Ethical Dilemmas in Participatory Action Research: A Case Study from the Disability Community
Meredith Minkler, Pamela Fadem, Martha Perry, Klaus Blum, Leroy Moore and Judith Rogers
Health Educ Behav 2002; 29; 14
DOI: 10.1177/109019810202900104

The online version of this article can be found at:
http://heb.sagepub.com/cgi/content/abstract/29/1/14

Published by:
SAGE
http://www.sagepublications.com

On behalf of:
Society for Public Health Education

Additional services and information for Health Education & Behavior can be found at:

Email Alerts: http://heb.sagepub.com/cgi/alerts
Subscriptions: http://heb.sagepub.com/subscriptions
Reprints: http://www.sagepub.com/journalsReprints.nav
Permissions: http://www.sagepub.com/journalsPermissions.nav
Citations http://heb.sagepub.com/cgi/content/refs/29/1/14
Ethical Dilemmas in Participatory Action Research: A Case Study From the Disability Community

Meredith Minkler, DrPH
Pamela Fadem, MPH
Martha Perry, BA, RN
Klaus Blum, BA
Leroy Moore
Judith Rogers, OT

Participatory action research (PAR) is a collaborative approach to inquiry for education and social change that is gaining increasing prominence in health education. This case study explores the use of PAR by and with a community of people with disabilities in addressing a polarizing issue in that community: death with dignity or physician-assisted suicide legislation. Following a brief review of the debate within the community about this issue and the goals, methods, and findings of this project, the authors examine four key ethical challenges. These are dilemmas in issue selection when the community is deeply divided over a problem area, inclusion and exclusion in study team makeup and sample selection, insider/outsider issues, and how best to use findings in ways that can unite and strengthen the community. The implications of these issues for health educators and others engaged in community-based PAR efforts are presented.

Public health educators engaged in community practice increasingly are turning to participatory action research (PAR) as an approach to working collaboratively with communities in studying and acting on complex health and social problems. Defined as “systematic inquiry, with the collaboration of those affected by the issue, for the purposes of education or effecting social change,” PAR is committed to blurring the lines between...
the “researchers” and the “researched” and the “strengthening of people’s awareness of their own capabilities” as researchers and agents of change. As such, it complements public health’s historic roots in concerns for social justice and health education’s commitment to the empowerment of people and communities through strengths-based practice.

PAR is particularly well suited to addressing controversial issues because of its emphasis on dialogue and participation, and its commitment to education and social change as part of the research process. In this article, we examine the use of PAR as an approach to addressing a particularly contentious topic in the community of people with disabilities: death with dignity, or physician-assisted suicide legislation. We begin with some background on the debate within the community about this issue and then describe the genesis, goals, methods, and results of this PAR project. The second half of the article then is devoted to an examination of four of the key ethical dilemmas that emerged in the course of the project and that have relevance for health educators and others engaged in community-based PAR efforts. These dilemmas were questions about issue selection when “the community” is deeply divided over a problem area; inclusion and exclusion in both university research team makeup and sample selection; issues of power and misunderstanding related to the insider and/or outsider status of team members; and how best to use findings in ways that can unite and strengthen, rather than weaken, the community.

Despite the ethical challenges faced, PAR was found to be an empowering research approach, building individual and community capacity in the process of the study and helping to increase dialogue both within and beyond the community. The article concludes with implications for health educators, including the utility of PAR as an approach to collaborative study, education, and community building in controversial health-related areas.

BACKGROUND

Although not a topic with which health educators typically engage at a professional level, death-with-dignity legislation is becoming an increasingly important health policy issue in the face of dramatic improvements in the biotechnology of life extension and the aging of populations. Health educators in hospital and managed-care settings, as well as those working with vulnerable communities that may have real and understandable fears concerning end-of-life choices and legislation affecting such choices, should become more conversant with this growing policy challenge.

To date, only the state of Oregon has passed a Death With Dignity Act. The Oregon act (permitting doctors to prescribe a lethal dose of barbiturates to a terminally ill patient, provided a series of conditions and guidelines have been met), although passed by voters in 1994, was followed by a series of legal challenges and did not go into effect until 1997. By the end of the year 2000, 70 people had used their prescriptions to end their own lives. Their average age was 70, and almost three-fourths had terminal cancer. Fully 81% were receiving both hospice care and pain control.

