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Disability Studies and the Disability Perspective

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Abstract

At a meeting of Society for Disability Studies Anthony Bale presented a paper in which he called for a statement of the perspective of the disability community. He observed that most members of the Society for Disability Studies use the terms "disability studies" and "disability" in commonly accepted ways. However, as Bale observed, there is no commonly accepted view of the disability perspective. In response to Bale's call this paper presents the disability perspective. It is based upon the phenomenon of being a survivor with the empathy, gentleness, and understanding which comes out of that experience. From that understanding comes a sense of justice, or rather injustice, about society. This moral imperative leads to the investigation of how to change society and why society treats its marginalized members in such a frustrating and deathly way. The paper concludes with reflections upon how to open society up to disabled (and non-disabled) persons.

Keywords: inclusion, disability studies, disability perspective

A number of scholars in the field of disability studies over the last two decades have written about the field and its foundation. For example, Zola (1982a, 1982b), Pfeiffer and Schein (1987), Pfeiffer (1993, 2000), and the National Institute on Disability and Rehabilitation Research under the leadership of Katherine Seelman (U.S. Department of Education, 2000) all discussed the foundation and the paradigm of disability studies. DeJong (1983) discussed the basis of the independent living movement and Albrecht (1992) wrote about the disability business. All of them were insightful discussions.

Still today there is an ongoing effort in the field of disability studies to refine the disability paradigm (Pfeiffer, 2001), but the broad outlines are agreed upon. As Bale (1988) pointed out some years ago, scholars in the field are interpreting or reinterpreting phenomena from the perspective of the person with a disability.

Bale (1988) said that previous work on workers' compensation laws was done from the perspective of explaining the growth of the welfare state, from the perspective of jurisprudence explaining the appearance of new law, or from the perspective of political theory presenting an understanding of the political system. He, however, viewed the workers' compensation laws from the role of the disabled worker who played an important and decisive role in the creation and growth of these programs. As he wrote (Bale, 1988: 7), the passage of workers' compensation laws "...can be seen as a pioneering attempt by disabled Americans to identify some of the social sources of their disability and seek money and justice in the courts."

Yet, according to Bale, there was something missing from the discussions of disability studies and he was correct. No where was there nor is there even now a statement of the disability perspective. What makes the approach of disability studies unique and different from other fields is the paradigm used, but that is only part of it. There is also the perspective which comes out of that paradigm. More accurately, it comes out of the experience of being a person with a disability. The paradigm is only the first formal statement of that experience in a way which distinguishes disability studies from other fields. It is incumbent upon scholars in the field to set forth the disability perspective.

The key element of the disability perspective is that the person with a disability is a survivor. The experience of being disabled - whether at birth, as a young person, after becoming an adult, or as an older person - is one which matures and gives a unique viewpoint upon society and the world. (Murphy, 1987, 1989) It is similar to the experience of being initiated into adulthood found in many cultures. It is similar to having survived boot camp, having survived combat, having survived doctoral training, having survived medical or law school, having survived the first several years of a new job, having survived the experience of giving birth, having survived living as a minority in a bigoted society, and having survived the tenure process.

Some persons in our society avoid all of these and similar experiences and are the worse for it. Some persons undergo too many of these experiences. But the successful negotiating of one or more of these experiences makes us more humane in our treatment of others and more understanding of our environment. It makes us more of a human being.

Not everyone successfully negotiates these experiences and not everyone survives (literally as well as figuratively) these experiences. We all know many people who have failed. In fact, all of us have failed at least once and I would guess many, many times. The survivor perspective is only the beginning.

Some people who survive these experiences are able to live out their lives in an advantaged position. One of the unique things about the disability experience (as well as some of the other experiences) is that survival does not guarantee any advantage other than the maturity mentioned earlier. Part of this maturity - perhaps the mark of it - is an empathy with other disadvantaged people. There is a considerable overlap among disabled people and other disadvantaged people.

