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Collective Consciousness and a Profile of Issues

Social movements are motivated by demands for change, which are derived from a type of belief system we call a collective consciousness.[1] These belief systems consist of ideas that transform perceptions and ultimately legitimate opposition to extant cultural beliefs or social structural arrangements (Mueller, 1987). This opposition to cultural beliefs is necessary in order to motivate people to seek change, because cultural beliefs naturally seek to conserve the social and political order. Some scholars have called a collective consciousness an "oppositional consciousness" because the problem identification, explanatory framework, and proposed solutions suggested by a collective consciousness will be in opposition to the cultural explanations with which those activists were raised (Groch, 1994). It is this oppositional consciousness that can cause people to engage in risky contentious political action.

A collective consciousness provides a lens through which a person's existence can be newly viewed and thus reinterpreted (Katzenstein, 1997: 8). In the women's movement, for example, "having your consciousness raised" meant becoming conscious of—and using—explanations that were group-based rather than explanations that focused on your own individual situation (Cassell, 1977: 16). Raising the consciousness of both women and men was the goal of one faction of the movement (Freeman, 1975).

The collective consciousness of a social movement suggests that personal problems result from unfair treatment rather than from a lack of personal effort or ability (Klein, 1987: 23) because, if it did not, there would be no reason for collective action to be taken to solve the problem. Therefore, collective consciousnesses are likely to suggest that, in the phrase used by the women's movement, "the personal is political." A collective consciousness identifies a problem, suggests a solution, invokes the necessity for collective action (Klein, 1987: 23), and impels its adherents to take that action. It provides the social movement with "justification, direction, weapons of attack, weapons of defense, inspiration, and hope" (Blumer, 1995: 73).

Collective consciousnesses also include delineation of group boundaries (Gould, 1993; Whittier, 1997). That is, they identify who is "with us" and who is "against us."

There were predictions that the development of a collective consciousness among people with impairments would be difficult, if not impossible. People with one type of impairment do not always identify or feel a commonality with people with other types of impairments. The problems faced by different impairment groups, and the solutions they seek, are sometimes not just different but completely contradictory. This makes the development of a shared consciousness problematic (Scotch, 1989). This is demonstrated by the fact that people with one type of impairment frequently stigmatize people with other types of impairments (Johnson, 1983). People with unseen disabilities are prejudiced against those with visible disabilities (Safilios-Rothschild, 1976: 45), people with physical impairments are prejudiced against those with mental impairments, and people without developmental impairments are prejudiced against people with such impairments (Ferguson, 1987).

Against these predictions, however, a collective consciousness did develop that was strong enough to impel contentious action. This chapter is concerned with that collective consciousness and its associated demands, which have motivated contentious actions taken by and for people with impairments since 1970. The chapter outlines two sets of demands. One set consists of demands that potentially apply to people with all types of impairments. Following Longmore (1997), Pelka (1997), J. Young (1998), and Zola (1987) we call these *cross-disability* demands. The second set of demands differs by impairment type; we call those *impairment-specific* demands.

CROSS-DISABILITY DEMANDS

Old and New Social Movement

Recently, some scholars of social movements have distinguished between old and new social movements. In their view, old social movements are concerned with issues of rights and the distribution of resources, for example the civil rights movement of the 1960s (Tarrow, 1992). New social movements are concerned with values (primarily postmodern and postmaterialistic), lifestyles, and self-actualization, especially among marginalized groups (Klandermans, 1991).[2] They are concerned with what some call *identity politics* (Anspach, 1979).

Cross-disability demands appear to be split into two major sets. Old social movement demands are concerned with the extension of the frame of civil rights to people with impairments; basically these civil rights are concerned with access (Barnartt and Seelman, 1988). The new social movement demands are concerned with lifestyle and attitudinal issues. DeJong (1983) calls the two sets of demands those for civil rights and civil benefits, while Pfeiffer (1993: 727) calls this the split between demands for rights and demands for services. The two groups of demands may also be called the disability rights movement and the independent living movement, although some people writing about collective action in the disability community seem to use the words interchangeably.

If these two sets of demands exist simultaneously, this suggests that both an old and a new social movement may be occurring contemporaneously. It is not clear without examination of data whether the split between the types of demands being made is wide enough to support this argument. This issue will be examined in later chapters.

If social movement theorists are correct, this conjunction of old and new social movements should be impossible. However, it is clear that it has happened before, in the 1970s women's movement, when one part of the movement demanded an extension of the frame of civil rights, equality, and nondiscrimination and the other part focused on consciousness-raising. The demands were being made by two distinct sets of supporters, who also used different tactics to achieve their ends—protests used by the former and consciousness raising sessions used by the latter (Freeman, 1975). It also occurred in the civil rights movement, when the black power movement was concerned with values and lifestyles at the same time that the other segment of the movement was concerned with civil rights. In that situation, also, it appeared that the people in these movements were different.

In the current case, it is not as clear that there are two separate groups of people. Pfeiffer (1988) claims that they overlap, but we will be unable to examine that claim empirically because of the limitations in the data we are using. We examine the argument that there is a split in demands in chapter 5.