California, Washington, and most recently Maine (2000) have all considered and rejected ballot measures that would have legalized death with dignity (DWD) or physician-assisted suicide (PAS) legislation, and there has been fierce public debate about the issue in both Michigan and New York. Two 1997 U.S. Supreme Court cases firmly returned the

* According to the Oregon law, patients must ask twice for the assistance, with 2 weeks in between; they must be 18 or older, be terminally ill, and must not be clinically depressed. Finally, the patient must be able to self-administer the medication once it is prescribed.
debate about PAS from the federal courts to the individual states, and Alaska is currently awaiting a state supreme court decision in a pending case. However, although DWD or PAS has been a deeply divisive issue in the United States, it has a particular history of polarization in the community of people with disabilities. The organized disability rights community has historically taken a strong stand against such legislation, including mobilizing to defeat California’s proposed Death With Dignity Act (Assembly Bill 1592) in 1999-2000 and vigorously opposing Oregon’s Death With Dignity Act. Indeed, all of the leading disability institutions, including the World Institute on Disability, the National Council on Disability, and the American Association on Disability, as well as the issue-specific and widely publicized groups Not Dead Yet and ADAPT, have official positions opposing DWD or PAS legislation.

This opposition is based on recognition of the marginalized status of people with disabilities as a vulnerable population in our society due to well-documented historical and continuing stigmatization and discrimination. Although the Americans With Disabilities Act, signed into law in 1990, was designed to eliminate discrimination in employment and other arenas, there is still substantial work to be done in overcoming both attitudinal and structural barriers. Within this context, legislation permitting DWD or PAS is seen as inevitably leading down a slippery slope to denial of fair and equitable life choices and unwanted and unnecessary deaths among people who are disabled, poor, elderly, and otherwise vulnerable.

Although a strong position opposing DWD/PAS legislation frequently is put forward as representing the views and interests of “the disability community,” this issue, in reality, has engendered deeply polarized positions within disability policy, advocacy, and community arenas. Concern has been expressed, moreover, that fear of criticism among people with disabilities who fail to support the stated “community position” on such legislation may have led to a stifling of open discussion within the community. A 1999 survey conducted by New Mobility magazine, for example, resulted in a huge volume of responses, with 37% of those who favored the legislation also reporting fear of censure from their own community if they voiced such opinions. This lack of open dialogue may potentially contribute to the exclusion of disability community representation in state-wide and national policy development bodies.

The project described in this article was undertaken in the San Francisco Bay Area in 1999-2000 following receipt of approval from the University of California, Berkeley’s Committee for the Protection of Human Subjects. As noted above, the study was designed to uncover the attitudes of people with disabilities toward DWD/PAS legislation, toward the end of helping to depolarize the discussion within the disabled community. By finding common ground, the project team further hoped to help better position the community to become active participants in the ongoing legislative and policy debate on PAS.

ADHERENCE TO PAR PRINCIPLES IN STUDY METHODOLOGY

PAR is characterized by several major criteria. As summarized by Israel and her colleagues:

1. It is participatory.
2. It is cooperative [engaging community members and researchers in a joint process in which both contribute equally].
3. It is a colearning process.
4. It involves systems development and local capacity building.
5. It is an empowering process through which participants can increase control over their lives.
6. It achieves a balance between research and action.

Finally, as Bell\(^{19}\) and Maguire\(^{20}\) have argued, PAR principles also should include prominently attention to the centrality of issues of gender, race, class, and culture, as these affect every aspect of the research enterprise.

This project attempted to follow the principles of PAR in several ways. As described in more detail below, the problem was identified by members of the disability community itself, and the research was conducted largely by members of the disability community.

**Community Advisory Group and University Research Team Roles and Composition**

A strong Community Advisory Group (CAG), composed of five natural helpers, informal leaders in the community,\(^{21}\) and a trained researcher who also was highly identified with the disability community, was formed at the project’s inception and involved in all aspects of the research. Two of the three University of California, Berkeley research team members, and all six members of the CAG have physical disabilities.

Although we were unsuccessful in recruiting either Latinos or Asian Pacific Islanders to the CAG, it was in other respects a highly diverse group, divided evenly between African Americans and whites and women and men, and including people of varied educational, religious/spiritual, disability, and other backgrounds. Finally, and although the university research team never asked potential CAG members about their own attitudes toward DWD legislation, we were pleased to learn, during dialoguing in the course of the study, that a considerable range of opinions was held by those members who chose to share them.

