

Leonard Davis:

- ideology of normalcy <sup>akin to</sup> (whiteness studies)
- Quetelet's concept of the average  
(l'homme moyen, les classes moyennes)  
middle class bourgeois normalcy arises

The norm hasn't always existed.

It was created.

Emerged in 1840s - 1860s.

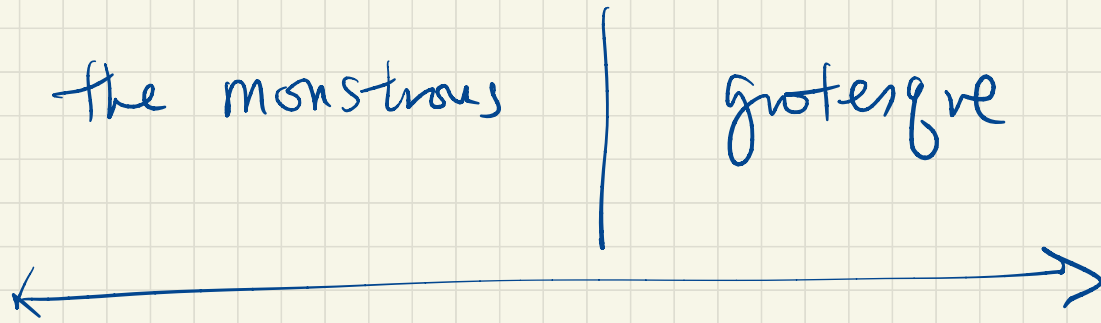
ABLEISM

heterosexuality

- racism

- sexism

ideology of  
normal & average  
as desirable.



reproduction

eugenics

eliminate

to avoid passing down "undesirable" traits

The historically loose association between  
disability + criminal activity  
mental incompetence  
sexual license

connections:

} ⇒ educational system today?

Richard Berger

★ not all disabilities are visible!  
physical      intellectual

disability / impairment

accomodation / universal design

medical model

↙ ↘  
kill or cure

social constructivist  
model

Exs:

① visual impairment  
corrective vision

②

wheelchair  
baby carriage.

others what the wheelchair user was ordering, as if they were incapable of speaking for themselves. At the same time, the researchers also learned of many acts of public kindness, where the nondisabled offered wheelchair users much appreciated assistance, which ran counter to the view that people with disabilities are uniformly stigmatized and treated badly (see also Bogdan and Taylor 1989; Makas 1988).

All this is to say that it is important to understand “disability” as a social phenomenon, an experience that cannot be reduced to the nature of the physiological impairment. Rather, it is a product of societal attitudes and the social organization of society. This view is sometimes referred to as a **constructionist**, or **social constructionist**, approach to disability, which understands disability as constructed by or residing in the social environment, in contrast to an **essentialist** view, which understands disability as a condition that resides or is inherent in an individual’s particular impairment (Baker 2011; Omansky 2011; Wendell 1996).

To complicate matters further, disability scholars note that impairment itself is a product of social definition, as in the case of medical diagnosis and classification systems that are themselves subject to dispute and change over time (Brown 1995). Take the case of

## 10 *Introducing Disability Studies*

**autism**, for example, which is now understood as consisting of a spectrum of conditions that includes people who are considered very “low functioning” and very “high functioning.” Autism was discovered separately but nearly simultaneously by Leo Kanner, a US child psychiatrist, and Hans Asperger, an Austrian pediatrician, in 1943 and 1944, respectively. Both Kanner and Asperger chose the term “autism” from the Greek word *autos* (self) to refer to the children’s “powerful desire for aloneness” and “anxiously excessive desire for the maintenance of sameness” (Kanner 1943:242, 249). People with autism have difficulty with face-to-face interaction, lacking the ability to empathize with others and appearing emotionally detached. They become attached to routines and can become anxious when these routines are disrupted. They often become focused on special-

in a world without feeling ashamed” (2008:69). In almost every case, Siebers adds, people with disabilities have a better chance of enjoying a fulfilling life if they accept their disability as a positive aspect of their identity that provides them with a unique and at times contentious way of being in and viewing the world.

