Attitudes Toward Disabilities

A Research Note on Activists with Disabilities

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This research note explores the difficulties and importance of obtaining research data on attitudes of disability-rights activists. Remarkably little research has been done on the attitudes that people with disabilities have about their disabilities. This is especially interesting in light of the development and formation of the disability-rights movement and the minority-group perspective about disability. This article discusses the methodological and pragmatic complexities and concerns in obtaining data from people with disabilities who participated in Americans Disabled for Assistance Programs Today (ADAPT) social action events. ADAPT members are one of the groups most highly associated with identity politics of the disability-rights movement; they are also extremely mistrustful of outsiders who they fear may be interested in disrupting their activities. The authors discuss how sufficient trust and engagement was achieved to carry out this study without compromising sound research principles. Some findings are also reported. These results suggest that this group of people with disabilities identifies closely with their disabilities and seems to adhere to a minority-group perspective. Many identified so closely with their disabilities at a personal level that they indicated that they would not choose to be cured even if this were "magically" possible.

A major issue in the formation of rehabilitation policy revolves around the attitudes people with disabilities may hold about their disabilities. Surprisingly little research has been conducted on this topic, even though a few studies disclosed some unexpected results. For example, a survey by Weinberg and Williams (1978) of a relatively small number of delegates to a state conference on disability found almost evenly divided opinions about whether or not they wanted to be cured. Many were reluctant to have the understandings they derived from everyday experience with their impairments removed from their lives. In a research agenda dominated by medical efforts to eliminate disability, quantitative investigations of the attitudes of citizens with disabilities often have seemed to be ignored or neglected.

Increasingly, however, a new interest in this subject has been prompted by the emergence of the disability-rights movement and by a growing attention to the concept of empowerment (Scotch, 1989, pp. 382–383). Schriner (1998, p. 2) has hailed "the beginnings of a long-term research agenda that may answer questions about the participation of people with disabilities in democracy" (see Note). As an initial step toward this objective, some social scientists are starting to reexamine measures of "group identification," "group consciousness," or "identity" which have been previously found to affect levels of political participation (Barnatt, 1996; Miller, Gurin, Gurin, & Malanack, 1981), along with more enduring structural factors such as socioeconomic status (Conway, 1991) or the accessibility of community facilities. Other researchers have begun to speculate about possible explanations regarding why some people with disabilities have become highly involved in the disability-rights movement while others have not. Hence, an important empirical study by Schur (1998) examined the impact of psychological variables on the political participation of people with spinal cord injuries. In addition, Barnatt (1996, p. 5) has suggested that involvement in social movements often involves the development of a "collective consciousness" that serves to link members to each other and legitimize their opposition to social norms and values that serve to oppress or discriminate against them.

Part of the explanation for the lack of research on the attitudes of persons with disabilities can also be ascribed to methodological obstacles. Area or cluster sampling to locate a probability sample of potential respondents has been impeded by the unpredictability of geographic concentrations of noninstitutionalized people with disabilities. Therefore methods of collecting data from persons with disabilities based on random sampling techniques that usually entail the use of elaborate screening questions are seldom cost-effective. However,
there are major pitfalls involved in the compilation of information from nonrandom samples of people with disabilities. Snowball sampling, for example, may yield findings that are affected by hidden patterns in the network of informants included in the study. In fact, such samples may be skewed by the simple fact that in a population where isolation is known to be a problem, not all potential respondents may know many other people with disabilities (Albrecht & Levy, 1981, p. 23; Zola, 1983, pp. 50-51).

Although it would be preferable to have a random sample in most cases, in areas that are exploratory in nature and have received little attention in the literature, it is generally considered more important to investigate basic concepts and ideas than to overly adhere to systematic representation (Fellin, Tripodi, & Meyer, 1969, p. 256; Schutt, 1999, pp. 14-17). One element of such an exploration is to consider within the population separate subgroups that have the potential to serve as "archetypal categories" and who are "information rich" on a spectrum of responses to disability (Morse, 1994; Patton, 1987, p. 53). This is consistent with the logic of "critical case sampling" which is used to identify important factors and attributes that may be standards for generalization or comparison in subsequent studies (Morse, 1994, p. 229).