The CAG met monthly with the university team from Fall 1999 to Spring 2001 and was actively engaged in determining the criteria for sample selection and identifying potential study participants, developing the research instrument, conducting interviews, doing data analysis, and in final report preparation and presentation to the study participants. As discussed later, several CAG members also will be involved in meetings with local policy makers and other stakeholders as the project continues its work in the arenas of education to broaden the dialogue and foster full inclusion of people with disabilities at the policy table.

**Sampling**

The project involved qualitative in-depth interviews with a diverse sample of 45 people with substantial physical disabilities. Physical disability was defined as either congenital or acquired and requiring the use of accommodations and/or assistance with activities of daily living (ADLs), such as bathing and dressing, or instrumental activities of daily living (IADLs), such as cooking and housecleaning. In an effort to involve those who often have not been included in the discussion of this topic, outreach to communities of color was undertaken. A combination of methods was used to develop a sample that, while not random or representative, would include considerable diversity in terms of
nature of disability, race/ethnicity, and socioeconomic status. Targeted sampling was used in which basic ethnographic “mapping” of the population helped to determine representation. Through snowball sampling, respondents were asked for the names of other people with disabilities who might wish to participate and particularly those whom they believed might hold views toward DWD or PAS legislation different from their own. In addition, local disability community resources were contacted, such as independent living centers, outpatient rehabilitation services in local hospitals, disability student services at college campuses, and county social services and senior centers. A special effort was made to contact agencies working disproportionately with people of color. Flyers describing the project were mailed or hand delivered to all the above sites and posted.

Sixty percent of sample members were people of color, primarily African Americans and Asians, and sample members had considerable diversity along such dimensions as age (20s through late 80s), educational level (less than high school through postgraduate), and length of disability. Sixty percent of sample members were women, and all but one had been disabled for at least 4 years. (Reference 23 provides a detailed description of the sample.)

**Questionnaire Construction and Interviewing**

The university research team worked with the CAG during three months to develop and pretest an instrument consisting of 29 semistructured and open-ended questions in two parts. The first part included background information on demographics, daily routine, social support, discrimination experienced, and relationships to health care providers. The second set of questions specifically addressed end-of-life decision making and feelings, and opinions and experiences regarding DWD legislation. CAG members played a critical role in this process, adding new question areas (e.g., regarding experience with chronic pain), calling for the simplification or definition of jargon terms such as accommodations, and reminding interviewers to incorporate into their questions whatever terms the participants used in naming or referring to their disabilities.

The one to one and a half hour interviews, which took place at sites most convenient for participants, were always conducted by a team member with a disability. Interviews were taped and transcribed primarily by a team member with a disability, and participants received a $50 honorarium for their participation.

**Data Management and Analysis**

A code book was developed by the university research team to numerically code those questionnaire responses that lent themselves to such analysis. Transcripts were each coded independently by two team members, and a high degree of interrater reliability was found, with any discrepancies discussed and reconciled. Although the nonrandom nature of the sample precluded any generalizing of findings, this process enabled the project team to uncover associations between attitudes toward DWD legislation and variables such as religion, race/ethnicity, educational level, gender, and whether or not respondents self-identified as members of the disability community. CAG members were involved in helping to identify possible associations for examination and subsequently in discussing their potential usefulness in providing contextual data for the qualitative analysis.

A qualitative data analysis software program, QSR NUD*IST 4.0, was used to generate reports based on coded words, for example, *terminal*; phrases, for example, *easy way*
out; concepts, for example, autonomy; and numbered question responses. Several members of the advisory group and the university research team worked together for 3 months to analyze the data and identify emerging themes and patterns.

Out of concern for confidentiality and respect for the time constraints of CAG members, the university research team members first examined all transcripts and computer printouts to remove any potential sample member identifiers and extraneous material. Some data that members of the CAG might have felt to be helpful in their analysis may well have been excluded through this initial condensation process. However, the sheer volume of transcript data and the need for ensuring the confidentiality of study participants who might conceivably have been identified through certain of their responses made this a necessary step in the process.

Returning Data to Study Participants

The major themes collaboratively identified by the CAG and the university research team were compiled in a booklet for study participants. Presentation of findings occurred at two community report-back luncheons, which were attended by about half of the study sample. As discussed below, participants were afforded the opportunity to comment on and question the findings, to suggest alternate interpretations, and to discuss ways to use the findings to further the needs and best interests of the disability community.

Following a brief look at the findings that emerged through this collaborative study process, we return to the methods and implementation of our project to examine in more detail several critical ethical dilemmas that arose and how they were addressed.