At its core as a scholarly discipline, disability studies rejects approaches to disability that seek to eradicate it. This does not necessarily mean that it opposes rehabilitative interventions that might enhance a person’s ability to live the life she or he most wants to live. What it does aim to do is critique “the widespread belief that having an able body and mind determines whether one is a quality human being” (Siebers 2008:4). In doing so, it identifies a source of oppression, **ableism**, which is comparable to racism, sexism, and heterosexism in constituting a system that subjects people to “political, economic, cultural, or social degradation” (Nowell 2006:1179). Ableism assumes that some people (and bodies) are “normal” and superior while other people (and bodies) are “abnormal” and inferior, and it entails institutional discrimination on the basis of this distinction (Linton 1998; Papadimitriou 2001).<sup>13</sup> Siebers calls this the “ide-

ology of ability,” which in its simplest form constitutes a preference for able-bodiedness, but in its most radical form “defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons” (2008:8). As a dominant or hegemonic ideology, ableism is so taken for granted that it remains unconscious and invisible to most people, even though it constitutes an overarching regime that structures the lives of people with disabilities. Disability studies aims to unmask the ideology of ableism, to deconstruct it, to bring it out in the open for all to see.

## The Disability Rights Movement

One cannot begin to approach disability studies without crediting its very existence and conceptual thrust to the contemporary **disability rights movement**.<sup>14</sup> The social movement for disability rights is an

disability and for what purposes?" (1996:23). Insurance companies or government agencies, for example, may have particular administrative criteria they use to define who is eligible for payments or benefits, and it may be in the interest of these providers "to define disability narrowly" in order to save money (1996:24).<sup>6</sup> Similarly, laws that entitle people with disabilities to services, such as children in schools who need special accommodations, may utilize different criteria. Indeed, anyone who tries to negotiate the administrative-legal system will often find themselves entangled in a maze of competing and contradictory definitions of what it means to be disabled, or disabled "enough," to qualify, whereby they fit "some bureaucracies' definitions of disability and not others" (1996:24; see also Altman 2001; Grönvik 2009).


The field of disability studies, however, is not governed by such administrative-legal criteria; and in this field a discussion of definitional issues typically begins with a distinction between impairment and disability, whereby **impairment** refers to a biological or physiological condition that entails the loss of physical, sensory, or cognitive function, and **disability** refers to an inability to perform a personal or socially necessary task because of that impairment or the societal reaction to it. Although it has been common in the past to also use the term **handicap** to refer to the social disadvantage that accrues to an individual due to an impairment or disability, handicap as a concept is rarely used in scholarly or activist circles these days, largely because it has negative connotations when used to refer to

persons with disabilities as inferior or deficient in some way (Miller and Sammons 1999; Wendell 1996; Whyte and Ingstad 1995).<sup>7</sup>

For our purposes, therefore, the distinction between impairment and disability is what is most germane. Thus, for instance, people who use a wheelchair for mobility due to a physical impairment may only be socially disabled if the buildings to which they require access are architecturally inaccessible. Otherwise, there may be nothing about the impairment that would prevent them from participating fully in the educational, occupational, and other institutional activi-



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## Opinion

## DISABILITY

## 'Cure' Me? No, Thanks

By Ben Mattlin

March 22, 2017



Dadu Shin

Near the end of last year, the Food and Drug Administration approved [the first drug for the treatment of spinal muscular atrophy](#). A number of my Facebook friends rejoiced. “A Christmas miracle!” one of them declared. But I am not so sure.

Yes, S.M.A. is the No. 1 genetic cause of infant death. And the new drug, Spinraza, sold by Biogen and developed with Ionis Pharmaceuticals, will be a godsend for many. Without it, babies born with this condition, which causes debilitating muscle weakness, have only slightly better than a 50-50 chance of surviving past age 2.

According to clinical studies of more than 170 patients who took the drug, 23 percent of infants died and 40 percent achieved an otherwise unlikely or impossible degree of motor function, such as the ability to sit up unassisted and even, in some cases, to stand and walk.

Spinraza is supposed to be beneficial for those with a later onset, too, because it works by increasing the body’s production of the SMN protein, which is what’s lacking in those of us with S.M.A. But the long-term effects are unclear. The F.D.A. approved the drug in less than three months under “priority review.”

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As someone born with S.M.A. 54 years ago — a wheelchair user since the age of 3 who has never walked or stood — I fear for those like me who may never look at their lives the same way again. I fear that Spinraza, while giving hope, and perhaps a stronger and longer life, to some, may also release a torrent of self-doubt, of pent-up insecurity about our inexorable dependence and emaciated bodies. In some ways, it could make it harder for many of us to live with this type of disability.

