

What Persons with Disabilities Can Teach Us about Health Care

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Most discussions that take place around health care distribution focus on insurance issues. Cries for universal access to health care have taken center stage in recent years. But within these discussions, and in our very health system, there is a deep bias that seldom gets highlighted or even attended to, namely, the distinction between acute and chronic care. Too frequently, our society looks for the magic bullet cure-all and ignores the basic everyday care that millions of individuals require. Part of this is due to our society's low regard for caregiving, but another part is due to our misunderstanding and fear of disability.

The goal of acute care medicine is to save lives and to bring individuals back to a level of independent functioning. There are some individuals, however, who are either born with or acquire conditions that make this impossible. They may need assistance from others for short or long periods of time.¹ When these individuals are limited in performing a major life activity, we usually refer to them as persons with disabilities.² The conundrum in which society finds itself is that as technology saves lives and people live longer, there will be more individuals who become disabled.

We cannot decide on how to care for these individuals, however, without first recognizing that distribution issues are not made in a vacuum, but come out of value systems. If we live in a society that puts a high premium on independence and rugged individualism, then persons who need long-term care might be viewed as expendable and a drain on society.

Persons with Disabilities

In the United States, persons with disabilities have been treated in various ways during different historical periods, but throughout these diverse eras they have been regarded as anomalies. During most of our history, they have been stigmatized and viewed as deviants. As recently as 1990, when the Americans with Disabilities Act was passed, we read that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continues to be a serious and pervasive problem."³

Erving Goffman, in his book, *Stigma*, states that individuals who are stigmatized possess attributes that are deeply

discrediting and incongruous with a stereotype of what a given type of individual should be.⁴ This definition automatically highlights how the concept of stigma is a relational concept, for it is not so much the attributes that make one stigmatized, but how those attributes compare to other attributes. In other words, in order to classify someone as stigmatized, deviant or abnormal, there must be a group who are not stigmatized, deviant and abnormal. Perhaps this was why Mama Mwanza, a character in *The Poisonwood Bible*, was not considered abnormal in her culture for the author writes: “Used to be, Adah was the only one in our family with something wrong with her. But here nobody stares at Adah except just a little because she’s white. Nobody cares that she’s bad on one whole side because they’ve all got their own handicap children or a mama with no feet, or their eye put out. When you take a look out the door, why, there goes somebody with something missing off of them and not even embarrassed of it. They’ll wave a stump at you if they’ve got one, in a friendly way.”⁵

It is *culture* that determines which attributes of difference should be stigmatized, and in our culture that has been persons with bodies and minds that do not fit some kind of norm. Persons with disabilities do not fit the cultural rules of what bodies and minds should be or do.⁶

As a result, these persons were frequently viewed as freaks and became the objects of stares. Rosemarie Garland Thomson in

her book, *Extraordinary Bodies*, traces how the American Freak Show (1835-1940) objectified persons with disabilities by putting them on display and charging people fees to stare at them. P.T. Barnum was the master of this approach. Displaying persons such as Joice Heth, Miss Julia Pastrana (the Ape Woman), Sartje Baartman (the “Hottentot” woman), Charles Tripp (the Armless Wonder), midgets, giants, two headed women, etc. earned Barnum fame and fortune. In the process, these persons were reduced to pure bodies through representation.⁷

Martin Norden, in *The Cinema of Isolation: A History of Physical Disability in the Movies*, shows how the cinema historically portrayed persons with disabilities. He highlights how these individuals were seldom the central character of any movie and were isolated from their able-bodied peers as well as from each other. Nevertheless, because members of mainstream society have also had a desire to stare at persons with anomalies, there have always been individuals willing to offer glimpses of them for the right price.⁸ In modern society, movies have taken over the role of the circus sideshow. Norden’s book meticulously documents how this was accomplished in various time periods.

In the twentieth century, society changed its concept of persons with disabilities from the “freakish” to the pathological. Now the person with disabilities does not only challenge some aesthetic law, but a biological code. Persons are stigmatized

because they do not match some scientific formulation of what it means to be normal. Extraordinary bodies are no longer merely the objects of stares, but are also objects of repair, rehabilitation and scientific experimentation.

This switch to the medical model was not only brought about by the overwhelming importance of science in our culture, but also by the fact that many of the persons with disabilities in the twentieth century became disabled as a result of war. In other words, there was a before and after. Many young men and women left for the war with one type of body and came home with another. Their new bodies were viewed as damaged and in need of repair and rehabilitation so they could return to their “normal” selves.⁹ Hence, there was not only a cultural norm, but also a personal norm, and digression from that norm showed a loss of some “species typical functioning.”¹⁰ Medical professionals had now gained control of the body.

Persons with disabilities are usually measured against some sort of norm of which they are not a part. Their placement outside of that norm has led others to stare at, pity, fear, isolate, experiment on, and attempt to rehabilitate them. Seldom have persons with disabilities had input into what should constitute the norm and, in most cases, they have been objectified and denied their own subjectivity.

