

# TWO FUTURES OF PEOPLE WITH DISABILITIES



Recently Chair of Department of Public Management, The Sawyer School of Management, Suffolk University (Boston, Massachusetts), Professor David Pfeiffer articulates eutopic and dystopic futures of disabilities in this article. In so doing, Pfeiffer also sounds warning notes about Dr. Jack Kevorkian's views and genetic engineering. Yet he ends on a hopeful note. Dr. Pfeiffer's article stems from a lively presentation and spirited debate at the Futures Discussion Group on 19 July 1996. David Pfeiffer has relocated to the middle of the Pacific Ocean and is affiliated with the Center for Disability Studies, University of Hawai'i at Manoa--v.k.p.

by David Pfeiffer

There are two possible scenarios leading to what may happen to people with disabilities in the future. The first one is very pessimistic, and the second one is more optimistic. Which one is more likely remains to be seen, but it is my hope that the optimistic one wins out. Although both scenarios are applicable worldwide, they are mainly focused upon what has happened and is happening in the United States.

People with Disabilities. In the United States, people with disabilities are generally seen as being physical and mental cripples. It is not expected that we would participate in any major decision making process. We are not allowed any role in anything of importance. We are not expected to hold any major position. We are to stay out of the way and let the "real" people act.

Our disability is a stigma (Goffman, 1963). We are not supposed to talk about our stigma, our disability. If it is a hidden disability (like a seizure disorder, herpes, or AIDS), we are not supposed to disclose it. If we do disclose or if it is inadvertently disclosed, then the stigma is even worse because at one moment we were seen as normal and the next moment we are both feared and pitied. A visible stigma--like using a wheelchair--is hard to hide; this makes the stigma both easier and more difficult to manage.

Why are we treated in this fashion? It is because we are perceived to be in the "sick" role (Parsons, 1951). A person in the "sick" role is expected to consult the professional (a medical doctor usually) and follow the orders of the professional. Only if you follow orders, will you get well.

While you are in the "sick" role, you are exempt from social obligations. If a colleague comes to work not feeling well, then he/she is exempt from following social obligations such as office etiquette. Excuses will be made and accepted. Often coworkers will offer or actually take the colleague's work to do, expecting reciprocity when their time comes.

However, being exempt from social obligations also means that you do not have rights. You are not an independent actor in society. You are dependent on others and must follow orders of others. And you are dependent upon the professional not only to cure you, but also to verify that now you are well, now you have rights.

The problem for people with disabilities is that they are never going to get well. A wheelchair user, a blind person, a person with a seizure disorder will always use that wheelchair, be blind, or have seizures. That fact is very frustrating to the professional whose career, and maybe very life, is focused upon healing, helping people get well.

It is also very frustrating to persons with disabilities because they are not allowed to leave the "sick" role. They will always be exempt from social obligations. They will never have rights. They will always be dependent on others regardless of their need.

However, people with disabilities should not be viewed as being in the "sick" role. Disability is not a health issue. It is not a medical question. Disability is a policy issue--a political question. A person with a disability is not "sick" because of a disability. That person may be "sick"--with a cold or with a progressive, chronic disease--but being disabled and being "sick" are not the same thing.

The Pessimistic Scenario. The pessimistic scenario is already with us. For example, in the debate over Medicare funding it is said that some 30% of the money is unnecessarily spent on people during the last month of life. These persons, the argument runs, are people who are elderly, who chronically ill, and who are disabled. And as Richard Lamm, formerly governor of Colorado, said, people have a duty to die.

In other words, when a person's quality of life declines, she is considered better off dead. If one can not do it herself, then someone, perhaps a medical doctor, should assist her in ending her life. Furthermore, the ideals of eugenics (which underlies much of American thought disguised as Social Darwinism) requires that the weaklings be eliminated. Persons who can not contribute to society should not continue to live. Nazi Germany epitomized this type of thinking. Genetic engineering is coming close to this view.

According to Carlson (1996), for over thirty years Western medicine has encouraged the abortion of fetuses with birth defects. An indication of Down Syndrome results in far more abortions than would be expected, even though Down Syndrome is not terminal and although it can not be proven that a baby with Down Syndrome has a life not worth living. Various studies show that around 90% of women carrying a fetus with Down Syndrome opt for abortion. Many of these women say that they were pressured into the abortion. At the same time many physicians favor starving a Down Syndrome baby to death or refusing them simple, lifesaving surgery.

Jack Kevorkian is a representative of the position that certain people should not continue to live. Kevorkian, according to Longmore (1996), sees people with disabilities as having useless lives and as a burden to society. In August 1990, Kevorkian said to a court in Michigan: "The voluntary self-elimination of...mortally diseased and crippled lives taken collectively can only enhance the preservation of public health and welfare" (Quoted in Longmore 1996).

Kevorkian favors giving medical doctors the power to decide whether a person with a disability should die. The only deciding factor is the quality life of that person. Every day people with disabilities in hospitals have their life support systems removed or do not receive treatment that they would receive were they not disabled.

Kemp, Funk, & Colgrove (1996) point to a recent study of physician assisted "suicide" in the Netherlands where it is legal for a medical doctor to assist with the consent of the dying person. However, the report shows, that in 1990 a thousand people were killed without their consent and without their knowledge.