The Old Social Movement Demand: An Extension of the Frame of Civil Rights

The most basic demand made by people with impairments is that the frame of civil rights be extended to them. In the process of frame extension, a frame originally applied to one group or several groups is extended to a new group, in what is essentially a process of cultural recategorization. Through this recategorization, it becomes legitimate for the new group to be making demands that had previously been seen as being inappropriate for them to make. Frame extension does not guarantee that the group's demands will be met, but it does suggest that the demands have some justification. Unjustified demands will never be met; justified demands might be. A successful frame extension is not a one-step process, but, rather, involves several stages: frame stripping, frame modification, and reframing.

Frame stripping involves justifying the inaccuracy or inappropriateness of the old frame through which an issue or group was viewed, so that it can be removed. After it is stripped off, a vacuum is created into which a new frame can be inserted. It is not a given that the new frame will be an extension of the desired frame, but this can be one outcome. Frame stripping may be done by the social movement, through protests as well as other means. It may also be aided by conscience constituents, especially in academic or media publications, who attempt to show why the old frame is outdated or perhaps empirically incorrect.[3]

Often the process involves *frame modification.* If this happens, modifications to the frame are formulated (and reformulated) both within and outside of the social movement. By the end of this stage, the social movement must have achieved some degree of consensus about which modifications it is willing to accept and which it rejects.

Reframing involves attempts by the social movement to apply the (possibly now modified) frame to its issue or group, which by this time has stripped off its old frame and is ripe for a new one. It also involves the social movement's attempts to make sure that the desired frame rather than another is inserted into the vacuum left by the frame stripping process.

Demands for the extension of the frame of civil rights, and for the actual rights that accompany the frame, form the core of one set of cross-disability demands propounded by people with impairments. These demands say that people with impairments want a change "from good will to civil rights," in the oft-quoted title of Scotch's (1984) book. Adherents use phrases such as "new paradigm" or "paradigm shift" to discuss the ways they want disability to be viewed by the public and for policy purposes. They want disability to be viewed not as a medical condition but as a social condition, not as a condition that causes pity but also one that does not carry with it an automatic denial of basic civil rights. Below we examine the demands that people with impairments were (and sometimes still are) making about how this process should occur.

Frame Stripping

If the frame of civil rights is to be extended to persons with impairments, there has to be recognition that they are worthy or capable of having civil rights. This meant that three extremely deep-seated ideas—the essence of the frame by which our society has understood disability—had to be removed. These ideas are (1) that disability was a medical problem, (2) that people with impairments were deviant and therefore stigmatized, and (3) that disability was an individual problem that would only be ameliorated by individual effort.

Disability as Sickness

The first aspect of the old frame that had to be eliminated was the medical model of impairment. In that model, persons with impairments are seen as having a medical problem; they therefore must assume the sick role (Parsons, 1951). This role defines sick people as passive, dependent, childlike but also exempt from ordinary social responsibilities. This view of people with impairments assumes that, because they are sick, they are incapable of performing their socially prescribed tasks. They are in need of help from doctors and other medical personnel who specialize in their particular type of pathology, and they are expected to cooperate with such personnel until they are cured. This model of disability has been the basis for federal laws that still provide monetary support for people with impairments because they were assumed to be unable to support themselves (Berkowitz, 1987).

Disability as Deviance

Disability is also been seen as being a deviant social role. Exemption from normal social roles meant that a person was both normatively and "morally" deviant and was, therefore, stigmatized. Although disability is not the same as criminality, Goffman (1963) suggested that the stigmas are comparable. Our culture does not accept stigmatized people on an equal basis; thus, stigma had to be removed before people with impairments could seek integration and equal opportunity, which are a central part of the frame of civil rights (Cook, 1991).

Disability as an Individual Problem

In order for the extension of the frame of civil rights to succeed, there had to be a change in the attribution of causality (Stone, 1989). Sickness and disability are seen in our society as individual problems, caused by individual traits or situations, and therefore amenable to improvement or solution only through individual rehabilitation and effort. For people with impairments, this involved cooperation with treatment personnel in areas such as vocational rehabilitation or physical rehabilitation. This was the basis for those laws about disability that mandated vocational rehabilitation and training (Hahn, 1985a, 1985b). In order to view disability as a civil rights problem and people with impairments as victims of discrimination, this view of causality had to change. Disability had to become viewed as being caused by society—and therefore amenable to solution at the societal level—instead of being caused by and solved by individual effort or the lack thereof (Hahn, 1988).

These three aspects of the cultural lens through which people with impairments have been viewed—disability as sickness, deviance, and individual problem—had to be removed before the civil rights frame could be applied to people with disabilities. Stigmatized people are not seen as having the right to demand civil rights or to claim discrimination. People with impairments have to be seen as people who wish for, and can live independent, fulfilling, and self-supporting lives. They have to become viewed as people who constitute a minority group that has suffered from a lack of civil rights in order for an extension of the frame of civil rights to be possible.

Frame Modification

The frame of civil rights could not be applied to people with impairments without some modifications. For example, the right to vote is worthless if the voting booth is inaccessible, so accessibility of voting booths has to be included as a civil right under a modified civil rights frame. Previous civil rights legislation reshuffled seating patterns but kept the same equipment, so to speak, in order that blacks should not have to sit only at the back of the bus. But people with some types of impairments needed new or modified equipment on buses so that they could ride them at all (Berkowitz, 1992). The frame modification that was needed for people with impairments also had to involve the recognition that issues are of differential importance. For example, while accessibility was one of several important civil rights issues for members of racial or ethnic minority groups, it is *the* civil rights issues for people with impairments. Issues would have to change their salience hierarchy within the frame of civil rights in order for its extension to people with impairments to be able to succeed in satisfying their grievances.

