

INCLUSIVE RESEARCH AND THE PROBLEMS OF REPRESENTATION

Research Subjects as People

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Having people labeled developmentally disabled involved in research is not new but up until thirty years ago they were included only in the narrowest of ways. In the early history of the field, the times when people with disabilities were called “mentally deficient” or “mentally retarded,” the intellectually slow were objects of research. They were examined, measured, tested, categorized and classified--researchers treated them more like specimens than people. Social scientists did not seek people labeled developmentally disabled’s opinions or try to ascertain their attitudes and perspectives through interviews, questionnaires, or naturalistic observation. They were not approached as human beings with concerns and who had understandings about who they were, how they wanted to be treated, and what they wanted to become. It was as if researchers thought they were too dumb to have agency, a point of view, and not intelligent enough to be enlightening. Because of this, much of the early research reinforced societies views of the developmentally disabled as incompetent rather than challenge negative common sense assumptions.

In the 1960s and into the 1970s qualitative researchers from anthropology and sociology began paying more serious attention to people labeled developmentally disabled. At first these researchers spent time with ex-institutionalized adults trying to understand their experiences as citizens living in the community. Later the researchers branched out to schools, agencies and other places where people labeled developmentally disabled learned, played and lived. Although the contribution of this early research was noteworthy in that it called for us to understand those labeled developmentally disabled as people, the interest in this work was not widespread and some aspects of it reinforced the notions of “them” and “us.” None-the-less this research launched new studies of people with

disabilities that were more inclusive, more respectful of the subjects as having a point of view. This more inclusive form of study went along nicely with ideological changes in human service professions going on at the time and captured by such ideas as “empowerment,” “mainstreaming,” “integration” and “inclusion.”

In the last decade, sparked by more general happenings in the social sciences (the post-structural and critical theory critiques) and by disability self-advocacy movements, even this more inclusive form of research has been criticized. Some hold that people without disabilities can never truly understand those labeled disabled and should not claim to or attempt to. The concern has not been just with the accuracy of the findings. The political implications of research are at issue as well. Questions have been raised about whose interests are served by research? Does social science research promote positive social change? Some suggest that researchers should not speak for people labeled disabled; people labeled disabled should speak for themselves. While not all researchers have been moved by these concerns, some have employed research strategies to have people labeled developmental disabilities as research partners or even as co-researchers. Many social science researchers have become sensitive to issues surrounding the negative depiction of people with disabilities in the literature and have dedicated themselves to the promotion of a more positive view.

This issue of the *Scandinavian Journal of Disability Research* is devoted to exploring the theoretical, methodological and ethical issues involved in studying people labeled developmentally disabled. All the authors are concerned with including people labeled developmentally disabled in research in a more positive and inclusive way.

Traustadottir’s contribution, “Doing Research with Others,” is the author’s reflection on studying women from three different groups that are marginalized in Iceland: lesbians, immigrants and woman labeled developmentally disabled. Approaching the methodological and ethical challenges from a feminist perspective she provides both theoretical insight and practical strategies for managing the imbalance of power between the researcher and the researched. By not just focusing on people labeled “disabled” she makes an important contribution in expanding the discussion to more general implications of researchers responsibilities to their subjects as well as the relationship between different forms of oppression. Traustadottir takes an activist position in regard to research. She is not only interested in understanding her subject’s point of view, she is dedicated to having research be instrumental in directly improving their condition.

Professor Gustavsson is not new to the problems of including people labeled developmentally disabled in research. His on-going work of listening to the personal experiences of young people who are labeled developmentally disabled and who grew up in Sweden during a period of progressive social policy is the bases of his important contribution to the literature. In the paper included here he advocates for including the personal stories of developmentally disabled people in research but cautions us to live up to the responsibilities all social scientists have, to provide an in-depth analysis of the historical and socio-cultural conditions that underlie personal experiences. In other words, giving voice may be a legitimate aspect of research but, according to Gustavsson, the social scientists job is broader than that. Researchers need to present the insider's perspective in such a way as to provide the consumer of research with a more conceptual rendering of the situation.

Taking a position similar of Gustavsson only arriving at it somewhat differently, Professor Calvez's is concerned with the degree to which the researcher has to be close to his or her subject, or be like his or her subject, to come up with valid findings. He argues that insiders do not necessarily have better insight about their situation unless they provide theoretical frames and integrate findings into sociological understandings. He also advocates researchers being more reflective in their research encounters so that they can confront their own preconceived notions and prejudices. These reflections need to be full and through to display the circumstances surrounding the collection of first person material and its analysis.

In their paper, Lyn Harrison, Kelley Johnson, Lynne Hillier and Ria Strong offer the kind of reflection that Calvez calls for as they examine a research project they were involved in, an action research study with people with intellectual disabilities around the topic of sexuality. They look at what the literature states to be the basic characteristics of action research and discusses their own work in relation to the criteria. An interesting dimension to their work is the inclusion of the participants in the project labeled developmentally disabled commenting on her involvement in the project. The title of this paper "Nothing about us without us," a phrase taken from the developmentally disability self-advocacy movement indicates the authors sentiments. The article documents the difficulties in putting the sentiments into action in the world of the world of research and practice.

Diane and Phil Ferguson's paper provides a sophisticated integration of theory; methods and empirical research to address basic questions about culture and the place of people with severe cognitive disabilities in it. The research subject is Ian, the Ferguson's adult son who has been labeled severely developmentally disabled.

The paper is not a traditional research report but the insights it provides are the product of in-depth observations and reflections on the Ferguson's and other people's relationship to their son. The paper is an effort for them to discover what adulthood, and the self-determination that comes with it, might mean for Ian in a society that has many barriers to thinking through the breath of the issue.

The topic of this issue of the journal and the author's contributions are a very positive sign of progress in the study of developmental disabilities. We are cautioned to be reflective, to be sure we are listening to the subjects in a way that leads to understanding ourselves, to be sensitive to the political implications of our research, and work toward a form of research that contributes constructively to better life for our subjects. To write is to take a stand about how you see the world, the subject matter, and the people you choose to write about. All writers, not just social scientists, need to be reflective and thoughtful but that needs to be balanced with courage to take a stand knowing you might get it wrong. Although we need to be careful when our subjects are vulnerable, to be too careful is to risk paternalism. People labeled disabled should have the same right to be included in research as everyone else. We have a tendency to think that being a research subject is bad or dangerous. We forget the other side. That being a research subject can be something positive, a hallmark of personhood in a postmodern world.

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