

Disability Research: The Person or the Paradigm?

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When examining bridges between the disability movement and non-disabled persons a question continually arises about the place of the non-disabled person in the movement. What role should a non-disabled activist or researcher have in the movement? As an activist who was the primary organizer of the first cross-disability, state-wide coalition in Massachusetts, a researcher with over 175 publications, a person disabled for the last 56 years since the age of nine, a university professor for 37 years - having taught disability studies courses for the last 14 of them, a past-president of the Society for Disability Studies, and the present editor of this journal (submitting an essay at the invitation of the guest editor), I would like to examine the role of the non-disabled person in the field of disability studies.

As my starting point, I take an essay in the March 19, 1999, issue of *The Chronicle of Higher Education*, by Leonard Cassuto. It is titled "Whose Field Is It, Anyway? Disability Studies in the Academy." Cassuto presents the question of whether being disabled is necessary to be accepted in the field of disability studies. He uses his own experience at the 1998 meeting of the Society for Disability Studies as evidence. Although never stating whether he is or is not a person with a disability, he implies that a non-disabled person is not accepted in the field. In a subsequent issue of *The Chronicle*, several letters were printed responding to Cassuto. These letters either pointed out that the field of disability studies is an attempt to help scholars with disabilities find jobs in academia or else raised an incoherent complaint that exclusion dooms the field to dismal failure.

As in black studies and feminist studies, there is no doubt that being a member of the group being studied makes it easier to be personally accepted by other scholars in the field who are also members of that group. There is nothing unusual about such a situation. But the question goes further than personal acceptance. It relates to the quality or worth of disability research that is carried out by non-disabled persons.

To fully understand this question a person must be aware of the reaction that some people with disabilities have toward non-disabled persons. For most of their lives, or at least since becoming disabled, many people with disabilities are continually being told by non-disabled professionals where they should live, what if any job they should seek, what places they can enter, how they must manage their private lives, and many other things that non-disabled people seldom, if ever, hear. Any question about disability status must be viewed in this light.

Having said this, it must be clearly stated that disability status is not what determines the *quality of the research* in disability studies. This quality is determined by something the commentators never mention: the paradigm underlying the research. If research is based on the medical model, then the work is not very relevant to persons with disabilities and is not of significant worth. If research is based on the disability paradigm, then the research (assuming good methodology) can be of relevance, worth, and interest. Disability studies, in this way, is no different than racial, ethnic, and feminist studies, and it should not be different. And in this way, it is no different than any other academic field; but not everyone perceives it as so.

In his essay Cassuto wrote: "After the members of my panel had all spoken, an audience member lobbed a question at us from the back of the room. 'I noticed,' she said, 'that none of you addressed your own disability status. Would you speak to that?'"

It is curious that Cassuto says that "everyone in the room interpreted" this question to be, "Are you disabled?" In no way can I fathom how he knows this fact. Did he canvass the room? No, it was his interpretation without verification.

He states that one member of the panel "deflected the question with humor." This person

had done research on advocacy groups of people labelled mentally retarded. His humor was that the audience could plainly see that he was not retarded. That retort is a plain example of handicapism which states that being retarded was a bad thing and that he - a professional researcher, probably a holder of a doctorate, probably a college professor - could not be mistaken for those poor bastards he studied.

From personal conversations, I know that Cassuto is not the only person who feels excluded at meetings such as those of the Society for Disability Studies. Both persons without disabilities and persons with non-obvious disabilities have said to me that they feel uncomfortable at these meetings and other meetings. But persons with disabilities who are not academics also feel uncomfortable (or maybe bored) attending panels at the meetings of the Society for Disability Studies.

I have attended meetings of at least ten other academic associations and I have felt excluded, uncomfortable, and bored at most of them. I usually become bored and leave panels at least once each year at the meeting of the Society, but that says nothing about the quality of the work being presented. If the research is of poor quality, I will stay and say so during the question period.

The quality of research in the field of disability studies is judged by its underlying paradigm (is it relevant?) and its methodology (is it sound?). The quality of its presentation depends upon other factors, not all of which are in the control of the presenter (at one of my panels the power failed twice). These factors may influence the presentation's immediate reception and that type of reception may be what Cassuto and others are describing.

Anyone (disabled or not) can produce good quality research in disability studies. The research paradigm and the methodology followed will determine its worth, not the disability or lack of disability of the author. Recognizing that truth and the connection which comes from it between people with and without disabilities in academia may be the most important bridge of all.