Finally, the modification of the frame of civil rights had to involve the recognition that, although civil rights for blacks or women can usually be achieved for free, civil rights for persons with disabilities might cost something. The modified frame had to accept the premise that it was appropriate for society to bear at least some cost. Because a large amount of the opposition to extending the frame of civil rights to people with disabilities was based upon its presumed cost to businesses and to society, the frame of

A demonstrator's sign at a New Jersey public transit accessibility protest illustrates the core civil rights issue for people with impairments: accessibility.

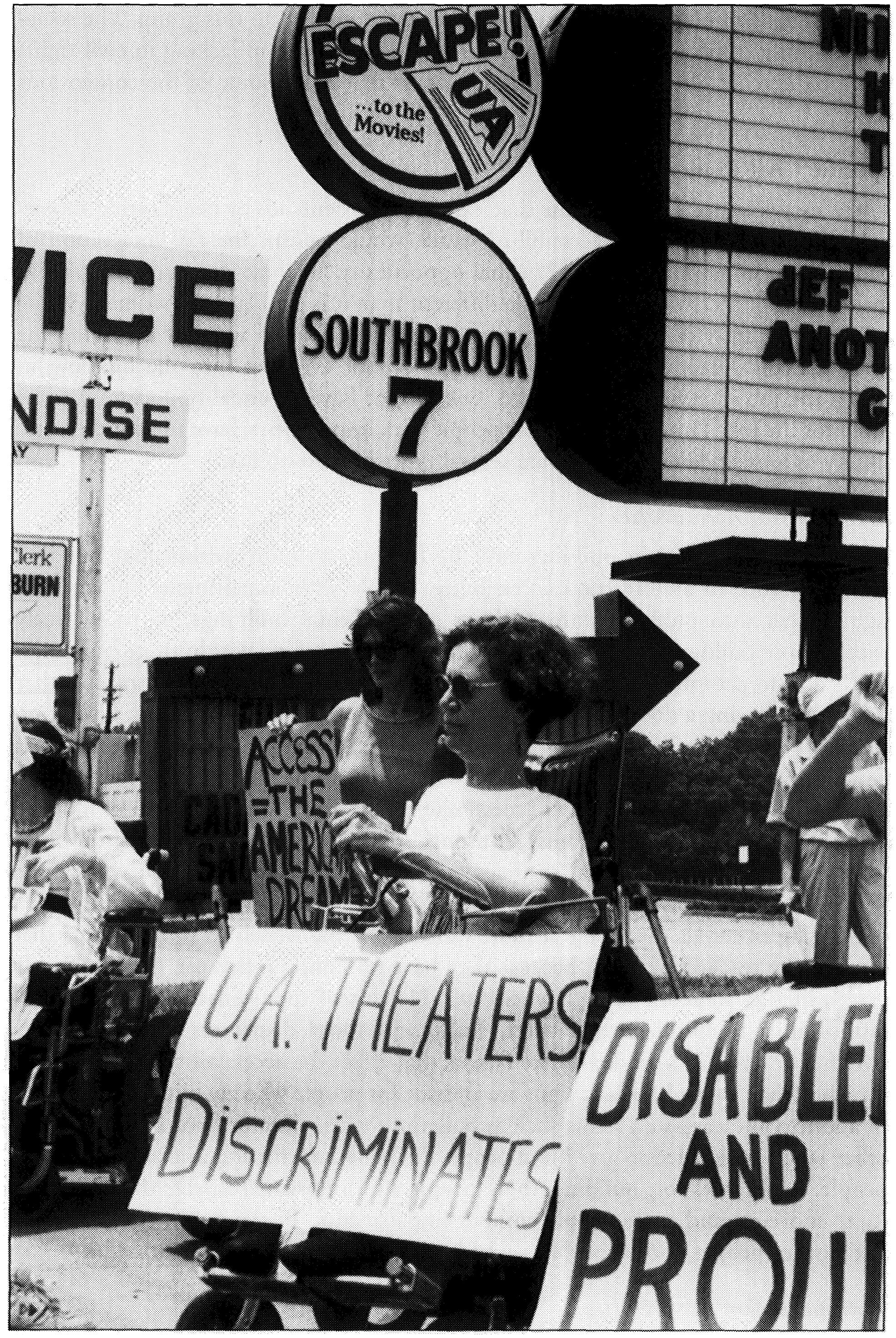
civil rights was modified to include the acceptance of costs that did not pose an "undue burden" upon a business. The modified frame said that employers had to make "reasonable accommodation" unless to do so would cause "undue hardship." These notions were not included in the 1964 Civil Rights Act or in other laws that codified the notion of civil rights when applied to blacks or women.

Reframing

People with impairments demanded that American society accept a new model of disability. This new model would view persons with impairments as a minority group,[4] would indicate that discrimination was one of the most important sources of problems, and would accept the idea that problems could be fixed if civil rights were given to people with impairments.

Demands for acceptance of this new model of disability began in the 1970s (see Kleinfield, 1977) but were more frequent in the 1980s (see Meyerson, 1988; Stroman, 1982). Academics (e.g., Deegan, 1981; Barnartt, 1986; Barnartt and Christiansen, 1985; Christiansen and Barnartt, 1987) as well as advocates (Gleidman and Roth, 1980; Hahn, 1985a, 1985b) emphasized that lower incomes, economic discrimination, and political powerlessness characterized people with impairments as they did members of other minority groups.

