

Some Reflections for the SDS Retreat

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I am speaking mainly from the perspective of a trainer, program developer and activist working in non-academic settings. Much of the work that I do involves education and training groups who have limited knowledge of disability issues to include people with disabilities and the disability perspective in their programs, policies and practices; these are mainly nonprofit groups in the human services. For me, the field of disability studies has helped make the case for inclusion. Not only it helped reinforce the paradigm shift of disability as defect, deficit and health issue to disability as a civil rights issue, as initially emphasized by the disability rights movement, but it has helped shift the paradigm considerably further to disability as an asset and a source of rich culture. As the result of disability studies, I now argue that people with disabilities and disability issues should be included not only because it is morally and legally right and required, but also because it benefits all, nondisabled and disabled.

For personal and professional as well as political reasons, I would like to see disability studies gain much greater public recognition and influence more fields and disciplines. Most people in the non-academic world have at least heard of African American Studies, Women's Studies, and, to a lesser degree, Queer Studies. Far fewer lay people - and academics as well - are familiar with Disability Studies. There is need for a fuller public education and public relations campaign, with many concrete examples of how the disability studies perspective enhances learning and our understanding of the world, and how the disability experience is an aspect of diversity and multiculturalism. Related to this is the need for greater clarification of the definition of what disability studies is and is not, in terminology that is readily comprehensible to non-academics as well as academics. There seem to be many definitions of disability studies floating around that leave too much room for misunderstanding.

In addition, I would like to see a more clearly defined link between disability studies and disability rights/activism. At times the relationship seems muddy and has a quality of competition rather than collaboration. I do not think one can exist without the other. This may be my bias, but I feel particularly concerned about disability studies existing in an academic setting without an activist stance. Related to this, I think there is need for further discussion and clarification, as difficult as these are, about the roles and relationships of people with and without disabilities in the development and evolution of disability studies. There is need for a safe environment to conduct this discussion in an ongoing way. In doing so, it would be useful to draw upon the experiences and expertise of African-American, women's and other "studies;" this issue is not unique to disability studies.

I see SDS taking an active role in addressing many of the needs I have described above. To do that, SDS may need to go through its own evolution. As a relative newcomer, my perception is that much of SDS's focus until now has been on putting together the annual conference and, to a lesser extent, on producing the conference proceedings and DSQ. Such focus, as well as the relative small size of the membership, has enabled SDS to work in a relatively informal, quasi-familial way. Such informality has been a source of considerable pleasure and comfort to me, facilitating my own participation and learning so I hesitate to question it. But I suspect that should SDS decide to take on more and broader tasks, it will need to expand its group of active workers and formalize its ways of working. I think SDS can and should take a leadership role in defining disability studies; in promoting its inclusion in more disciplines, more academic institutions, and more academic societies; in examining and clarifying the roles of people with and without disabilities in disability studies; in clarifying the relationship between disability studies and disability rights; and in educating the larger public about disability studies and its contributions to society as a whole. The challenge will be to create an organizational structure that will facilitate the achievement of such extensive work while still creating a welcoming home for its membership.

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