FINDINGS

Seven key findings or themes emerged in this study and are described in detail elsewhere. Briefly these were the following:

The existence of a great breadth and diversity of opinion with respect to attitudes toward DWD or PAS legislation. In the words of one of the CAG members,

There seems to be one public position on behalf of people with disabilities about death-with-dignity legislation put forward by disability community spokespersons and groups, but when you go deeper into the community, there are many different opinions. An individual’s opinion seems to depend on their own character, personal experience [of self or a loved one] with near-death or death, among many other things.

The importance attributed to self-determination and autonomy in the way people with disabilities live and die. Regardless of where they stood on the topic of DWD legislation, all respondents reported wanting their independence and autonomy in life choices to be respected. All but one reported that, if they were close to death or experiencing intractable pain or loss of cognition, they would want to have their own opinion about ending or continuing life respected.

The pervasiveness of discrimination based on disability. Close to 90% of respondents \( n = 39 \) reported that they had experienced discrimination based on their disability,
whether from employers or potential employers, teachers, health care practitioners, social service or government agencies, members of the community, or their own families. This experience of discrimination had a profound impact on participants’ opinions about DWD legislation and their trust in society to respect the life (and death) choices that people with disabilities may make. One respondent said, “I have heard people say to disabled people, ‘Why don’t you die’,,” while another talked about the patronizing attitude of able-bodied legislators who “still see it as we’ll take care of you.”

Contradictions between personal experiences and abstract or political beliefs shaping attitudes toward DWD or PAS legislation. A sizable proportion of sample members reported having had personal experiences or anticipated changes in their own lives that would cause them to have opinions at odds with their abstract or political beliefs regarding DWD legislation. As one participant remarked, “Largely I have a problem with it being legalized. Which is distinct from my personal view for me—meaning there should be one law for me and then a general law for society.”

Abstract or political beliefs for many were largely based on perceptions of, or direct experience with, discrimination based on disability, race, or class. A distinction was made between ideal and real societal conditions. As a participant in her 60s stated,

If we lived in a different kind of society, you know, a much more humane, socially viable society . . . an egalitarian society where we wouldn’t have to worry about doctors deciding, “Well this is—this Negro here ain’t worth saving anyway.” I could see lots of room for abuse. Lots of room for abuse with legislation like that. Since there’s already so much abuse.

Misinformation about the Oregon law and its implementation was common. As noted earlier, the Oregon Health Division’s annual report on the Death with Dignity Act for the year 2000 indicates that the great majority of people using their lethal prescriptions have been those with terminal cancer who were receiving end-of-life palliative care. In stark contrast to these facts, many of the participants in this study harbored major misconceptions about the law, including beliefs that it was or could be used heavily to hasten death in people with disabilities. One respondent, for example, told us, “I hear that people are almost forced into agreeing to end their life,” while another said that “once suicide was legalized, an expensive drug for pain was not covered by insurance companies.” For many, misinformation about the Oregon experience appeared to color personal feelings about such legislation in general.

Fear of criticism from other disabled people in relation to the expression of attitudes toward DWD legislation is common. Close to half (24 of 45) of the participants either had experienced, knew someone who had experienced, or feared they would experience criticism if they spoke out in favor of DWD legislation, regardless of what their own opinion actually was. A woman in her 50s who was ambivalent about the legislation expressed the views of many when she said,

There have been a few [disabled] people who wanted to end their lives, and the disabled community has come out in force against it. They think, “Oh no. That’s what we fear, we fear people will pull the plug on us if we are in the hospital or another vulnerable situation.” But, I think we need to listen to all voices . . . to understand where they are coming from, given their situation.
Lack of association between attitudes toward DWD legislation and a host of factors, including disability identification, religion, race, class, social support, and relationship with one’s own physician. Contrary to expectation, many of the factors that the disability community and members of the project team felt would play a major role in shaping attitudes toward such legislation did not bear a significant relationship to attitudes for the group as a whole. Although the nonrandom nature of our sample precluded any generalization of these findings, they were interesting nonetheless in pointing up the importance of avoiding stereotypes and untested assumptions. Of particular interest was the finding that of the almost two-thirds of sample members who self-identified with the disability community (29 of 45), half reported having considerable ambivalence about the legislation. Contrary to a widely held assumption both within and outside the disability community, people who strongly identified with the disability community frequently did not express the strong negative views about DWD legislation that have been put forward as the disability community’s position on this issue.

