charity model** sees the disabled individual as a flaw who is set apart from society. It sees them as someone to be pitied and saved by both the medical and social establishment. The charity model tells us that disabled people are "less fortunate." It says that disabled people are less fortunate because they are disabled, not because of the structural inequities upheld by the more fortunate.

## WHAT KIND OF WORLD ARE THESE MODELS CREATING? WHAT DO THEY MAKE POSSIBLE?

The **medical model** is a world where there is only one way of moving through the world. The medical model is building a world where people are unnecessarily isolated and excluded from full participation in society because their bodies are different. Disability becomes a symbol for the "other," existing as either an object of pity (**charity model**) or barely existing at all (**psychological illness model**).

The world that the **charity model** creates is one where concern for a fellow human is less a responsibility and more an active moral choice, where able-bodied people are obligated to improve society by helping the disabled. In our world, the charity model upholds social structures because as long as people are charitable, there is less need to disrupt social and economic hierarchies that disadvantage people in the first place.

The world that the **psychological illness model** creates is one where disabled people are limited by stigma and **inspiration porn**. **Inspiration porn** latches on to disabled people who have "pushed through" their illnesses and tells a story where disabled people are inspirational only because of their disability. This creates a world where disabled people are thought to be "less" and so anything they do is seen as special.

The **social model** is building a world where disability becomes an integrated part of the society we live in, where society's design reflects every body's needs. It imagines a world where all people are involved in all aspects of decisions regarding their participation in society. The social model imagines a world that is possible when we love and are responsible for one another. In the stories the social model of disability tells, the *return* involves society adapting to welcome all different bodies.

## ENDINGS

Under the medical model of disability, stories have one of two endings: a *happily ever after* ending, or an *unhappy* ending. The *unhappy* ending is the one where one is in a "lesser" body, to be someone who cannot function at the same level as other bodies, essentially to be in pain. This false binary of story-endings banishes disabled people to the realm of *unhappy* endings. It does not allow for the idea that there can be goodness in pain, that there can be happiness in struggle. Even the social model of disability engages in this binary; for the social model, the cure is an *unhappy* ending because society did not transform to meet the protagonist's needs.

*So why don't we just build wheelchair ramps and call it a day?*

Because wheelchair ramps or accessible washrooms do not erase pain or fatigue, and we cannot abandon those who also experience bodily factors of disability like chronic pain or aging.

## COMPLEX EMBODIMENT

**Complex embodiment**, a theory created by disability scholars, combines the social and medical model of disability to acknowledge the effects of disabling environments on people's bodies and also the bodily factors affecting disability like chronic pain or aging.

It understands that disability and able-bodiedness are both merely points on an enormous spectrum of human variation. If we understand human variation through the story of **complex embodiment**, it doesn't make much sense to think about happiness as a binary, but rather as a spectrum. Obviously, it is possible to move from being happy to being unhappy and back again throughout life, just as it is possible, through medical and social interventions, to move between ability and disability.

## WHY DOES ANY OF THIS MATTER?

Whether you understand yourself as disabled or not, we all exist on the spectrum of human variation that complex embodiment acknowledges. Too, we all want a world where our needs are met, where we don't need someone to lose in order for us to succeed.

This means that we want a world where we are not separated by fear of "otherness."

## SOLUTIONS

The trick is to tell stories in a way that outlines injustice but also calls on community and the social structures in place to change so that anyone might be able to reach for success in the future. The **charity model** shows us that it is not enough to be "nice," and instead we must tear down the structures that maintain inequality.

Leduc, Amanda. "Disabled: a Fairy Tale." In *Disfigured: On Fairy Tales, Disability, and Making Space*, 35-60. Toronto, Canada: Coach House Books, 2020.