The widespread use of "do not resuscitate" (DNR) orders is the beginning. Most persons who enter a hospital are encouraged to sign a DNR order. People with disabilities are actively encouraged to do so. If they refuse to sign one, they are harassed and even denied admittance to the hospital (Kemp, Funk, and Colgrove, 1996). Some of the worst stereotypes about the quality of life of persons with disabilities are found among medical professionals. For example, many medical professionals cannot imagine that a person with a disability (especially a severe one) could lead a satisfying life. A happy, optimistic person with a disability is praised for her courage when, in reality, that person is really happy and optimistic. Of course, a person with a disability

would like to see life changes made, but so would a person without a disability. Many medical professionals transfer their frustration with not being able to "cure" a person with a disability onto that person and infer that her quality of life is so poor that she would gladly end her existence.

In this scenario, society will be systematically cleansed of anyone who might be or even might become a "burden" or a "cost" to society. If people with disabilities are seen as burdens, are treated as worse than second class citizens, and are kept in the "sick" role, this scenario will be realized. In this scenario people with disabilities will not be born, will be left to die after birth, will not receive treatment that would otherwise save their lives, will be encouraged to commit suicide, and will, to be blunt, be murdered when it is determined that their quality of life is too low.

The Optimistic Scenario. In the optimistic scenario disability is viewed as a policy issue. That is, disability is something which can be changed by the policy system, the political system. The political system is what produces policy and policy is what defines disability. For example, eligibility for certain services related to disability is defined by a policy. In 1961 the American Association on Mental Deficiency established a definition of the label "mental retardation." In 1973 they changed the definition and automatically some 13% of the population which had been labeled "mentally retarded" no longer fit the definition.

The same thing happened in Great Britain when a new definition of physical disability made a million persons with a physical disability no longer physically disabled. The way in which questions are asked in the United States Census screens out about half of the population of persons with disabilities. And vocational rehabilitation, at one time, defined a person with a disability as having an impairment which meant the person was unemployed. I could never figure out why I was not considered disabled simply because I had a job.

Laws (which are policy statements) do not necessarily change attitudes, but they can change behavior. Laws such as the Americans with Disabilities Act, the Air Carriers Access Act, and the Individuals with Disabilities Education Act are changing behavior toward people with disabilities. As we leave the margins of society and become involved in the decision making processes, we become less stigmatized. Over the last thirty years there has been a marked change in the way in which people with disabilities are treated. As businesses begin to view us as potential customers, changes occur.

Actually, as a result of the Americans with Disabilities Act, changes in physical and sensory barriers resulted. When we could enter into stores--jewelry stores, grocery stores, book stores, liquor stores--then we were seen as customers. Being viewed as customers caused changes in still existing barriers including attitudinal barriers. A similar thing happened when we became coworkers and even supervisors of non-disabled people. And as a taxpaying citizen I have a right to be able to enter government offices and conduct my business there.

In the optimistic scenario, there is a radical change in the way that disability is viewed. Disability is a normal part of life and is not a stigma. Everyone will, some day, become a person with a disability. Some people will be disabled only briefly just before death from something like a heart attack. However, most people will spend a considerable time as a person with a disability. And it can happen very quickly and at any age.

Disability does not exist, however, in the optimistic scenario. It is seen as a normal part of life. The only time disability does exist is when there is discrimination based on what we now define as disability. Physical, sensory, and attitudinal barriers will disappear in the optimistic scenario.

There will still be discrimination because people are human and finite. Someone will dislike another person because of his/her actions or statements. But there will not be a public policy which mandates or permits discrimination on the basis of a disability.

Conclusion. If we continue to keep people with disabilities in the "sick" role and stigmatized, we will eventually have a cleansing of the race. That is the pessimistic scenario. If the concept of disability does

disappear, we will have a better society. That is the optimistic scenario.

Which scenario will come into existence? Both of them now exist in our society. There are places and times when, to me, disability does not exist. There are other ugly times when my stigma is thrust into my face.

The disability movement has achieved some policy change. We have also achieved considerable barrier removal and attitude change. We have done these things through foresight, planning, and decision making involving as many persons as possible. As Jim Dator wrote: "Foresight must also and necessarily be a political, ethical, esthetic and very broadly participative project" (1993:7). This description typifies the advocacy of the disability movement. Without using the name, we have been futures researchers. We now reach out to everyone to join with us to ensure that the optimistic scenario is the future.

### Acknowledgments

This paper was made possible by support from the Sawyer School of Management at Suffolk University and the Center for Disability Studies at the University of Hawai'i at Manoa. The opinions expressed are those of the author. The paper is based on a 19 July 1996 presentation at the Hawaii Research Center for Futures Studies. The author expresses his warm thanks to Robin Brandt, Vincent Pollard, and Nancy Robinson for their encouragement and support.

### References

Carlson, Tucker. 1996. "Eugenics, American Style: The Abortion of Down Syndrome Babies." *Weekly Standard*. 20-25. 2 December.

Dator, Jim. 1993. *Futures Studies and Sustainable Community Development*. *Manoa Journal of Fried and Half-Fried Ideas (about the future...)*. 1: 1-11. August.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, New Jersey: Prentice-Hall.

Kemp, Evan J. Jr., Robert J. Funk, and Ann Colgrove. 1996. E-mail communication. 12 November.

Longmore, Paul. 1996. Private e-mail communication to David Pfeiffer. 8 September.

Parsons, Talcott. 1951. *The Social System*. New York: The Free Press.

[Home](#) | [Back to Contents](#)