In sum, the findings of this study revealed a tremendous diversity of opinion within a community of people with disabilities on the highly controversial and divisive issue of DWD or PAS legislation. At the same time, they highlighted the pervasiveness of disability-based discrimination and the very strong desire for autonomy among people with disabilities in matters of both living and dying.

ETHICAL ISSUES AND CHALLENGES

This project illustrated that PAR using qualitative interviewing methods can be a powerful means of not only uncovering a breadth of opinions and attitudes on a controversial topic and the sources of those feelings and thoughts but also contribute to individual and community capacity building. Members of the CAG, for example, developed skills in research methods including sampling, questionnaire construction, and data analysis, as well as compiling and returning data to the community. One member with no prior research experience also participated in interviewing participants and preparing data for use with a computer software program for qualitative data analysis.

In accordance with a core principle of PAR, members of the university research team also saw again and again how much they gained as colearners in the PAR process and how much the research component of the project was strengthened through this colearning approach. As noted earlier, for example, the CAG members’ emphasis on the importance of using participants’ own vocabulary in relation to their disability provided a critical lesson for the able-bodied members of the team, and their sharing in the identification of study themes greatly strengthened the study. Similarly, the project team paid special attention to giving voice to people beyond the white middle class, since low-income persons and people of color have often been underrepresented in discussions of this topic. This is consistent with the emphasis that both participatory researchers of color and feminist participatory researchers place on the centrality of issues of race/ethnicity, gender, and social class. The commitment to diversity in the CAG, as well as in the study sample, helped achieve the goal of diversity in the study and further laid the basis for helping to expand discussion of DWD legislation into previously often neglected sectors of the disability community.

Despite these successes, the use of PAR, while always challenging, proved even more so in the present project. We turn now to four of the major ethical dilemmas that emerged in the process of this project and our attempts to grapple with them.
A fundamental tenet of PAR involves ensuring that the issue to be investigated and acted upon comes from the community and not an outside professional or funding source. The three ethical principles that lie at the heart of PAR—respect for self-determination, liberty, and action for social change—indeed “reflect an inherent belief in people’s ability to accurately assess their strengths and needs and their right to act upon them.” Yet, as Labonte has pointed out, communities are rarely homogeneous, and consequently there may be considerable disagreement over the merits of an issue selected for study and action.

The topic of this project came originally from one of us, who at the time was a graduate student and was deeply rooted in the local disability community. She and her professor discussed at length her concern about the difficulty her community was having in openly dialoguing about the very polarizing issue of DWD legislation. The professor then expressed her own interest in working with the student to develop a PAR project that would address this community concern. As Reason has pointed out, one of the great ironies in PAR is that while the process is “radically egalitarian . . . paradoxically, many PAR projects would not occur without the initiative of someone with time, skills and commitment, someone who will almost inevitably be a member of a privileged and educated group.” As a person who occupied such a position of privilege and who was not a member of the community, the professor played the role of initiator, with the understanding that the project, in fact, would be of, and very largely by, the student and her colleagues in the disability community.

Topic selection in this case involved a major ethical dilemma. For, while nine major disability rights organizations had taken firm stands opposing such legislation, a growing group of individuals, including the graduate student, was concerned that those “official” views did not necessarily reflect those of “ordinary folks” with disabilities. Like the nondisabled, they argued, people with disabilities have a rich array of attitudes and opinions on this topic. As noted earlier, the latter concerns had been echoed in the results of the 1999 poll of people with disabilities, many of whom also shared their concern that people in their community could not speak freely about this topic for fear of censure.

To begin to address the dilemma of choosing an issue that was highly polarizing within the community, we arranged a meeting with colleagues at the World Institute on Disability (WID)—a locally headquartered organization with a powerful reputation for its research and advocacy with, and on behalf of, people with disabilities. Although we knew that WID was among the organizations to go on record opposing DWD legislation, we had hoped to dialogue openly with its staff about our idea for a PAR project and ideally to seek their collaboration as equal partners in such an undertaking.

A frank and sometimes difficult talk ensued, and by the end, the WID representatives had concluded that while their organization could not legitimately cosponsor this project, they did not oppose its being undertaken. One representative suggested that it indeed might be good to open the conversation, and WID decided that it did want an organizational representative on the CAG. The WID representative who volunteered brought not only an important organizational affiliation but also considerable knowledge and experience in PAR within the disability community. Sadly, and for a variety of reasons, this individual did not participate actively on the CAG beyond attending a few meetings.