In the ancient world, persons with disabilities were viewed as representing the

supernatural and often the sacred. Sacred refers to those things that reside beyond the boundaries of convention, that which is unbelievable, impossible, and extraordinary.¹¹ It was only with the Enlightenment, and humans’ desire to master the natural world, that extraordinary bodies lost their connection to the supernatural,¹² and came to be discussed in the terminology of pathology.

Human Dignity

We need to recognize that persons with disabilities are fully human. Church documents remind us that a person is more precious for what that person is than for what that person does. The preparatory Committee for the Jubilee Day of the Community with Persons with Disabilities stated: “the person with disabilities has rights and duties like every other individual.”¹³ It made the further point that “disability is not a punishment, it is a place where normality and stereotypes are challenged and the Church and society are moved to search for that crucial point at which the human person is fully himself.”¹⁴ Pope John Paul II stated in his address to the International Symposium on the Dignity and Rights of the Mentally Disabled Person that “the disabled are not different from other people which is why, in recognizing and promoting their dignity and rights, we recognize and promote our own dignity and rights and those of each one of us.”¹⁵

Health Care Implications

From a health care perspective, we need to

begin by recognizing that persons with disabilities are entitled to the same level of health care as everyone else. Some persons with disabilities will have few health care needs, while others may have multiple needs. Many persons with disabilities, some with adaptive equipment, are quite capable of living independent lives. Others will require assistance with activities of daily living (ADLs), while some might require more sophisticated and intense medical interventions. Nevertheless, whatever level of medical assistance is needed, persons with disabilities should not lose their dignity because of this need. As Pope John Paul states, "The world of rights cannot only be the prerogative of the healthy."¹⁶ These rights include those of inclusion and those of care.

This means that persons with disabilities should be participants in their health care decisions. Too frequently when one is in a wheelchair others speak to the person pushing the wheelchair about the person in the wheelchair as if he or she is not present. Persons with disabilities need to be respected and not patronized. Needing help from someone to push a wheelchair does not reduce one to an infantile level. Likewise, when one has a cognitive disability, that person should still be entitled to participate in health care decisions as much as possible. Persons are often capable of making some decisions even though their ability regarding decision making might be limited in other areas. Persons with disabilities have voices and one should always listen to their voices even when their voices cannot be expressed orally.

Likewise, medical facilities and medical equipment should be accessible to persons with disabilities. Although most medical facilities are now ramped and have elevators, there is still often a problem with medical equipment. Females with disabilities sometimes have a difficult time finding a place to have a gynecological exam. Offices of ophthalmologists are often ill equipped to deal with individuals who cannot sit in their chairs. Likewise, dental care can be an issue. It is sometimes difficult to do CAT scans or MRIs on individuals who cannot lie still. There are even physicians who do not like to care for individuals in wheelchairs because these patients and their chairs frequently chip the paint in the physicians' offices. All of this often leads to a lower standard of care for those with disabilities. It was not too long ago when equipment favored those who were right-handed. The same changes need to be made to accommodate persons with disabilities.

A more subtle form of discrimination sometimes comes into play when dealing with individuals with disabilities. We live in a fast-paced world where time has become a billable commodity. Many persons with disabilities move slowly. If it takes a person longer to get to the examining room, disrobe, and climb onto a table, income is lost. Or what if that person has a speech impediment and needs to repeat him or herself several times before being understood? Patience is not a virtue cultivated in our society and speed is of the essence.

Rehabilitation Medicine

In addition to standard medical care, many individuals who have disabilities can be helped a great deal through rehabilitation medicine. Yet rehabilitation medicine often has a lower status in the health care system and is frequently poorly financed by insurance agencies. Patricia Benner writes from a nursing perspective that “the power and money flow that accompanies a medico-centric cure approach to disease causes the human issues associated with experiential learning, craft, or practical wisdom in managing a chronic illness to be overlooked.”¹⁷ Physiatrists, doctors of physical medicine who usually oversee rehabilitation, are at the lower end of the pay scale. According to www.payscale.com a physiatrist’s annual salary range is from \$78,200 to \$248,884 whereas a neurosurgeon’s pay range is from \$88,774 to \$567,436.

