



The SAGE Encyclopedia of Children and Childhood Studies

Disabilities

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Book Title: The SAGE Encyclopedia of Children and Childhood Studies

Chapter Title: "Disabilities"

Pub. Date: 2020

Access Date: August 17, 2020

Publishing Company: SAGE Publications, Inc.

City: Thousand Oaks,

Print ISBN: 9781473942929

Online ISBN: 9781529714388

DOI: <http://dx.doi.org/10.4135/9781529714388.n233>

Print pages: 643-647

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Children with disabilities remain in the shadows of disability theory and are also marginalized in childhood studies literature. While children with disabilities are arguably the purview of both fields, discussions of childhood and disability are confined to psychology and children's literature. This entry offers an overview of dominant, or popular, knowledges of disability that frame how children with disability are socially constructed through language. This entry also offers an overview of major works on childhood and disability.

Medical Knowledges

Medical knowledges of disability are the dominant discourse through which parents come to know their child, often before the child is born. This is often problematic, as medical discourses have been developed to describe systems and problems, not to characterize people. The medical model of disability categorizes individuals as healthy or unhealthy by prescribing a model of normativity that compares all bodies against an ideal. For example, a child who is at no risk of experiencing physical pain and discomfort due to their disability is still faced with everyday divisions such as disabled and nondisabled, disabled and healthy, and healthy and unhealthy. Such binaries define the body and mind of a child as normal or abnormal.

Children with disabilities grow to know themselves and their role in the family and community through such frames. We can say that medical discourses of disability not only serve as means for clinical definition; they also function as what we might call public pedagogies of disability. That is, media discourses are an everyday, laypersons' way of learning about disability. They constitute the dominant public discourse of disability and are remade in different ways across numerous forms of public media (e.g., newspapers, television, film, and the Internet) and in an array of social fora.

The World Health Organization's (WHO) definition of disability is, perhaps, the most popular public pedagogy of disability, with their definitions establishing global models for disability service provision. According to the WHO, disability is a word that describes the following: (a) impairment, which is defined as a functional or structural problem; (b) activity limitation, which refers to difficulties in performing particular activities and actions; and (c) participation restriction, which refers to an individual's capacity to participate in life.

In their definition of disability, the WHO acknowledges the intersection of health-related challenges, environmental barriers, and social barriers faced by people with disabilities. The WHO also makes clear that while all humans share basic health needs (such as immunization), a variety of factors impact the access of people with disabilities to these services. The families of children with disabilities may experience social exclusion and poverty born from dealing with the expenses associated with disabilities. Access to adequate health care and rehabilitation is impacted by these social and economic factors. Additionally, secondary conditions associated with disabilities (such as urinary tract infections) impact the health of children with disabilities. The combination of these factors means that children with disabilities are more likely than nondisabled children to experience health issues not directly related to a particular disability, but as such issues are a formative part of the child's day-to-day life, they can impact on senses of what is achievable in life. Another powerful set of knowledges about disability can be found in religious and spiritual beliefs about disability. Just as medicine and medical knowledges are a foundational part of how we understand what it means to be human, religion and spirituality define how we see the world and those in it for many people.

Religion and Spirituality

Despite their prevalence and social power, medical discourses of disability are relatively new. Biblical and historical trajectories of disability map the lives of people characterized as blind, deaf, lame, or in some way with God. These knowledges far predate Western medical science. Historically, religious organizations delivered welfare and health care to individuals with disabilities, so the church and other religious institutions have long been much needed community disability service providers. While the various challenges of raising a child with a disability can place stress on the family unit, research shows that the majority of families positively adapt to life with a child with a disability, loving their children and raising them to be emotionally

healthy beings, maintaining successful marriages, and often extending support outside their own family to other families and educators who live or work with children with disabilities. For many, religion can play a significant role as a coping resource. Further, much research suggests that it is religious beliefs, rather than specific religious practices, that offer the most support to families with children with disabilities. While religious and nonreligious families do not differ categorically in their acceptance and adjustment to life with a child with a disability, families who are religious perceive religion as a strong supportive mechanism.

For many parents, a transition period may be required where a new relationship with their religion is developed. This may involve a transition from blaming God or asking why they were singled out with a perceived burden, to considering the child as a gift that they were especially equipped to handle. Often parents of children with disabilities also feel that their religion will provide ongoing support as they learn to accept and accommodate their child's needs. Religion and spirituality provide a source of faith for many that the life of the child with a disability will be successful. Religion and spirituality are also often used as a way to give meaning to the reality of having a child with a disability. If families cannot transition from considering their child an unfair burden, or if they belong to religious communities that are unaccommodating of their child's needs, religion can constitute a form of stress rather than a support.