Hard questions around issue selection continued to arise throughout the course of this project. A prominent national disability leader, on being told of the study, responded,
“Why would you look at that when there are so many more important issues?” In the course of dialogue, this individual agreed that perhaps it would be good to open the conversation but experienced a resurfacing of ambivalence at different points in the course of the study. This individual’s opinion may well reflect that of others in the movement who, while respectful of the idea of open discussion of DWD or PAS, may find such conversations personally and professionally troubling.

In contrast to such views, a member of our study sample concluded the interview by saying that “this is so much more important than one more study of accessible transportation.” Our own conclusion, after much critical reflection and dialogue with members of the community, was that despite its contentious nature, attitudes toward DWD legislation was a topic that did need to be aired in the community. We further believed that there was sufficient sentiment in favor of more open dialogue to make venturing into this admittedly risky terrain worth any discomfort or difficulty.

Inclusion and Exclusion in Selecting Team Members and Study Participants

A second dilemma involved the ethics and the politics of inclusion and exclusion in the selection of project team members and study participants. Because this was to be a study of and largely by people with disabilities, we were anxious to recruit student members of the research team who themselves had significant disabilities. Furthermore, because the controversy over DWD legislation has been most pronounced in the community of people with physical disabilities, we hoped to limit students, advisory group members, and study participants to those with a primary physical disability, rather than a sensory or mental disability, or a disability secondary to AIDS or other conditions.

Restricting participation in the study to physically disabled individuals was a source of dismay to a number of people, however, whose primary impairment was blindness, hearing loss, HIV/AIDS and so on and who wanted to be involved.* Students without physical or mental disabilities but who worked in the field of disability also expressed concerns about being categorically excluded. One such individual, who had excellent qualitative research skills in addition to prior work experience in disability, was brought on board when we were unable to find more than two university students with physical disabilities who wished to participate on the study team. Although in part a sad commentary on the small number of disabled students in a major U.S. university, the decision to include this able-bodied student on the research team was in retrospect a good one, both for the skills she was able to provide and for the additional colearning opportunities afforded. Unfortunately, this student’s unexpected move across country necessitated her leaving the project early on so that the final university research team was composed of two students with disabilities (the project director and a psychology student who was also a nurse) plus the able-bodied faculty member.

As noted earlier, a major concern in this study was with broadening the dialogue within the physically disabled community to include people who historically have been on the margins of the movement—people of color and low-income people with disabilities. We therefore used, as part of sample selection, a targeted sampling method that would help us find and include more individuals from these underrepresented groups.

*A number of people who met the criteria for physical disability but who currently were being treated for depression also were unhappy about being excluded, even though we explained that this was a requirement of our institutional review board agreement.
Unfortunately, this meant turning down as participants some people who wished to take part in the study but who were in the white and middle-class populations that already were overrepresented in our sample. A number of people who were unhappy when they were excluded on the basis of race asserted that nonwhites would have a different position on the issue of DWD or PAS legislation. Our response was always to assure everyone that the results of the study would be made available to the community broadly and that the study would help us understand if race or ethnicity did indeed have a major bearing on opinions toward this legislation.

In most of the above instances, the dialogue that is a central feature of PAR proved an important vehicle for helping those excluded come to a better understanding of why this study was centered on creating a safe space for people with physical disabilities, and particularly those from underrepresented groups, to discuss their attitudes and feelings. We also took names and contact information from all who had hoped to be included and could not be and promised to invite them to the first public presentations and discussions of our study findings so that they also could express their views and enter the discussion. However, despite these efforts, issues of inclusion and exclusion were difficult and reemerged at different points throughout the project.

Insider-Outsider Issues

The potential conflict between insiders and outsiders in community-based research has been much discussed in the literature. Wallerstein has noted, even outsiders who pride themselves on being community allies and trusted friends frequently fail to realize the extent of the power imbued by their own, often multiple, sources of privilege and how it can adversely affect interactions and outcomes.

One simple manifestation of insider-outsider tensions involved the difficulty in conducting a participatory community project within the time frame of the academic and funding calendar. The often conflicting time pressures and constraints between community members, community-based organizations, and academic researchers have been discussed elsewhere and have frequently been found to lead to frustrations on all sides. As anthropologist Janice Perlman once remarked, community people often are “less interested in making history than in making life” or, in this case, putting a voluntary research project above the issues of day-to-day survival and fulfillment. As a case in point, two of our CAG members are noted creative artists, and their often demanding performance schedules not infrequently required a change in CAG meeting times or a very late arrival.

