Disability Studies and the Future of SDS

Adrienne Asch

In what follows, I've tried to raise some of what seem to me to be valuable intellectual, political, and organizational questions plaguing our field, our movement, and our organization. Although the questions are broad, and my appreciation for diverse fields and approaches is genuine, I'm sure I've left out critical perspectives that to others are the heart of their version of disability studies. As I reread what I've written, I also know that I haven't neatly separated the intellectual from the political questions for the field and the movement of which it is a part, and to which it contributes.

What, if anything, is essential to life with disability? If there ever were to be a society that genuinely included and valued the uniqueness and potential of all its members, how would having a disability differ from not having one? What would a society look like that succeeded in fostering the capacities of everyone and that wanted everyone to feel as though she or he belonged, was appreciated, had something to contribute to communal life?

Disability has often been construed by the medical model as the inevitable reason why people cannot have all the life experiences as the nondisabled. The social model puts the society, the environment, as the explanation for any differences in life experiences. How "different" are these life experiences, and what accounts for them? Are they, or do they need to be, "different" in any way that is more significant than any other difference occasioned by human variation? Why do human beings appear to construe something like the absence of eyesight, or atypical cognitive functioning, as of far more significance than whether someone's eyes are blue or green, or whether some people prefer studying science and others like art?

These are some of the key questions behind my interest in disability studies. They have been integral to the courses I have taught on disability since 1982, to the writing I have done, to my interest in this field. Understanding disability, like understanding most other interesting topics, requires using multiple perspectives, drawing from as many ways of thinking as possible. Thus, I want to study the phenomenon of disability using literature and the arts, social and behavioral sciences, natural science, law, medicine, public policy, and other professions. What have different fields said about disability? What are the values and assumptions in their fields and professions that now keep people with disabilities marginal, and how do such values and assumptions need to change? How do disciplines and professions need to change to encompass the disability experience, and is there "a disability experience", or many experiences that still have enough in common to make for a field, a political bloc, a social movement, an intellectual claim? Let's not forget what a revolution feminism has caused in the academy, and let's revive many of the wonderful theoretical and research questions posed in books like Gliedman and Roth's *The Unexpected Minority* (to take just one example). Are the changes that will improve life for people with disabilities the same sorts of changes needed by all the other people now disenfranchised by virtue of race or ethnicity, sex, sexual orientation, or age? Are they changes that will benefit everyone, regardless of ability, or will some changes that might aid the disabled population in any way be likely to hurt the nondisabled majority?

Some of these questions are particular to the lives of people with disabilities in the United States at the end of the twentieth century, but some might apply in other countries, other cultures, at other times. Which questions persist and which ones disappear is also a topic of interest and study, because even that question is a way into understanding what about disability differs from not having one.

I want a field of disability studies that encompasses everyone we now describe as disabled and asks, among other things, what is the interaction of physiology and environment now, what could it be to permit a rich and full life? We in SDS know a lot that is wrong with the medical model, a lot that is right about the social model, for answering some of these questions. I would submit, though, that as a political movement and as an intellectual discipline, we haven't done the hard work to encompass a lot of people the ADA considers "disabled", and we must.

What is the environment people with autism, multiple chemical sensitivity, Down syndrome, or schizophrenia need in order to function, and does figuring out that set of questions force us to broaden, refine, make much more detailed our social model? How do we incorporate concerns about public health, about maintaining capacity through health and social services, and prevention of secondary disability activities into a scholarship and politics infused with the social model?

Such questions have inherent in them my constant interest in topics like ethics, like what is a "rich and full life", like what is equality, how are social, moral, and legal equality achieved without expecting sameness. Some of this set of questions is fueled by my work in bioethics, but I would say that the questions more accurately represent a quest we are all on, of how to achieve a satisfying social, personal, communal life.

To the extent that the characteristic of disability influences how people with disabilities construct their lives, how others influence (for good or ill) those constructions, why some people flourish and others do not when affected by their own or another's disability, why for some people disability becomes a major point of identity and for others it does not, all of these fall under my understanding of "disability studies." Inherent in the questions is a vision of disability studies that encompasses social change.