As noted, many establishments throughout history that catered specifically to people with disabilities were founded by religious institutes or persons, including those from Christianity, Judaism, Buddhism, Hinduism, and Islam. Cultural and religious attitudes toward disability have varied greatly across these sites. Many cultures around the world have believed that infants with disabilities were possessed by demons, and either murdered them or abandoned them to die. Others attached religious significance to disability, believed people with disabilities could ward off evil, or even believed that their bodies could bring luck, cure disease, or be used for magic.

Depictions of disability vary in religious documents. Eastern religious documents often portray disability as a spectacle of freakery and something to fear, with the Mahabharata, for example, featuring a blind king who concedes his crown as he was deemed a poor fit for ruling. The Quran advises accommodation be given to people with disabilities, especially when it comes to civic and social service. The Bible has many mentions of disability, with the Old Testament focusing more on disability as a punishment from God, and the New Testament often presenting disability as something to be healed. These knowledges are significant as they shape the ways children with disabilities are known in history, are understood in families and communities, and how they come to know themselves.

Popular Culture

Another very important popular pedagogy of disability is popular culture or entertainment culture. Accessible entertainment material also shapes understandings of children with a disability. For example, nondisabled children who read books featuring characters with disabilities demonstrate an increased acceptance of children with disabilities as friends. Literature plays an important role in children's education in establishing models of social equality, with research suggesting that children at a young age are able to read beyond literal plots to discern and internalize the cultural and political messages. Even as the stories fade from memory, individual attitudes remain.

Fictional or popular culture characters with disabilities undertake the same kind of work in children's literature as figures with a disability did in mythology and biblical works. For example, Angharad Beckett and four of her colleagues surveyed 100 texts aimed at primary-aged children. The selection was chosen based on recommended books featuring disability-related topics published since 1990. Thirty of the books contained outdated or discriminatory language, 33 presented stories that focused on the tragedy of disability, eight contained unrealistically feel-good endings (such as a miracle cure), seven presented people with disabilities as curiosities or freaks, and eight presented disability as a lesson in morality or spirituality. On a more positive note, approximately half of the texts portrayed disability as part of diversity, with 15 texts actively challenging social barriers associated with disability. Representations of children with a disability—and, indeed, adults

with a disability—in children’s literature are crucial, as they shape how young people come to think about disability.

The representation of certain disabilities does not necessarily relate to the prominence of those disabilities in society. World War II brought about an increase in appearances of disability in literature aimed at young readers; however, certain disabilities were far more prominent than others. Writers tended to choose disabilities with obvious physical manifestations, presumably for the simplicity of writing about a disability younger readers could understand. The return of injured veterans from the war at this time meant that physical disability became a noticeable part of post–World War II society. One third of disabilities depicted in juvenile fiction from 1940 to 1975 were orthopedic problems. The second most common disability was vision impairment, which occurred 6 times more frequently in fiction than in reality. The appearance of less visible disabilities became slightly more common in children’s literature of the 1960s and 1970s, and this simultaneously created a need for more skilled storytelling, as writers could not rely on cues such as the use of a wheelchair.

Historically, visual, literary, live art, and mainstream media representations of disability have featured characters and figures that carry religious messages; disability is often used to teach moral stories. As noted above, disabled characters in European and American literature traditionally represented a punishment from God issued for breaking the moral order of the world. Characters such as Ahab in *Moby Dick*, Quasimodo in *Hunchback of Notre Dame*, Clara in *Heidi*, Captain Hook in *Peter Pan*, Long John Silver in *Treasure Island*, and many more, can be, and indeed have been, read as characters that teach readers to stand up for themselves and not allow the powers that be to bully them, to do good and to be good, or face the wrath of God in the form of impending disablement.

Characters with disabilities also appear in popular culture that is aimed either partially or entirely toward children. Historically, disability in these characters tended to manifest in a handful of distinct ways. Characters such as Tiny Tim in *A Christmas Carol* and Pollyanna in *Pollyanna* are presented as figures of purity and inspiration due to their positive outlook despite their disability. Katy in *What Katy Did* and Colin in *The Secret Garden* are bitter about their disability, but with the help of their cousins learn to appreciate life and are eventually cured. People who use wheelchairs, such as Professor Xavier in *X-Men* and Stevie Kenarban in *Malcolm in the Middle*, are geniuses; villainous pirates, such as Captain Hook in *Peter Pan* and Captain Barbossa in *Pirates of the Caribbean*, have crude prosthetics where limbs are missing. These representations are unlikely to provide characters whom children with disabilities can identify with because they often limit characters to being inspirational, pitiful, superhuman, or evil. However, in recent years, representation has improved, with high-grossing films like *How to Train Your Dragon* presenting multiple unique characters with disabilities who are capable and not objects of pity.