In the present study, competing CAG member time demands were complicated still further by the realities of “DP” or “disabled people” time—the often inevitable delay in any life activity—including when interviews or CAG meetings could occur, due to bad weather, illness, or physical barriers (e.g., inoperable bus lift or rapid-transit elevator). The frequent need to change scheduled meetings or begin them one hour later than the appointed time sometimes created insider-outsider tensions when the university or funding cycle deadlines proved difficult or impossible to meet. Although dialogue about “DP time” and other sources of conflicting time frames helped the able-bodied team member become more realistic in her expectations, conflicting time lines remained an issue. With the approval of the outside funding agency, the project eventually was extended for a year beyond the original termination date, thereby relieving some of the tensions around time pressure.
Differences in frame of reference between insiders and the outsider academic were also apparent in the sample selection and analysis phases of the project. The outsider researcher’s training in gerontology, for example, led her to push for the inclusion of a large number of older people with disabilities in the sample to be able to test her informal hypothesis that older individuals would be more favorably disposed toward DWD legislation than their younger counterparts. Inclusion of this population was not a high priority for community members, however, whose insider knowledge suggested that the lived experience of people with a long-term disability often forces them to confront issues of life and death numerous times during the life course—and sometimes when very young. Although a compromise was reached in including a minority of older persons in the study, different perceptions about the importance of specifically seeking out older sample members remained an issue of debate.

Finally, insider-outsider conflict also appeared in relation to understanding the disability experience of discrimination. Although many of those interviewed expressed a mistrust of doctors and the health care system, for example, this mistrust existed within a broader societal context of disability-based discrimination and oppression. In addition, the majority of respondents shared painful experiences within a broad range of social settings. The academic-outsider perspective (which was shared by the insider team member who had training as a nurse) continued to emphasize health care–related discrimination, even though close to two-thirds of sample members reported good patient-doctor relationships. For the project director and some members of the CAG, this was seen as reinforcing the traditional “medicalization” of people with disabilities. Through the continued dialogue and shared reflection that are hallmarks of PAR, the insider perspective did prevail in the final analysis. Discrimination at the hands of the medical care system was examined as simply one of many diverse and troubling forms in which prejudice against the disabled took place.

Dilemmas Around the Sharing and Use of Findings

This project faced a difficult ethical and political challenge from the onset, since much of the formal leadership of the disability community was opposed to the presentation of anything but a united front against DWD or PAS legislation where the community was concerned. Our findings revealed that many participants, including the majority of those who strongly identified with the disability community, did not share the blanket, negative view of such legislation and indeed held a rich and complex set of opinions. Such findings required that careful attention be directed to how best to use the study findings in ways that could unite and strengthen the community.

Among the many rich findings of this study, the most pronounced theme was also the one identified by the project director and her peers on the CAG as providing unique common ground for fostering a dialogue that could indeed offer a basis of such strength and unity. As noted earlier, that theme involved the finding of overwhelming agreement among study participants on the desire for autonomy and choice in how they live and how they die, regardless of where they stand on DWD legislation. By preparing a booklet of study findings for the participants that began with this critical point of unity, the project director and other team members played a key role in setting the stage for productive and strengths-based discussion.

As noted above, following the PAR principle of community ownership of study findings, the university research team and CAG began by giving back study findings to the
participants, who were asked to share their reactions and comments, as well as their opinions about how the findings should be used. Roughly half of the study participants took part in the two community report-backs, and many shared their belief that “getting the word out” was an important next step. As one young woman put it, “I think society at large has a very simplified view. They think just because we’re all disabled we have the same opinion. We’re just as complex as any other body of people.” Another participant remarked that “the study echoes over and over again the society we’re part of.” He added that “when you’re in conversation with people you admire, you tend to agree with them. But when you’re at home on your own pillow between the sheets, you think.” In reference to the strongly held position opposed to DWD legislation by the formal leadership within the disability community and the reluctance of many people with disabilities to voice an alternative opinion, still another participant said, “Nobody wants to rock the boat, to be on the fringes.” Yet, he also suggested the need to foster more open discussion.

Several participants spoke of the potential for using this study as a jumping-off point, both for a larger study and for increasing the dialogue within the community through a variety of means. One young man suggested that the participants stay in contact and continue their own dialogue through the Internet. A contact list was circulated for this purpose, and a participant offered to begin the process of coordinating this effort.