The notion that people with impairments were a minority group was not accepted instantly. Some academics (e.g., Lerner, 1985; Meyerson, 1988) and journalists



A local independent living center in Memphis, Tennessee, protests the common practice of forcing people who use wheelchairs to sit in the front rows of movie theatres.

(Davis, 1988) disputed the notion that the concept applied to this group. The societal reframing of people with impairments as a minority group lacking in civil rights was a basic tenet of the collective consciousness that drove some of the contentious actions.

Specific Civil Rights Demands

There are two aspects of this frame that are central to demands by people with impairments for civil rights: (1) accessibility, which would permit the full integration of people with impairments, and (2) equal opportunity. In these demands the relative importance of the two issues is a little different than it is for blacks or women. While equal opportunity is important, it often cannot be achieved without achieving the prior demand—accessibility. That is, if one cannot even get into the building in which the job interview is being held, one cannot have an equal opportunity to be hired for the job. Thus, civil rights for people with impairments have to include accessibility as a basic demand. There are several types of accessibility.

Architectural Accessibility

The ability to get into a building and the freedom to move within that building are the essence of architectural accessibility. People with impairments demand the right to get into public, commercial, or governmental buildings, to travel freely within those buildings, and to know where they are traveling within those buildings. Being able to get into a building may involve having a ramped or flat entrance rather than steps, having a doorway wide enough to accommodate a wheelchair, having no thresholds in the doorways, having automatic doors, or having other features (such as handles instead of doorknobs) that permit someone to be able to open them easily.

Once inside a building, other accessibility issues arise. A wheelchair user must be able to go into offices, bathrooms, bathroom stalls, and into all other areas in order to have a level of access equal to that of a person who does not use a wheelchair. Wheelchairs can easily be blocked or hindered by raised thresholds as well as by types of flooring materials that make it more difficult for the wheels to move. Floors that can only be reached by steps, because they have no ramp or elevator, are completely inaccessible to someone using a wheelchair. Heights of appurtenances such as countertops in a reception area; faucets, sinks, and towel dispensers in a bathroom; switches or desks in a work area are factors that affect the accessibility of inside areas for wheelchair users. Labels or signs are an issue for people who are blind. Braille signs or auditory indicators on items such as bulletin boards, elevator floor indicators, and office labels are needed to give blind people the same information available to sighted people. In an accessible building, then, people with impairments have the same ability to move around as do people without impairments. To the extent that there is a free flow of people, those people may be both with and without impairments.

Transportation Accessibility

People with impairments also demand the ability to use public transportation systems on the same basis as people without impairments. Transportation accessibility has to do not with where people sit on a bus but with whether they can get on the bus at all—and whether they know when to get off. At its most basic level, for transportation to be accessible a person cannot be denied access to it. For people who use wheelchairs, accessibility requires vertical access to the vehicle, station, or stop. Steps, whether into a station, onto a train platform, onto a bus or a subway train, or from the ground to an airplane, prohibit access for wheelchair users if there are no alternative access routes. In addition, accessibility means that there is room inside the vehicle for the person and the wheelchair. Completely accessible transportation would permit people with impairments to go to the same places, on the same schedules, with the same number of choices of times and routes, and with prices that are not higher than those charged to people without impairments.

There are also communication accessibility issues within transportation systems for people who have visual or hearing impairments. If transportation systems are to be accessible to those groups, information about times and places of arrivals and departures, both within stations and within vehicles, must be presented visually as well as aurally. Announcements of upcoming stations, schedule changes, equipment changes or breakdowns, or emergencies must be presented in both modalities. Communications using TDDs must be possible with ticket agents, and recorded announcements must be made available for TDD callers as well as for voice callers.

Communications Accessibility

People who have hearing or speech impairments demand communications accessibility. An environment that has communications accessibility has a lack of barriers to, and therefore access to, visual or auditory communication. Communications accessibility permits people who have hearing or speech impairments to be able to express themselves in the manner they choose with the assurance that they can be understood. Communications accessibility not only includes the removal of barriers that prevent access by the person with the impairment, as is the case with architectural barriers, but it also includes removal of barriers that prevent the flow of information between people with and without impairments.

Communications accessibility requires both proximal and distal accessibility. Proximal communication takes place through written or spoken words, through voice synthesizing equipment, or through the use of interpreters or captioning (either real-time or installed). Interpreters can either be sign language interpreters, who translate from spoken language to sign language or vice versa, or oral interpreters, who relay spoken language that cannot be seen to a person sitting quite close to them. Communications accessibility for distance interactions permits communications to take place through equipment, such as phone amplifiers, TDDs, or FM-loop systems, which permit all parties to send and receive information directly in a modality that they can interpret. Accessible distal communication can also occur indirectly using a telephone relay system, in which a third party can type words onto a TDD for the deaf person or read words from a TDD for a hearing person.

In a workplace, complete and ideal communications accessibility would mean that all work-, safety-, and personnel-related information would be communicated through a modality that the worker with an impairment could understand. Information in all events, including training sessions, staff meetings, office parties, and water fountain gossiping sessions, would be accessible. Off-site work, such as interviews, presentations, or professional meetings, would be equally accessible for all participants. Complete accessibility of a professional meeting for a hard-of-hearing or deaf person would include the same choice to attend or not attend sessions or to change sessions in the middle that a hearing person would have, instead of limiting the person to specific times or sessions for which interpreters are scheduled. All personnel, including coworkers and supervisors, would be able to communicate with, and to understand the communications of, the worker who has a hearing or speech impairment.