Like many disabled adults, I’ve long since become accustomed to my physical limitations and all they entail. Call me set in my ways, but I can’t fathom *not* tooling around on wheels or no longer needing assistance with all manner of physical tasks, such as brushing my teeth and driving my lift-equipped minivan. I’m comforted to be always in the company of helpful people and devices, to truly understand the notion that no man is an island. This is the only way I’ve ever known.

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Even as a child I felt this way. My mother, a firm believer in the power of modern medicine, would tell me about Jonas Salk and his polio vaccine, to shore up her hope of an S.M.A. cure. I recall responding that I didn’t want to give up everything I’d grown used to, everything that made me *me*. My disability experience had already informed my perspective on the world, and I had no interest in risking any alteration.

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I know now that it’s not all about me. My disability takes a toll on my family. It’s a drain on my wife’s energy and time, not to mention the wherewithal of our children. It’s a financial burden on my father and stepmother, who help with the bills (my personal-care attendants alone cost \$40,000 a year).

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Yet none of them are urging me to take the leap. It’s not as if Spinraza is truly a cure anyway. It may slow or stop the progression of weakness in some users, but the underlying condition remains. While approved for every age and for every stage of S.M.A., it’s apparently most effective with kids (and adults with a recent onset of symptoms). So although it might restore a modicum of muscle tone, I may already be too far gone.

I concede that less deterioration sounds desirable. But what of the risks? Listed side effects include possible respiratory infections, kidney toxicity and blood clots. None of which would faze me if I had nothing to lose, but I do.

Equally daunting, the drug has to be injected directly into the spinal column several times a year. So it’s a commitment. It’s also an enormous investment, costing as much as \$750,000 the first year and \$375,000 annually forever after.

To be sure, surmounting fears and obstacles like these is how I’ve lived much of my life. Even Spinraza’s newness — the sense that those who sign on are being guinea pigs — wouldn’t stop me if I were hankering for a medical solution to my life’s complications. Furthermore, I recognize that I wouldn’t have survived as long as I have without medical interventions. So it’s not passivity or some kind of technophobia that gives me pause here.

My primary objection comes from my hard-won sense of self-esteem. Long ago I decided that if I was going to like myself, I had to make friends with the disability that was inherently part of me. Living with a disability is not easy. That’s why I became an advocate of fair treatment and equal access: I knew deep in my bones that things could be better. It wasn’t that I had to pull myself up by my bootstraps. Rather, society had to change, become more inclusive, more open to and validating of people with disabilities.

If instead I’d put my energies into fund-raising for medical development, that would’ve been a betrayal of my core belief — namely, that I and all my brothers and sisters in disability are O.K. as we are.

This resistance to the cure mentality is shared by others and surfaced this month at the South by Southwest festival in Austin, Tex., where the title of a panel on neurotechnology — “[The End of Disability?](#)” — angered so many [participants](#) that it became a [heated topic and hashtag](#) on social media. Some thought it evoked eugenics. “Do they have an #EndOfAbleism session?” someone wrote on Twitter.

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The organizers of the panel later apologized, but did they truly understand that this is the difference between saying “the end of racism” and “the end of race”? One takes aim at the problem; the other, at the victims of the problem.

To be clear, I have nothing against any advancement that will help others. Not everyone with S.M.A. (or any other disabling condition, for that matter) has the support I’ve benefited from. But not all of us in the target market are actually seeking this solution. I can’t help feeling there’s a contradiction between taking pride in one’s disability and hankering for a cure. You don’t try to cure something you like about yourself.

I acknowledge that as I age with S.M.A., I am troubled by my increasing difficulties with swallowing and breathing and the now complete loss of use of my hands. Yet even if the drug did help head off further debility, I’d have to face feeling like a traitor to the movement, a turncoat to the cause of disability pride.

None of this is to say that medical science shouldn’t be pursued or that those who are drawn to this drug and its potential benefits should not take it. It’s just that it will never be the beacon of hope for me that it already is for others. Because I know that even if it did eradicate S.M.A., the disability community will still be plagued by unnecessary and unfair impediments to equality and justice. Those are ailments that medicine can’t do anything about.