Perhaps the most important of these classifications consists of the beliefs of people with disabilities who chose to participate, at the risk of arrest or personal injury, in protest demonstrations conducted by ADAPT. ADAPT is commonly recognized as one of the most radical groups within the disabled minority (Shapiro, 1993). Participants in ADAPT actions probably define the radical edge of politicized consciousness regarding disabilities. Clearly, the data obtained from the ADAPT surveys cannot be interpreted as representing the views of all disabled people or even of all members of the disability rights movement. However, they reflect the opinions of a portion that has displayed an especially strong commitment to the struggle for equal rights by engaging in acts of civil disobedience that could result in criminal punishment. In many respects, therefore, the attitudes of the participants in these demonstrations could be considered as a kind of benchmark against which the sentiments of other people with disabilities might be measured. These respondents are labeled in this research note as "ADAPTers."

The purpose of this research note is to present a brief report on an exploration of the attitudes about disability expressed by noninstitutionalyzed advocates of disability rights using ADAPTers as a case in point. Perhaps even more important, we will discuss some of the methodologic issues involved in gathering data from this group.

ADAPTers represent a relatively radical element of the disability community, which in some ways makes them ideal for studying certain aspects of the identity politics of the disability rights movement. The investigation of a sense of personal or political identity seems especially germane to an analysis of the participation of people with disabilities in debates about public policy. Unlike other segments of society, citizens with disabilities have generally not been able to form a cohesive interest group or constituency capable of exerting a constant influence on government decisions. Part of the problem can likely be traced to the effects of a legacy of guilt or shame that has long permeated prevailing sentiments about disability. In addition, although the images of people with disabilities were sometimes affected by the myth that they are unusually courageous, their problems were often blamed on a lack of proper psychological adjustment. Particularly in the era after World War II, they were relentlessly encouraged to overcome their disabilities (Phillips, 1985). Many found it difficult to develop a sense of identity with a trait that they were taught to "overcome" to become more like the nondisabled population. Moreover, most people with disabilities (at least those who are not institutionalized) live in families and communities where nondisabled people predominate. As a result, they have been deprived of a sense of history and a distinctive cultural tradition like that which has emerged for other groups that have adhered to common social, cultural, and political purposes (Hahn, 1984). As such they were deprived of a significant tool for organizing. Although there is some question as to whether people with disabilities have been able to develop a unique culture in the anthropological sense, in recent years many people with disabilities have developed a level of "disability consciousness" that has led to increasing mobilization of disability rights groups to press for their civil rights (Barnhart, 1996, pp. 6, 11).

Only in the final decades of the twentieth century did Americans with disabilities begin to define themselves as a minority group and to ascribe their problems primarily to attitudinal prejudice and discrimination (Scotch, 1989). Thus, they seem to be divided by a sense of "disability pride" and by the priority attached to the search for a cure for disabilities. Qualitative studies and anecdotal evidence is consistent with such a division, suggesting that people with disabilities vary in their attitudes toward their impairments, ranging from "bitterness" about their physical conditions to "embracing the disability" as a quintessential element of their identity (Weinberg, 1988, pp. 149-153).

Method

Instrumentation

The questionnaire developed for this study consisted of demographic measures and Likert-type items derived from prior studies of racial or ethnic identity. The included items adapted from scales such as the Collective Self-Esteem Scale (Luhtanen & Crocker, 1992; Luhtanen & Crocker, 1992) and the Multigroup Ethnic Identity Measure (Phinney, 1992). There were also several adapted scales used for comparison purposes, including the Satisfaction with Life Scale, the Internality Locus of Control Scale, the Powerful Other Locus of Control Scale, and the Rosenberg Self-Esteem Scale (Fischer
& Corcoran, 1994), as well as ten statements concerning views about disability designed by the senior investigator specifically for this study. Responses to the latter items about disability constitute the major focus of this research note. Because items of principal interest were either developed directly by the senior author or adapted and modified from items found in racial or ethnic identity scales, there is no prior information on reliability or validity. There are some psychometric data available on the scales from which modified items were taken that are reported elsewhere (Luhtanen & Crocker, 1992; Phinney, 1992). This research note does not propose a new scale; however, but rather presents individual items on the questionnaire. Therefore reliability and validity data are not reported. However, there were no significant differences between respondents who filled out the questionnaire at different ADAPT events.