Alternative positions were also expressed. One participant articulated his opinion that no discussion of DWD legislation was productive, since end-of-life decisions should be entirely “in God’s hands.” Another individual who had attended one of the meetings later confronted a member of the CAG to express her great displeasure with the study findings. And another participant told the project director that the disabled community would have no interest in the study findings, given that they contradicted the dominant view that is publicly presented.

The opinions of those who were unable to come or were uninterested in attending the community report-backs were, of course, not known. Many of these individuals had requested copies of the report, and it was mailed to them with encouragement to share their copy with others and to give us any feedback they might have. In retrospect, a more proactive approach, including phone call follow-up to study participants who had not attended the report-backs, might have been a helpful means of eliciting their input on the study findings and their feelings about the potential use of the information uncovered. However, it was also important to keep in mind that a PAR project regarding as deeply polarizing an issue as DWD or PAS legislation is for the disability community cannot repair all of the rifts within the community around that issue.

Despite their own differing attitudes toward DWD legislation, CAG members shared with the majority of community report-back participants a belief that the findings of this study provided a good mechanism for furthering dialogue on this topic. They supported making copies of the study findings widely available both within and beyond the disability community. Several also expressed a desire to meet with a local politician who had sponsored California’s unsuccessful Death With Dignity Act. Their hope was to discuss with her both the rich diversity of opinion concerning this issue and the fact that people with disabilities need and want to be included as full participants in any policy-level discussions of this contentious issue. This and other means of broadening the dialogue, including presentations to both community groups and national professional societies, now are being planned. It is our hope that such activities will contribute to a process through which respect for, and honoring of, the principle of full inclusion of people with disabilities at the policy table can take place.
IMPLICATIONS FOR HEALTH EDUCATION RESEARCH AND PRACTICE

This project has several important implications for health educators, related respectively to the topic of our inquiry, PAR as an approach to health education research, and the ethical issues that arise in this and other forms of community-based participatory research.

First, and as members of a profession concerned with creating the conditions for dialogue and empowerment, health educators are in a unique position to help facilitate discussion on the difficult, largely neglected, and increasingly important topic of DWD legislation. PAS and hastened death are occurring regularly in our society and, except in the state of Oregon, without any legal or ethical guidelines. Open and inclusive discussion of this topic in society at large is long overdue. Health educators, with their commitment to vulnerable populations, can help ensure that the communities, hospitals, managed care organizations, and other settings in which they work engage in such discussion and debate, including people with disabilities, among others, as full and equal partners.

Second, this project has pointed out the utility of PAR as an approach to research, education, and action around the kind of complex and often controversial issues with which health educators frequently are engaged. By actively involving people with disabilities in all phases of this project and breaking down the barriers between the researchers and the researched, the study was able to contribute to both individual and community capacity building. As one CAG member remarked 6 months into the project,

> When I come here to these meetings it lets me be on another plane. Out there I am in survival mode, you know, looking around and behind me, watching out for everything. But when I come in here, I am on another plane and can function differently. And I thank you for that.

Members of the CAG gained useful skills in data collection and analysis. In turn, they helped the university research team dramatically improve its research instrument, gain access to a highly diverse sample, interpret study findings with new community insights, and report those findings back to the community in ways that engendered further rich dialogue and plans for subsequent education and action.

Yet, as this article also has demonstrated, despite its many strengths and its clear philosophical fit with many of the most basic tenets of health education, PAR, like all community-based research, is fraught with ethical difficulties. In the present study, these included addressing a community issue that is a source of deeply mixed feelings, inclusion and exclusion in both team and sample selection, insider and/or outsider issues, and questions concerning how to share and use findings in controversial topic areas.

Despite the challenges and frustrations faced, dealing with the ethical dilemmas that arise in the course of a project like this one can itself contribute to the building of stronger, more competent communities. As Roe et al. have noted, “Strong communities know their history, understand how they are different than others, and find ways to honor their shared paths.” By helping to depolarize the issue of DWD legislation within the disability community and shining a spotlight on a critical point of unity and strength within the community, this study attempted to contribute to the process through which an already strong and rich community honors its shared path. Similarly, by demonstrating the usefulness of PAR in this process and pointing out the ethical challenges faced and how they were addressed, this article also has attempted to encourage more health educators to look
to PAR as an approach that well complements many of the most basic principles of our professional practice.

References