Toys with disabilities have also been developed over the years, with varying degrees of success. A Mister Magoo Car Toy in the early 1960s was met with protest from disability organizations for stereotyping disability. Down syndrome dolls by Helga Parks were met with mixed reception by the public, with some feeling they helped normalize disability, and others feeling they were a spectacle of freakery for nondisabled consumption. Mattel’s Share A Smile Becky, often known as Wheelchair Barbie, was widely popular but was unable to fit through the doors or elevators in the existing Barbie merchandise and was eventually discontinued. Some toy manufacturers, such as American Girl, now offer assistive accessories for their dolls, including wheelchairs and crutches. More recently, organizations like #ToysLikeMe have begun adapting existing toys to be more inclusive (such as featuring cochlear implants or wheelchairs) and lobbying existing toy companies to do the same.

Academic Perspectives

Disability studies began to gain academic attention from Western scholars and researchers in the 1970s. Since then, the study of disability has made a shift in focus from the applied areas of medicine and social work, to identity studies, following the path of the civil rights movement, Women’s Studies, and race studies.

Models of disability are particularly important when working with children with disabilities, as children are often referred to medical professionals by someone else, and therefore their issues are framed by a third party's interpretation. Understanding various models of disability helps broaden the perspectives of those working with children.

As outlined above, the medical model of disability remains prominent in public discourses of disability. As a response to this, a social model was widely adopted in critical disability studies and with disability organizations, beginning in the 1980s. The medical model does not really allow for children to have pride in their disability or, for example, to belong to a social community of people with disabilities. In contrast to this, the social model makes a distinction between impairment of the mind or body, and the social barriers erected by society that stigmatize, pathologize, and prevent access.

Most disability scholars agree that the prejudice and oppression faced by people with disabilities is often far more difficult to deal with than its physical aspects. This insistence that disability is socially constructed rather than individually embodied is the hallmark of the social model. Despite making this important contribution to knowledge, the social model has limitations. Primarily, scholars and organizations favoring the social model may be more reluctant to acknowledge hard links between disability and the body, such as when a disability results in experiences of pain and fatigue that are entirely separate from the social expectations and biases placed upon that individual. This is because these experiences are often viewed as detracting from the central message of the social model: that it is society that disables the individual, not impairment. Similarly, environmental factors (whether socially created or otherwise) can pose real challenges to people with physical and mobility needs. The social model has been criticized for privileging an ideal disabled subject—someone who is considered happy and healthy in spite of their disability. While this subject is illustrative of the ways in which society disenfranchises people with disabilities, it does not represent the experiences of all people with disabilities and can marginalize embodied experiences. There are many children who experience physical and emotional pain, along with secondary health issues, and the social model can be viewed as excluding them.

Other models for thinking about disability exist that address some of these weaknesses. The minority model of disability focuses on disability culture, emphasizing that children with disabilities are different from nondisabled children and that difference is a valuable part of their cultural identity. For example, children who are born deaf or hard of hearing may grow up to identify as Deaf (with a capital D). Being culturally Deaf is closely linked to language and is most common to people who are prelingually deaf and hence grow up using sign language as a primary method of communication. The families and friends of children who are deaf and communicate with them through sign language (along with interpreters and those who work with people who are deaf or hard of hearing) may also be considered to be a part of the Deaf community.

Another alternative model, coined by David Mitchell and Sharon Snyder, is the cultural model of disability. The cultural model follows the work of the social model in understanding the social disenfranchisement faced by people with disabilities but also understands that these social challenges may be paired with physical and environmental challenges. Although it acknowledges that disability is often a result of social discrimination, it also recognizes that experiences of people with disabilities may be unique in ways that are entirely separate from social disablement.

Similar to the cultural model is the transactional model, which not only acknowledges the importance of environment in the experiences of children with disabilities but views environment as an interactive structure. For example, an infant who behaves in ways that are perceived as difficult may, in turn, influence the ways in which the parental figures of that child interact with them. If a parent decides to engage less frequently with a child they perceive as exhibiting difficult behavior, it can cause developmental delays in the child as they grow older. Similarly, a child with a physical disability may be less likely to attempt challenging physical movements in the presence of their nondisabled peers, which over time could result in their developing more restricted movement than they would have if surrounded by children with similar mobility needs. The transactional model shows that environments can have both positive and negative impacts on children with disabilities and that non-supportive environments impact not only how a disability is perceived but how that disability tangibly

develops over time.

Overall, there is no single correct or 'best' way of thinking about children with a disability. Each perspective we discuss above has its uses. The most important thing to remember is that children with a disability join an already existing culture of disability, which celebrates difference and accepts disability. While representations of children with disabilities are still fairly rare in children's screen media, they are prevalent in children's literature and are increasingly becoming part of children's popular culture. Acceptance and recognition of children with disabilities starts with the everyday.

See also [Disability Studies Disability Studies in Education](#); [Special Education](#)

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<http://dx.doi.org/10.4135/9781529714388.n233>
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