Sample

One hundred and sixty-one demonstrators with disabilities were interviewed at two ADAPT social-action events. A deliberate effort was made to assure that the questionnaires were completed by disabled persons themselves rather than by nondisabled attendants, family members, or friends. Although no potential respondents refused to complete questionnaires, five were not deemed complete enough to keep in the study. This resulted in a final total of 156 completed questionnaires used in this analysis (n = 77 in 1995, and n = 79 in 1998).

The sample was almost evenly split between women and men. Most respondents were white, with a few Latinos (n = 9), African Americans (n = 15) and “others” (n = 4) represented. Respondents ranged in age from 17 to 73 years with an average age of 43 years. There was considerable variance in the amount of education of respondents, with some claiming to have had no formal education at all and some claiming to have had as much as 26 years. The average was 15 years. Fifty-six percent indicated that they were currently employed.

This was not the first ADAPT action that most respondents had attended. On average, respondents had attended six events, with some indicating that they had attended dozens. Only four respondents indicated that this was their first ADAPT event.

Data Collection

Data on the ADAPThers was collected during two demonstrations conducted by ADAPT in the Washington, D.C., area in 1995 and 1998. ADAPT was founded in 1978 by a “gang of nineteen” disabled residents who stopped public transit for over a day in Denver, Colorado, to force the city to install wheelchair lifts on buses. The name of the organization originally stood for American Disabled for Accessible Public Transportation. For years, ADAPT members engaged in tactics at the annual meetings of the American Public Transit Association, such as blocking buses for sightseers to promote a resolution supporting the rights of disabled passengers to use public vehicles. When this demand appeared to be included in the Americans with Disabilities Act of 1990, ADAPT (now renamed Americans Disabled for Assistance Programs Today) turned its attention to legislation that would redirect government funds from nursing homes to permit disabled individuals to live outside institutions by hiring their own personal assistants or attendants.

Research Settings

The settings were congested with wheelchair traffic and had a variety of logistical difficulties associated with having such a large number of disabled people gathered in the same place at the same time. The crowded hotel lobbies at the ADAPT demonstrations also resulted in frequent collisions and high levels of confusion and frustration. However, an increased sense of cohesion and strong feelings about the differences between “us” and “them” prevailed. These in-group feelings made it relatively easy to contact and to interview other ADAPThers with disabilities. In most cases, this constituted a convenience sample where the interviewer simply approached people with disabilities who had arrived for the demonstration. In many cases, the interviewer asked respondents if they knew of others who might also be interested in participating in the study, thus generating a snowball sample. There were also announcements made by the leadership about the research, which prepared participants for the possibility that they might be approached for an interview.

Findings based on such sampling techniques must be viewed more cautiously than those based on randomized samples. However, it is unlikely that a probability sample could have been generated for this group of respondents. Indeed, it seems likely that their willingness to participate in the research and their candor would have been compromised if the interviews had been conducted by a nonparticipant or a stranger. Questioning by any investigator who was unknown to the group could easily have provoked highly guarded responses or even a refusal to participate. Part of the climate of the demonstrations included plans to vilify the transit association, the nursing home industry, and other targets. Moreover, as previously noted, most participants were seasoned activists and therefore aware that outsiders sometimes try to infiltrate their activities and find out their plans in advance. Outsiders would undoubtedly have faced increased difficulty in securing the trust and cooperation necessary for research.