Communications accessibility in education would involve the ability for instructors and other students to be able to communicate with, and understand, students with hearing or speech impairments. Classroom interactions would be accessible, so that no student would ever be told, "Oh, just read the book." In addition, extracurricular activities, dorms, advising offices, and all other aspects of student life would be equally accessible to students with or without impairments.

Environmental Accessibility

People with impairments are demanding that all aspects of the built environment external to buildings be made accessible to them. One demand relates to curb cuts, which are needed by people who use wheelchairs or scooters. They argue that curb cuts also help several other groups of people, including parents pushing strollers, bicyclists, and rollerbladers. Another demand relates to streetlights. People who are blind are demanding that streetlights at intersections have audible indicators of when it is safe to walk. People with impairments are also demanding accessibility in parks and recreation areas that are built with public money. In some places they are demanding that paths be paved so that wheelchairs can move over them more easily or so that blind people can walk there more easily (Shribman, 1990).

Although access is a civil right sought by people with all types of impairments, impairment groups are somewhat divided on how best to operationalize the concept in some situations. This discussion of types of accessibility hints at some of the bifurcations that divide people with different types of physical impairments. Communications accessibility is a very different type of issue than architectural or transportation accessibility.[5] Thus, change that meets the accessibility needs of one group might interfere with the accessibility needs of another. For example, curb cuts help people who use wheelchairs but they pose some difficulty for blind people. Having auditory announcements of subway station stops helps people with visual impairments but not people with hearing impairments.

Equal Opportunity

The demand for equal opportunity as one component of civil rights for people with impairments does not differ markedly from demands made by blacks or women in their pursuit of civil rights. Equal opportunity means that people are not held back by characteristics such as race, sex, or impairment status in their pursuit of the good life. Some disability advocates call this the demand for "a level playing field." Equal opportunities for people with impairments include access to work and education.

Work

People with impairments are demanding equal opportunities in the area of work.[6] These demands apply to people who are already working, who are looking for work, or who want to look for work. In these situations, equal opportunity means nondiscrimination. Using the same language and conceptions used by blacks or women, people with impairments demand that there be no discrimination based upon impairment status in advertising, hiring, promoting, firing, or any other aspect of employment. The notion behind this language when it was first applied to blacks and women was that people with equal qualifications should be treated the same rather than being treated differently, based upon their race or gender. People with impairments demand that such nondiscriminatory policies apply to them as well.

People with impairments sometimes have additional needs that must be met if equal opportunities are truly to be equal.[7] A person might need the provision of an FM loop system for use during meetings, as well as a rule that makes sure that every speaker talks into the microphone that sends information to the user's hearing aid. Another person might need the installation of a ramp into the building, and another might need to be able to take extra rest breaks but then make up the time by working longer hours.

The presence of adequate and accessible transportation and education is related to the ability to work. If a person cannot walk or drive to work or be driven, and if the public transportation system is not accessible or if a transit system is expensive or unreliable, that person cannot get to work. Thus, the demands for accessible public transportation systems are also related to demands for equal opportunity in the area of work. In addition, if educational opportunities equal to those for persons without impairments are not available to persons with impairments, they will not be able to compete equally for jobs.

Education

Many advocates feel that equal opportunity for children with impairments should mean, as it does for black children, that separate is inherently unequal. The concept of integration, when applied to children from racial or ethnic minority backgrounds, means that they should be able to attend any public school and that the same rules for school and class assignments should apply to all children. For children with disabilities, the parallel notion is that they should be educated in integrated classrooms or in the least restrictive environment at public expense. In the United States this is called *mainstreaming* or *inclusion*.[8]

As with work-related demands, however, the situation relating to the education of children with impairments is not exactly the same as the integration of children of different racial backgrounds, so the specific demands are slightly different. One demand is that children with disabilities have the right to a "free" and "appropriate" education. In this case, free means that it will be paid for by the government, no matter what the cost. As children without impairments are educated at public expense, so should children with impairments be. Appropriate means that children should be educated in "the least restrictive environment." If that environment is a regular class in a public school, or a special class in a public school, that is where the child should be educated. If that environment is a private school, a segregated day school, or a segregated residential school, that is where the child should be educated.

Although the majority of the disability community supports the demand for mainstreaming, there is not complete agreement about this demand. In particular, there is a split between advocates for children with physical (primarily mobility) impairments and advocates for children with hearing impairments. The former are strong advocates for mainstreaming; the latter are not. Many leaders in the deaf community support sending deaf children to segregated programs or residential schools rather than to schools where mainstreaming is practiced. They believe that, in reality, the least restrictive environment for those deaf children for whom ASL is their native language is one in which the child can communicate with everyone using that language, one in which deaf adults can serve as appropriate role models, and one in which the culture of deafness is taught to every deaf child (Lane, 1992).

Activists who want the frame of civil rights extended to people with impairments think that in accessibility, work, and education people with impairments traditionally have not had civil rights. They emphasize the word *rights*. They demand the right to work without experiencing discrimination, the right to a free and appropriate education, the right to go into any public building or place, and the right to ride any mode of public transportation. These demands are cross-disability demands, although impairment groups do differ on some of the specifics.