The primary role of rehabilitation is to improve function. It deals with *quality* of life, whereas acute care medicine frequently deals with saving a life. *Yet it is cruel to save lives and then allow those individuals to languish.* Many individuals who could benefit from rehabilitation are denied it. The admission criteria for entry into a rehabilitation facility are designed to limit access.¹⁸ Although some of the criteria are based on prognosis, much is based on financial considerations. One of the primary criteria for acceptance into a rehabilitation program is the ability to pay for the services to be delivered.¹⁹ Yet, even if insurance does not provide

rehabilitation services, we are reminded by church documents that necessary resources need to be allocated to this sector of health care.²⁰

Once a person is part of a rehabilitation program, financial considerations are also constantly present. The therapy hours spent with the patient need to be supported by documented evidence that the patient is making progress in order for the rehabilitation facility to be reimbursed. Within rehabilitation medicine is the concept of “plateauing.” This means that if an individual does not make sufficient progress at a rapid rate, funding will be cut off, usually within a brief period of time. Yet, some persons suffering from a chronic condition may need rehabilitation for years. Likewise, there is often little recognition that rehabilitation also helps to maintain function and that without it the person may regress and have a poorer quality of life.

Conclusion

When thinking of persons with disabilities within the health care context, there are two fundamental concepts with which we need to come to terms. One is an understanding of difference and another is an appreciation of time.

Too frequently, we automatically arrange differences in some kind of hierarchical order. Persons with disabilities are fully human and the anomalies of their physical or cognitive functioning should not reduce them to a lower level of inclusion

and care. Their needs may be different but they, as with all of us, should have their needs addressed. In many cases, recognizing difference brings us to a fuller appreciation of what it means to be human.

Recognizing the rights of persons with disabilities should also lead us to reexamine our health care system's focus on quick fixes and acute care medicine. What is missing when we focus on the rapidity of time is time's depth dimension. In our society, waiting and being present have become undervalued. Yet true care giving involves presence, attentiveness, patience, and compassion. These require time. It is by being truly present to another over stretches of time that we come to know that person and form relationships. Too frequently our current health care system with its focus on rapid discharge encourages abandonment, not the faithfulness required for true healing. Pope Benedict XVI reminds us that waiting is not merely passive existence until the future occurs, but engaging the future in the present moment. It is responding to love. Embracing persons with disabilities and being faithful to them through their journey of life pulls us into a deeper dimension of living and teaches us the true meaning of health care.

References:

¹ There is a strong debate in the disability literature as to whether it is biology that causes disability or the way an anomaly in biology is interpreted by society. The first is sometimes referred to as the medical model of disability while the second is referred to as the social model of disability. Ron Amundson, for example, in his article, "Biological

Normality and the ADA," in *Americans with Disabilities* edited by Leslie Pickering Francis and Anita Silvers (New York: Routledge, 2000) states that normality of function is a myth. He states that although blindness is real this does not mean that the blind person is abnormal. It is the way that blindness is treated by society that makes the blind person disadvantaged.

² The Americans with Disability Act (ADA) defines disability to include "any chronic medical condition, physical or mental, that substantially limits one or more of the major life activities of an individual."

³ *Americans with Disabilities Act* (ADA) 1990 Sec.2, a, 2.

⁴ Erving Goffman, *Stigma* (New York: Simon & Schuster, 1963), p. 3.

⁵ Barbara Kingsolver, *The Poisonwood Bible* (New York: Harper Collins, 1998), pp. 52-53.

⁶ Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), p. 60

⁷ Ibid.

⁸ Martin F. Norden, *The Cinema of Isolation: A History of Physical Disability in the Movies* (New Brunswick, N.J.: Rutgers University Press, 1994), p. 5.

⁹ See David Yuan's article, "Disfigurement and Reconstruction in Oliver Wendell Holmes's 'The Human Wheel, Its Spokes and Felloes,'" in *The Body and Physical Difference*, eds. David T. Mitchell and Sharon Snyder (Ann Arbor: University of Michigan Press, 1997) pp. 71-88.

¹⁰ For a fuller discussion of what is meant by "species typical functioning" and what some arguments are in opposition to it see Anita Silvers' article "Formal Justice" in *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (New York: Rowman & Littlefield Publishers, Inc., 1998), pp. 13-145.

¹¹ James Aho, *The Orifice as Sacrificial Site*, (New York: Aldine de Gruyter, 2002), p. 15.

¹² Thomson, *Extraordinary Bodies*, pp. 74-75.

¹³ Preparatory Committee for the Jubilee Day of the Community with Persons with Disabilities, Rome, December 3, 2000.

¹⁴ Ibid.

¹⁵ Pope John Paul II, "Message on the Occasion of the International Symposium on the Dignity and

Rights of the Mentally Disabled Person,” January 5, 2004.

¹⁶ Ibid.

¹⁷ Patricia Benner, “Stigma and Personal Responsibility: Moral Dimensions of Chronic Illness,” in *Educating for Moral Action: A Sourcebook in Health and Rehabilitation Ethics*, eds. Ruth B. Purtillo, Gail M. Jensen, Charlotte Brasic Royeen (Philadelphia: F.A. Davis Company, 2005), p. 65.

¹⁸ Rita Gillis, *Traumatic Brain Injury: Rehabilitation for Speech-Language Pathologists* (Boston: Heinemann, 1996), p. 273.

¹⁹ Ibid.

²⁰ Preparatory Committee, Rome, 2000.