To me, having our organization carry the initials of SDS (reminiscent of the 1960's Students for a Democratic Society) is a point of pleasure and pride, because I want an organization with a commitment to making the world better for people with disabilities. My continuing rejection of identity politics, though, commits me to the socialism of the New Left, of the original SDS, to the fantasy of the utopia of the Israeli kibbutz. That surely is not everyone's vision of a good society, and plenty of us in our organization who would agree that social change must take place for people with disabilities to live good lives would nonetheless articulate different versions of utopia than the ones I carry in my head. That makes for fascinating discussion, and to me it shows that understanding the present past, and envisioning the better future for disabled people involves us in all the philosophical, political, psychological controversies that make academic and political life interesting and worthwhile.

We can and should learn from those who have studied and fought to improve the lives of people in power, and of others who are powerless. I would hope as a field, and as an organization, we could avoid some of the strife and frictions of factions that destroyed the New Left, that have made life unpleasant for people in women's studies, race/ethnic studies, and lately, gay and lesbian studies. Perhaps we can't avoid some of these tensions, but if the field, and the organization, is to take a broad, complex view of disability, it needs perceptions of all kinds of people with all kinds of experiences, intellectual tools, and political aims.

I want a disability studies that keeps the dream in mind of a better world, but looks hard and unflinchingly at the world we inhabit. I want an organization that looks at all disability experience, whether the disability is from birth or occurred two weeks ago; whether it is cognitive, physical, immediately apparent to an observer or not readily manifest; static or progressive, perceived by the person who has it, or imagined only by others.

My dream for our SDS, then, is one of an organization committed to studying the past and the present, as a guide to shaping the future. We have things to learn from professions as different as rehabilitation and law, from disciplines like body criticism and technology studies, economics, geography; from activists with disabilities, nondisabled friends, family, and allies.

We have much to decide as an organization for the short-term and long-term future: how to train new scholars; what kind of scholarship we most wish to encourage; how to best infuse our ideas into mainstream courses, academic programs, departments; how to change what is taught to future educators, health professionals, how to convince all sorts of professional schools and academic disciplines that they have things to learn from us.

Part of our time during the retreat at which we will look at these statements must include how our organization can become an increasingly important force in the future of our field. Do we need a new journal, or are there enough outlets for our work? Should we try to interest a publisher in a book series, or are our scholars finding places for their work? Where should we tell undergraduates to study, and how can we work together throughout the year, even if we are the only ones doing this work in our colleges and universities? And not all of us are in the academy, and how do we use the insights of policy-makers, activists, researchers in disability organizations or service agencies?

I want to end this rather question-filled "statement" with a story that captures something important for me, and that may be useful in our discussion. Before I ever came to study disability, I was an activist, and I have continued my commitments to such activism. One day, when talking with the leader of one of the activist groups to which I belonged, I asked what would happen if we found out, in carefully executed, methodologically unimpeachable studies that blind people took longer to exit airplanes than people who were not blind. "I would suppress the information, " he said.

Now, you can quarrel with the topic, or the answer, but my point is not that the topic may seem trivial, or that the answer smacks of censorship. My point is the following: I view the disability rights movement as putting forth a view of our moral equality and human worth that is not in any way contingent on obliterating differences between people with and without disabilities. The intellectual and political question is what do differences mean, and what, if anything, do we want to do about differences. My other point is this: our quest for social change, societal participation, a way to belong and to be valued must not be a quest that fears any truth we can learn by examining our experience. Our movement may inspire some of what we study, but it must never fear what we may learn by study.

To bring this discussion to life and death, and to my current work: I spend a lot of time contending that people who use prenatal testing and abortion to avoid raising children who would have disabilities might not do so if they knew that disability would not ruin their lives, or their children's lives. There is plenty of research to support the claim I make, but that claim is not unambiguous. It is a claim that must acknowledge difficulties for parents and children, many caused by society, some caused by physical pain, medical treatments, and the ineradicable biologic differences occasioned by disability.

We need the best research we can have about what permits some children and families to thrive, and what about living with disability proves crushing for others. We need to base our claim to equal worth and validity and humanity on something that does not depend on whether our lives are more or less of anything than anyone else's. If there is ever research that shows us things that make us sad, we must learn to use that research and not avoid it. I want study to help us; I don't want our politics to make us avoid learning something. It's why I'm now committed to academia, as a way of learning what I can to make things better for people.

Adrienne Asch, Ph.D., is a professor at Wellesley College.