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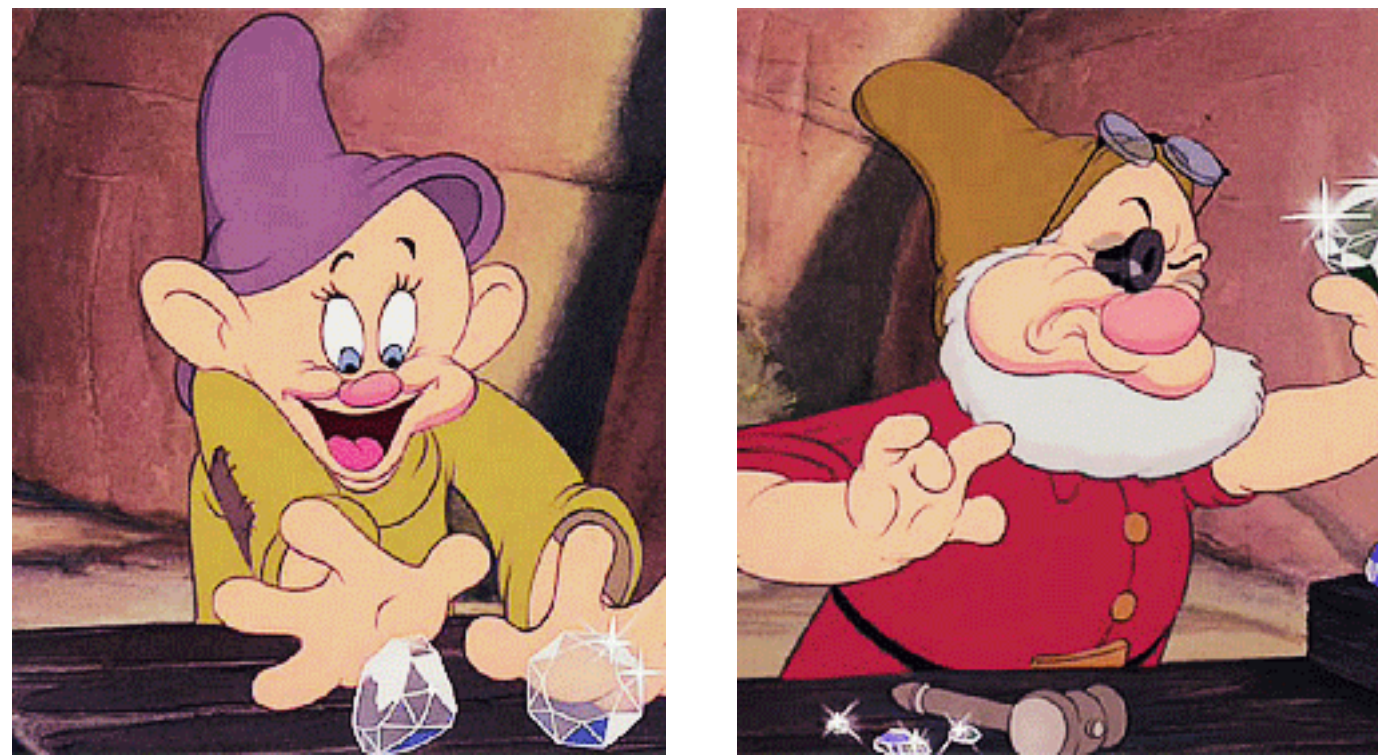
COLLAPSE 



## Disabilities in Disney Movies

By Ashley Gonzalez

Contrary to popular belief, disability studies and educational reform have become a major priority in the literary, critical, medical, and political world. Just recently in 1990, the Americans with Disabilities Act was passed to give civil rights to people with disabilities. This shows how oblivious many were to the severity of disabilities in society before this time, and also how people with disabilities have been ostracized and abused through out centuries. Popular theorists such as Ronald J. Berger and Lennard J. Davis introduce terminology and views on how to better understand disabilities. According to Berger, "disability studies- an interdisciplinary field of inquiry that includes representation from social sciences, the humanities, and the medical, rehabilitation, and education professions- is vital to an understanding of humankind" (Berger, *Introducing Disability studies*. 2013). Berger is definitely opening the doors and helping those with disabilities find their place in society. Davis, on the other hand, focuses on the "construction of normalcy" saying, "the *problem* is not the person with disabilities; the problem is the way normalcy is constructed to create the *problem* of the disabled person" (Davis, *The Disability Studies Reader*. 2006). Basically, society gets to label what is normal and what is not. Here, I will look at how Disney portrays disabilities and the treatment the characters receive.