Interviewer

Most of the interviews in the ADAPT survey were conducted by the senior investigator, who has used a wheelchair for most of his life. He also participated in several ADAPT demonstrations in earlier years. Although some critics may claim that these facts might compromise the objectivity of the research, there are strong reasons to believe that these factors may have
contributed to the truthfulness of the information obtained from this survey. Ironically, efforts to match the racial or ethnic characteristics of interviewers and respondents have become an accepted part of the methodological canons for research on these populations; comparable understandings have not yet been applied to the study of people with disabilities. However, the same logic that applies to research with ethnic and cultural minorities also applies to disabled people who identify themselves as a minority group. It is doubtful, as previously noted, that complete candor could have been achieved if the interviews had been conducted by an outsider or a stranger. ADAPT members were well aware of previous police attempts to infiltrate and gather intelligence about the plans of the organization. Questioning by anyone who was unknown to the group could easily have provoked a heightened sense of suspicion and distrust, creating a significant threat to the internal validity of the study. ADAPT leaders made a brief statement at a general meeting, urging everyone to return the questionnaires, and the appeal resulted in a short flurry of additional interviews. However, the events more generally were permeated by a skepticism about research. This was reflected most clearly by the relatively persistent question: “Why would you want to do this anyhow?” Participants in the demonstrations seemed satisfied by the statement that it was a way to let others know how people in ADAPT feel.”

Special Considerations for Research During Demonstrations

Researchers need to be aware of the impact of context on the outcome of their studies. One way in which the importance of context was reflected in this study was in the determination not to engage in data collection that might disrupt demonstrations. A critical feature of nonviolent protests is the element of surprise. Few of the participants, including the police and most of the demonstrators, know precisely when new events are likely to occur. Hence, no action by the senior investigator could be taken that might jeopardize or interfere with the unhampered flow of acts of civil disobedience. In practice, this self-imposed rule meant that no research could be undertaken during the long and often tedious hours on a picket line or blocking the entrances to a building while waiting for further instructions. Similarly, the researcher refrained from interviews during travel to the site of demonstrations and during meals.

Such contexts also require flexibility on the part of researchers and the ability to adapt methods as the situation requires. For example, it was hoped originally that the questionnaires would simply be distributed to persons with disabilities in the hotel lobby or corridors, then returned to a box outside the principal meeting room. This expectation proved to be unrealistic. Most of the ADAPPIers had significant impairments. A relatively large portion of them had manual or visual limitations that interfered with their ability to complete the questionnaire unaided. In addition, communication impairments often required careful concentration on what the respondent was trying to convey. Thus, data collection in the ADAPT survey was conducted primarily through face-to-face interviews instead of pencil-and-paper methods. It should be noted, however, that since the surveys were based on a social model that considers disability as a generic condition and a source of discrimination and oppression, no attempt was made to classify respondents in the surveys by diagnostic categories or functional limitations.

At the demonstrations, a principal concern was to prevent any interference with acts of civil disobedience. Under the circumstances, conventional assurances about anonymity and confidentiality were likely to be insufficient. As a result, the researchers tried to make absolutely certain the survey did not contain any questions that might conceivably produce self-incriminatory information. Although the data did not include any evidence that might possibly be admitted in criminal litigation, the realization that most law enforcement officers are relatively unfamiliar with the nature of academic research inspired increased efforts to defend the respondents against any potential schemes to subpoena this information. In short, every attempt was made to conduct the research on the basis of ethical principles consistent with the integrity displayed by these participants before and during their acts of civil disobedience.

Discovering What Is Worth Finding Out

The overwhelming interest in survey research, especially in the second half of the twentieth century, has seemingly encompassed every conceivable subject and all segments of the population. Occasionally, however, researchers may discover a group (such as people with disabilities) that has been relatively neglected and a topic (such as their attitudes concerning disability) that has been virtually ignored. Although the study of this segment of society has been impeded by methodological barriers such as sampling problems, perhaps the failure to explore the issue of attitudes about disability (as distinguished from attitudes toward people with disabilities) can be ascribed to the desire to repair or eliminate impairments and the assumption that there is little to be learned from prolonged experience with disabilities. In seeking to examine the conjunction between these examples, this research note explores differences in responses to statements about disabilities, especially constructed for this study, between two groups divided by their involvement in events that signify differences in political participation.