The New Social Movement: Demands for Independent Living

The second set of cross-disability demands centers around the ability of people with impairments to live independently. The concept of independent living for people with impairments has been around since the post-World War II years, when, as noted in chapter 1, the University of Illinois began to make it possible for returning veterans with impairments to attend college. It attracted more attention when Ed Roberts demanded, in the early 1960s, that the University of California at Berkeley let him attend. By 1976, twelve other students with severe impairments had enrolled (Pelka, 1997: 60), and the group worked to make the campus and the community accessible. In 1972 Roberts founded the Berkeley Center for Independent Living. (Funding for independent living centers was included in the Rehabilitation Act of 1973, and this spurred the growth of such centers around the country.)

The central demand of the independent living movement is that society should help to make it possible for people with impairments to be able to live independently. They should not be forced to live in institutions because they need care that only an institutional setting could offer them. Rather, they should be able to live in a community of their own choosing, in a residence of their own choosing, work at a job of their own choosing if they can, and associate with people of their own choosing. These demands revolve around choice, self-determination, and self-actualization. People who live in institutions are told what to do and when, where, and with whom to do it. Called total institutions by Goffman (1961), such places permit no choice or self-determination. Residents (or patients or clients, depending upon the terminology favored by a particular institution) are awakened at the convenience of the institution, they may be dressed in the uniform of the institution, and their activities are scheduled and limited by the institution. In short, they have no freedom of choice.[9] They do not determine their own lives; rather, they are put in childlike and dependent positions, consistent with the sick role they are assumed to be in. Some younger people with impairments live in nursing homes, whose populations are primarily older people, because that is the only way they can get the assistance they need for daily living activities.

The independent living movement is fighting this type of life. If society is willing to pay money to keep people with impairments in institutions, it should be willing to spend that same money keeping them out of institutions. Many people who now live in institutions would be able to live on their own if they had personal assistant services. Personal care attendants should be available to assist disabled people with those tasks of daily living that they cannot do for themselves. Help might be needed in tasks such as turning over in bed, getting dressed, bathing, eating, driving, house cleaning, and shopping. Activists in the independent living movement argue that people with impairments who have this kind of assistance can work and be contributing, tax-paying citizens. Furthermore, they can and should be able to control their own lives. They should be the bosses. They should hire their own attendants, who should work for them as for any other employer except that their place of work may be in their boss's house.

The independent living movement is also making monetary demands. One demand is for federal or state support for personal care attendants, in addition to, or instead of, such support for institutional care. Medicare or Medicaid assistance should not only pay for personal care within institutions but should pay for care within people's own homes whenever possible. Some activists wish to see payments for personal care attendants uncoupled from health insurance, while others would like to see the rules regarding government-sponsored health insurance changed so that it would pay salaries for personal care attendants outside of institutions (and under the control of the person using the services).

Independent living demands may appeal to different age groups and impairment types than the other demands discussed here. DeJong (1983) suggests that these demands are most relevant for people with severe impairments—primarily spinal cord injuries, muscular dystrophy, cerebral palsy, multiple sclerosis, and postpolio syndrome. This part of the disability movement focuses on older adolescents and younger adults of working age. It was initially not yet concerned with older people, although, as these younger people with impairments age, its focus is likely to shift.

Activists in the independent living movement are demanding a reconfiguration of disability policy (Ascher et al., 1988; DeJong, 1983; Zola, 1983a), which, at both the federal and state levels, has traditionally focused on income support and medical and vocational rehabilitation (Berkowitz, 1979; Liachowitz, 1988; Stone, 1984). Disability policies have been based upon the notion that people with impairments are ill, are involuntarily incapable of performing economic roles or social functions, and are therefore excused from them. Such people are deemed worthy of public support, because the "illness" is not their fault (Scotch, 1994).

Independent living activists are also demanding that the old lens through which disability was viewed be stripped off for policy purposes. Their concern, however, is less with extending the frame of rights than it is with "day-to-day life and making decisions that lead to self determination" (Pelka, 1997: 166). They want people with impairments not to have to live out the sick role but to be able, with assistance, to live out a "well" role. Faced with a person with an impairment who had a job but no accessible transportation, independent living activists would want to assist the person to obtain usable transportation, while disability rights activists would take action to make local transportation accessible to that person and all others as a matter of "rights." As Pfeiffer (1988) notes, the independent living movement is concerned with providing services that will make it possible for people with impairments to function independently. Activists in this movement want people with impairments not to be viewed as patients who need to live in hospitals, nursing homes, or other types of institutions, but as people who can, with some assistance, live well outside of institutions. They note that assistance outside of institutions costs less than the same assistance when given inside an institutional setting.

In part, this movement is challenging the professional domination of professionals in the fields of medicine, rehabilitation, psychology, social work, and related fields. As such, it is related to social movements such as the patients' rights movement, the consumers' rights movement, and the self-help movement (DeJong, 1983; Pelka, 1997: 61), all of which have similar demands.