It is not accidental that women and racial minorities seem to be over represented in the disability community. It is not accidental that persons who are in the lower socio-economic strata are over represented in the disability community. It is not accidental that the powerless and the oppressed are found in the disability community. (Pfeiffer, 1989)

This empathy with other disadvantaged people produces in the disabled person a gentleness toward others who are also struggling. Other disabled people, children, women, minorities, gays and lesbians, other disadvantaged persons, and even non-disabled persons who are struggling to understand the disability experience - all of these people are treated with a gentleness, an understanding, and a respect by people with disabilities. They are struggling and we are struggling. There is no need to do violence to them. That fact is a very important part of the disability perspective.

This empathy and gentleness produce a sense of justice, a yearning for justice. When uncaring and unfeeling people are encountered who act inappropriately and violate our rights, we become angry. We quickly learn that not everyone has this empathy and gentleness about the disadvantaged of the world. We then demand justice and soon learn that it is usually absent. Perhaps I should say that we develop a sense of injustice, but without a sense of justice we could never understand injustice.

This sense of justice (or injustice) makes us question why it can happen. Our experiences make us want to understand how people function as people. It makes us question everything. In order to cope with our disability we had to understand how people think and act. We now have to understand how systems function - political, social, economic, and physical systems. Using "society" as a term which encompasses all of those systems, we come to understand how society works (and does not work). Our experiences, our struggles as individuals with disabilities contribute directly to this understanding.

These struggles lead to wanting what is "right," but what is "right"? What moral code or set of ethical principles should guide individuals much less guide society? At this point the person with a disability comes to realize that there are numerous codes by which people say they make decisions. These codes are conflicting and people are not consistent in following codes even if the person insists that he or she is being consistent. There are a variety of ways of understanding the same event or thing. There are also numerous ways of decision making. And we come to realize that two persons with the same facts, the same moral code, and the same way of making decisions can come out with different conclusions, different decisions, different courses of action. Dealing with the same facts, code, and decision making processes does help in discussing the alternative outcomes, however. All of this is part of the disability perspective.

When society is viewed from the disability perspective, a peculiar thing about the US society appears. (It is not limited to the US society, however.) It is seen that the received wisdom and the official viewpoint in society is a dualistic epistemology and ontology. People are told that and are taught that the world is composed of material and non-material levels and that there are facts (material world) and values (non-material) world. This dichotomy of facts and values results in producing persons who "know" what is right by virtue of position, power, wealth, birth, study, or experience.

Again and again in history out of this dualistic epistemology and ontology came an authoritarian, paternalistic ethic which produced: the medical model for disabled people; Nazi euthanasia for disabled people (as well as death for Jews, Gypsies, Slavs, and others); quality of life decisions which led to the death of at least 24 children born with spina bifida in Oklahoma between 1997 and 1982 and denied medical care (Gross, Cox, Tatyrek, Pollay, and Barnes, 1983; Gerry, 1985); imprisonment in institutions for persons once labelled feeble minded and now labelled mentally retarded, mentally ill, or behavior problems (Pfeiffer, 1994); segregation for persons with disabilities and others in public school systems; and ultimately death - social, psychological, and physical - for persons with disabilities. This ethic also supports people who are advantaged, who have the power and the position in society. All of this knowledge is part of the disability perspective.

At this point many people with disabilities become very angry and they lash out at everything and everyone around them. Such expressed anger confirms the judgment of non-disabled people that persons with disabilities are not able to take care of themselves. Other persons with disabilities become depressed at the futility which they see in the struggle to overcome the restrictions, the discrimination of society. Other persons with disabilities become quite cynical that any change will every occur. Of course, all people with disabilities do all three of these things and often at the same time. Again, such action confirms the prejudices of non-disabled people, but this anger, depression, and cynicism are part of the disability perspective.

The empathy, the gentleness, the understanding, and the resulting anger, depression, and cynicism all comprise the disability perspective. Having survived the experience of being disabled, however, gives an impetus to try to persuade society that the world as they see it and live it (their values, their actions) means death for all persons. It means that individually and collectively people are slowly, but certainly, facing quick death. And death is the one thing which society fears most next to becoming disabled.

Yet the knowledge which individuals with disabilities gain through their experience gives a way to survive. Knowing how society works and with a clear philosophical understanding, they come to see a way to change society. Through laws and policies with a well functioning legal system strongly supported by political action society can be changed.

If society can be changed and opened up for people with disabilities, it can be opened for everyone. The struggle must continue. We must not fail. We must never surrender.

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