Table 1 presents the frequencies, in percentages, of responses to the ten statements about disability that appeared in the survey. Most respondents indicated that they were not ashamed of their disability and felt comfortable when children asked them about it. Three quarters or more of respondents


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<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Slightly disagree</th>
<th>Neither agree nor disagree</th>
<th>Slightly agree</th>
<th>Agree</th>
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| "My disability sometimes makes me feel ashamed."  
  (n = 155)                                                              | 41%               | 22%      | 5%                | 5%                        | 12%            | 12%   | 4%             |
| "I feel uncomfortable when children ask what happened to me."  
  (n = 153)                                                              | 42%               | 26%      | 7%                | 12%                       | 5%             | 4%    | 2%             |
| "In my opinion, people with disabilities should not be considered a minority group like Blacks or Hispanics."  
  (n = 153)                                                              | 50%               | 15%      | 3%                | 8%                        | 3%             | 9%    | 12%            |
| "On the average, others tend to react negatively or unfavorably to people with disabilities."  
  (n = 155)                                                              | 5%                | 6%       | 7%                | 8%                        | 19%            | 34%   | 21%            |
| "I feel proud to be a person with a disability."  
  (n = 155)                                                              | 3%                | 2%       | 3%                | 7%                        | 10%            | 27%   | 48%            |
| "I want to learn more about the history of people with disabilities."  
  (n = 155)                                                              | 4%                | 5%       | 1%                | 12%                       | 12%            | 26%   | 40%            |
| "Unlike racial or ethnic minorities, people with disabilities do not have their own culture."  
  (n = 150)                                                              | 42%               | 22%      | 9%                | 11%                       | 5%             | 6%    | 5%             |
| "Disabled people should be considered courageous for having overcome their disabilities."  
  (n = 149)                                                              | 42%               | 16%      | 5%                | 10%                       | 5%             | 11%   | 11%            |
| "The biggest problems that I face as a person with a disability are the prejudicial attitudes of nondisabled people."  
  (n = 149)                                                              | 4%                | 8%       | 6%                | 7%                        | 9%             | 23%   | 43%            |
| "Even if I could take a magic pill, I would not want my disability to be cured."  
  (n = 149)                                                              | 23%               | 17%      | 7%                | 8%                        | 11%            | 12%   | 22%            |

Expressed a desire to study disability history, had a sense of disability pride, and indicated that their main problems were the consequence of prejudicial attitudes. Over two thirds of respondents also felt that other people tended to view them unfavorably, believed that people with disabilities constitute a minority group, and supported the concept of disability culture. In fact, all of these statements appear to support a self-concept that is closely aligned with a minority-group concept of disability. It is difficult to imagine these responses having been elicited by using a medical-model concept of disability, which may increasingly cast into doubt measures of satisfaction or quality of life that do not take minority-group issues into account.

Respondents were almost evenly divided about wanting to be cured. The finding that most ADAPTers were at least unsure about whether they would take a "magic pill" to cure their impairments is consistent with previous studies (Weinberg, 1988, p. 142) in which only about half the respondents indicated that the desire for a cure was a high priority. Responses were bimodal. It is not surprising that many respondents would prefer to have less impairment. What is more interesting is that over half of the respondents were at least ambivalent about the notion of life without their disabilities. Clearly, for many, the regaining of physical functioning is not the highest priority, although it may well be one priority among many. This finding suggests that many disabled persons may find something so inherently important about their disability that they would not have their impairments or symptoms removed even if this were possible.