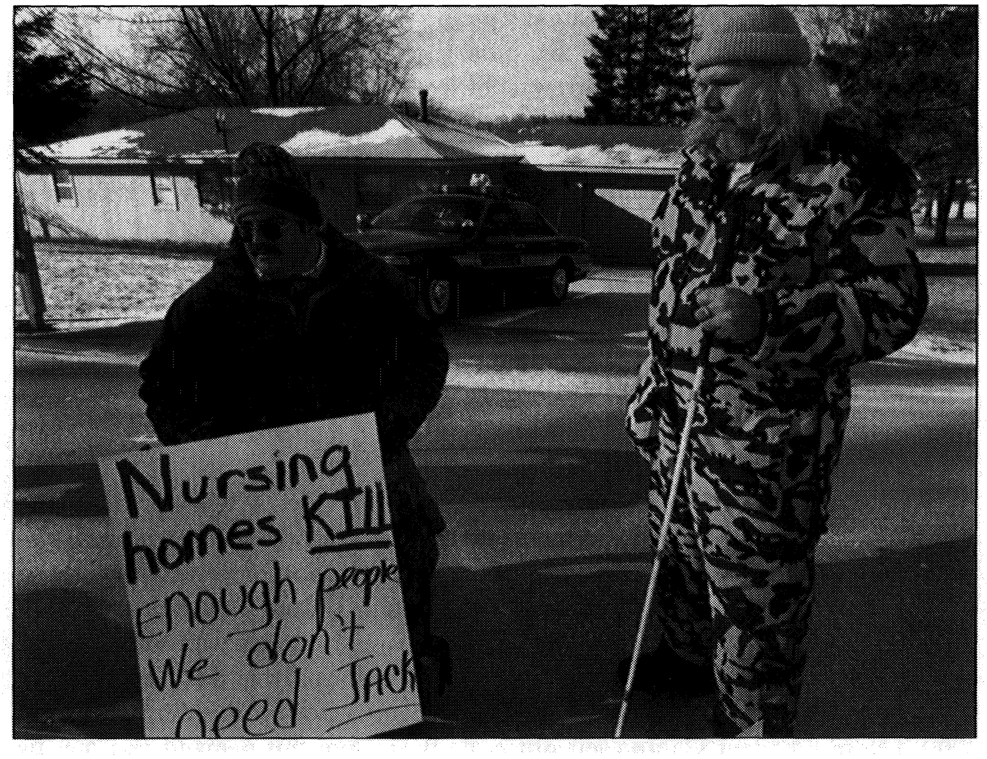
Overall, the basic independent living demand is that people with impairments should be able to direct their own lives and participate actively in the day-to-day life of the community (Ascher et al., 1988). They want self-actualization to be possible for people with impairments, societal integration for people who have been institutionalized or extremely marginalized or both, and they want personal assistance services to be provided so that living outside of an institution can be possible.

Both Movements

Pfeiffer (1988) notes that divisions between what are frequently called the disability rights movement and the independent living movement are not recent and he notes that sometimes the two movements are lumped together under the rubric of the independent living movement. Furthermore, he notes that if both do not occur, people who do not receive services may not be able to fight for rights. They are two halves of the coin that are necessary for people with impairments to be fully functioning citizens.

Other Demands

There are several other issues with which some cross-disability activists are concerned, including assisted suicide, disability culture, portrayals of disabilities, and telethons. These issues primarily concern how disabled people are perceived by society. These are important issues for many disabled activists, but their demands do not fit neatly into the categories of civil rights and independent living, so we consider them separately.



Disabled rights activists picket Jack Kevorkian's house in West Bloomfield, Michigan, to protest doctor-assisted suicide.

Assisted Suicide

Assisted suicide is one of the newer issues that concerns activists, although it is related to issues of genetic testing and abortion that have concerned some activists for many years. With national awareness of the situations in which Dr. Jack Kevorkian has helped some people to end their lives, people with impairments have become quite concerned about its usage. If assisted suicide becomes a legal way for people with impairments, seen as pitiable, helpless, and hopeless, to take their own lives, it can be used also as an excuse for society not to provide them with those services that would permit them to live satisfactorily. They admit that people with impairments who have not had services may not be surviving well. But, they argue, with services these people could survive quite well. The disability community is demanding that society provide services so that people can live rather than legalize assistance for them to kill themselves.

Portrayals

Another one of the issues that concerns people with impairments is how they are portrayed. One part of this concern relates to newspaper coverage of disability, which tends to fall into two categories. One category consists of "Tiny Tim stories," which focus on the sad, unlucky, disabled person, in need of pity and charity. These stories tend to focus upon the terrible situation a person with an impairment faced or faces; they imply that impairment caused that pitiable state. The other category consists of "supercrip" stories. These stories portray a plucky disabled person who, despite having an impairment that ought to make it impossible, can climb mountains, literally or figuratively. The spotlight is on someone who has achieved a goal that would have been a superhuman feat even for someone without an impairment and may be even more of a feat for a person with an impairment (Shapiro, 1994).

These two types of stories clearly derive from the medical model. The first "Tiny Tim" stories suggest that the person cannot be blamed for being sick, because one of the tenets of the sick role is that people are not responsible for becoming ill. And, the stories imply that people who are sick should be pitied because they are unable to participate in society. The supercrip story shows the opposite—someone who has gone from being ill to being superhuman. In the first case, the pitiable person needs charity, and in the second case, the person needs nothing.

People with impairments have tried for many years (mostly without success) to change the focus of these stories. In recent years, new demands have arisen relating to other aspects of portrayals. One set, related to a lack of realism or stereotyping, has to do with the memorial constructed to honor Franklin Delano Roosevelt. Although Roosevelt hid his impairment from the public, apparently mostly with success, some people with impairments want him to be portrayed realistically, so that his wheelchair shows in at least one of the several statues being constructed for this monument. (In 2000, before President Clinton left office, he made sure this demand was met by adding one more statue to the monument.)