The first Disney movie I would like to Discuss is *Snow White and the Seven Dwarfs*. All of the seven dwarfs have some kind of disability on top of having a growth impairment. The two main dwarfs are Dopey and Doc. Doc is the leader amongst the seven and suffers a speech impediment, having trouble pronouncing words correctly and often stuttering. He is also slightly bigger than the other dwarfs which makes the others look weaker. Doc's disabilities are a perfect representation of Berger's **ableism**- "assumes that some people (and bodies) are *normal* and superior while other people are *abnormal* and inferior" (Berger, *Introducing Disability studies*. 2013). Due to Doc's condition he was the most able dwarf and all the other dwarfs were secondary to him. Disney's representation of Doc shows that disabilities like or similar to his makes all the others lesser and more reliable to the "normal" or "most normal" person. On the other hand, Dopey is the complete opposite of Doc and ableism. Dopey's disability would put him in the **intellectual disability** category. Intellectual disability is significant limitations intellectual functioning and adaptive behavior, which covers many everyday social and practical skills, this is also the term now used for mental retardation. Dopey shows signs of this disabilities by not being able to talk and his child like behavior. Dopey also seems to be very clumsy, tripping over everything and trying to mimic the other dwarfs through out their daily routines. Disney, clearly depicts Dopey as a disabled person by making him the weakest dwarf and also with the name he was given.



<https://youtu.be/YPvIJ9otAM4>

Another Disney movie that shows a character with a disability is *Frozen*. Elsa's powers can be seen by how society outcasts people with disabilities. As a result of her magic power to make ice come out of her hands, Elsa was different from everybody else in the movie. Her parents kept her in isolation and taught her that her power was bad and she needed to always control it. This relates to Davis' theory that society controls what is considered normal. Davis says, "characters with disabilities are always marked with ideological meaning, as are moments of disease or accident that transform such characters. One of the tasks for a developing consciousness of disability issues is the attempt, then, to reverse the hegemony of the normal and to institute alternative ways of thinking about abnormal" (Davis, *The Disability Studies Reader*. 2006). Once Elsa ran away and completely confined herself from everyone, she was able to accept who she was and embrace it. Elsa also began to feel free and without shame or fear of her power. Towards the end of the movie she gets acceptance from society and was able to openly be herself without feeling like a monster for being different. *Frozen* also goes to show how Disney came along way with its portrayal of disabilities in movies.



The last Disney movie I would like to talk about is *Beauty and the Beast*. Lefou's character in the cartoon version could have had a disability. He was a lot shorter than all the other characters and also very clumsy. His physical appearance was also much different than those of the other characters. He always had a lost expression on his face and his tongue sticking out of his mouth but he was able to talk clearly. Lefou seems to show signs of having a learning disability or on the low spectrum of autism. There are a few times in the cartoon where Gaston refers to him as "stupid" or disregards his intelligence. Lefou also seemed very child-like and following Gaston around and trying to be like him. He can't do things like Gaston and kind of messes up everything he does due to his clumsiness. This also shows ableism and how easy it was for Gaston to use his superiority over Lefou to get him to do whatever he wanted. It also shows how people with disabilities can easily be taken advantage of and not even notice because they want to fit in. Lefou shows how some people with disabilities can easily be bullied by others because they want to fit in and get accepted.

There are plenty of other Disney movies that show characters with disabilities and how they are treated. I have noticed that the treatment of these characters change with the generation which the movie was released. Movies can play a role in how society sets the mold for people to know what's accepted and what is not accepted. Disney movies can be used to instill in the minds of children on who they can accept and who to outcast. They can compare character traits with those they see on TV and treat people with similar traits the way they see them getting treated in movies. Being that this is such a powerful outlet to relay messages especially to young children, Disney should start making more movies that accept people with disabilities and show ways to help them. This can help change society and form new opinions on disabilities.

APRIL 6, 2017 BY ASHLEY GONZALEZ  
ABLEISM, BEAUTY AND THE BEAST, BULLIED, BULLY, CONSTRUCTING NORMALCY, DISABILITIES, DISABILITY STUDIES, DISABLED, DISNEY, DISNEY MOVIES, DOC, DOPEY, ELSA, ELSA AND ANNA, FROZEN, GASTON, GRUMPY, HAPPY, INTELLECTUAL DISABILITY, ISOLATED, ISOLATION, LEFOU, LENNARD J. DAVIS, LET IT GO, MOVIES, OUTCAST, RICHARD J. BERGER, SEVEN DWARFS, SLEEPY, SNEEZY, SNOW WHITE AND THE SEVEN DWARFS, SOCIETY, STUDIES  
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