Most ADAPTers responded highly unfavorably to an item asking them if people with disabilities should be regarded as "courageous" for "overcoming" impairments. Responses suggest that most of the ADAPTers have a somewhat negative reaction to the concept of the "supercrip" who manages to adapt him- or herself to the nondisabled world regardless of adversities encountered. Within the disability-rights movement, there is a burgeoning sense that disabled people should not have to heroically adapt themselves to an unadapted world, but rather that the world should be modified in ways that accommodate their impairments. The ADAPTers' responses are consistent with the ideological notion that "courageous overcoming" actually hurts the movement by highlighting the successes of a few "heroes" while ignoring the fate of many others.
In recent years the judiciary has restricted its interpretation of the Americans with Disabilities Act (ADA) and related laws, which has presented a challenge to support for the minority-group model, arguments in favor of legal rights, and attempts to curb discriminatory attitudes. In this context, growing research interest in identity politics may help to re-focus attention on group identification and on the incorporation of disability into a sense of personal and political identity. Although these findings have limited generalizability and are exploratory in nature, ADAPTers have endorsed several positions that may contribute to feelings of empowerment. These feelings include a sense of disability pride, an interest in disability history, and a wish to explore the debate about disability culture. Educators may have a particular responsibility to include several of these topics, especially history and culture, in the curriculum at different levels of schooling. The finding that so many ADAPTers were ambivalent about seeing a cure as a priority may also indicate the need for additional teaching and research on bioethical issues.

Conclusion

This research note has examined attitudes about disability among a group of disability advocates who may be most militant in their support for disability rights. A major standard for the analysis was provided by the responses to the ten Likert-type items about disability from a convenience sample of demonstrators in an act of civil disobedience sponsored by ADAPT. Findings suggest that identification as people with disabilities is very high among respondents. While the evidence clearly deserves the familiar caveat about the need for further research, this study offers a tantalizing glimpse of data from a group that is frequently neglected, about a topic that is often ignored, on a subject that may be crucial to the development of a sense of identity and empowerment. These findings also suggest some interesting policy implications. Respondents frequently appeared to be relatively comfortable with their identity as people with disabilities, often appearing to be more troubled by prejudicial attitudes and policies than about their impairments. This is consistent with the thrust of disability rights activism which has stressed civil rights rather than focusing on medical treatment for impairments (Scotch, 1989).

In some ways, however, their responses to the magic pill question and apparent ambivalence about a cure are most intriguing and are reminiscent of Weinberg’s pioneering work. Many of her limited surveys were also of activists and were later extended to disabled students. She asked, “If you were given one wish, would you wish that you were no longer disabled?” Similar to the findings in this study, half of the respondents indicated that they would not use their wish on a cure (Weinberg, 1988; Weinberg & Williams, 1978). The magic pill question obtained a similar result in the current study. Weinberg’s wish question implies that the respondent could use the wish for some other reason than a cure (such as great wealth or a beautiful house). The magic pill question offers only cure as an option, yet received a similar response. This is a subtle, but important distinction. Weinberg’s question suggests that a cure may not be the highest priority. The magic pill question suggests that cure may not even be a desire for some people with disabilities. The seven-point scale used in this study also shows how polarized and bimodal responses tended to be. There appear to be several possible interpretations and policy implications to be gleaned from this finding. First, it may indicate the potential pitfalls of assuming without further investigation that disabled people, even activists, are attitudinally homogeneous or that either a random or a convenience sample can provide representative, valid, or accurate results about the viewpoints of the entire disability community. Any generalizations about the opinions of disabled people could require both methodological and substantive qualification.

Models of health care utilization could be expanded to incorporate views about the desirability of medical care or treatment as a social structural component (Anderson, 1995, p. 2). Subsequent studies are planned to examine additional variables, such as internal or external health-related locus of control, beliefs about self-help, and indices of disability identity, as well as other groups of disabled citizens or advocates. Many health services researchers frequently neglect the possibility that some patients may reject the promise of ameliorative medical treatment or may give higher priority to aspects of their experience with disability which, despite the discrimination they commonly encounter, could give them a distinctive perspective on the value and meaning of everyday life (Hahn, 1997). In fact, some disabled people contend that ethnographic accounts of the methods they have devised for circumventing or surmounting environmental barriers could be an invaluable resource in training physicians and other health professionals on how to assist future generations of persons with disabilities or chronic health conditions. The ramifications of this survey of ADAPT participants, therefore, could simply yield added methodological caveats, or it might spark a reorientation in analyses of the use of health care.

NOTE
Schriner (1998, p. 2) went on to say, “We invite our readers to comment, either through Letters to the Editors, or in subsequent scholarly efforts.”

REFERENCES