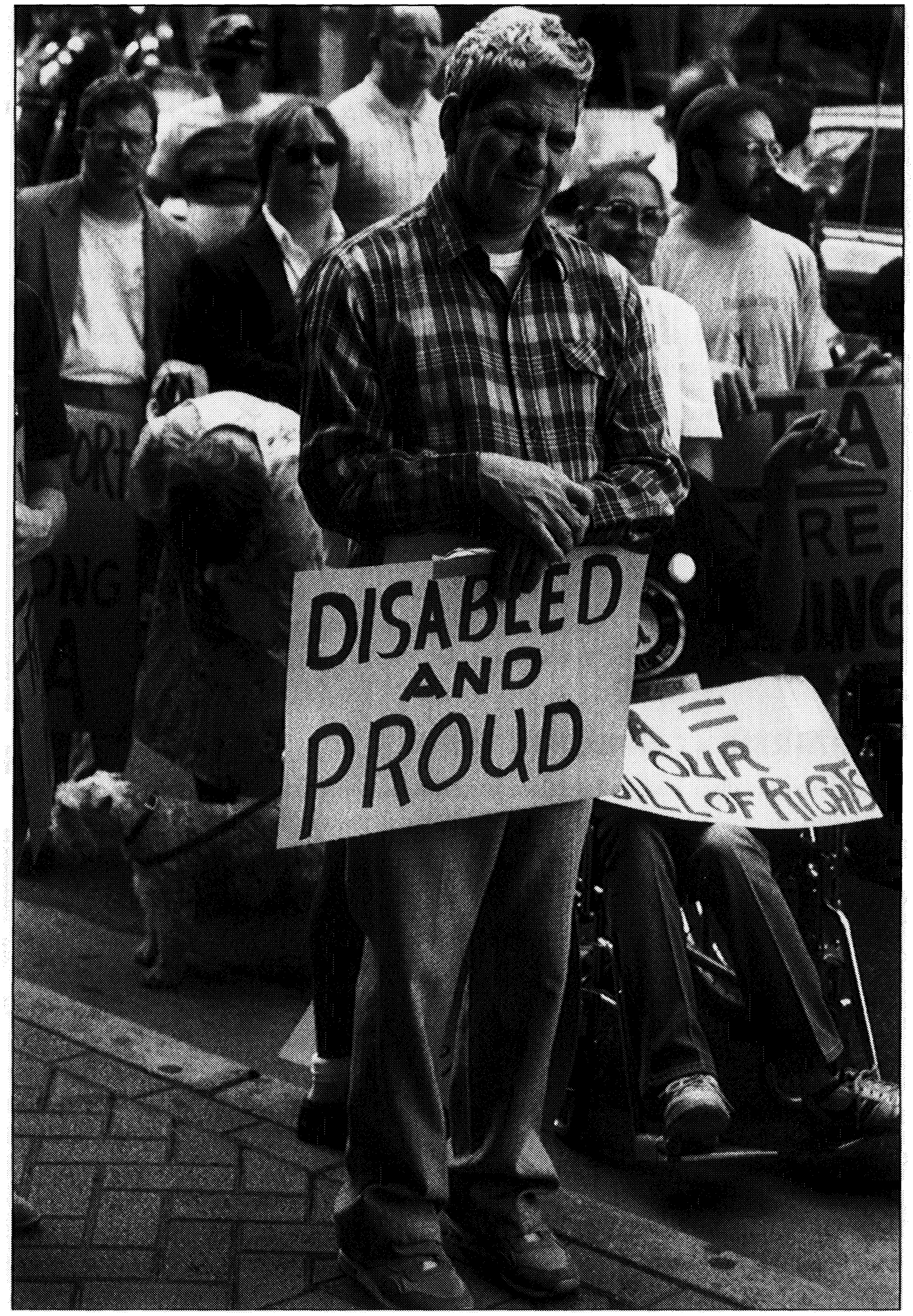
Who actually portrays a person with an impairment in movies or television programs is an issue that has incensed the deaf community for many years. There have been several instances in which hearing actors or actresses have played deaf characters either in movies or on television shows. People with other types of impairments also have rarely been portrayed in movies or advertisements, and activists have demanded their presence and accurate portrayal.

Telethons

Telethons are a type of portrayal that specifically concerns many activists. They represent one of the most despised aspects of disability history. In order to raise money, telethons emphasize many of the worst American cultural notions about people with impairments, portraying them as if they are incapable, pitiable, and in need of charity. Telethons are used to raise money to help people who are assumed to be unable to help themselves. All of the worst stereotypes are emphasized in an effort to pull at the heartstrings and purses of the general public. In the process, say the advocates, stereotypes about disability are reinforced, both for people with impairments and people without.

Disability Culture

Some activists within the disability community are demanding recognition of disability as a cultural aspect of a person and not just a physical aspect of a person.



The development of a minority group consciousness has given rise to a disability culture, which seeks to promote pride in the history, activities, and cultural identity of people with impairments throughout the world.

This culture, they say, has its own norms, values, symbols, jargon, and other components. Disability culture includes a group definition of people with impairments not as patients or welfare recipients but as an identifiable minority (Longmore, 1995). There is a public vocabulary (*persons with disabilities* instead of *the disabled*, or *deaf* instead of *hearing impaired*). There is also a private vocabulary, which persons without impairments should not use or do not know about (e.g., *supercrip*, a term used in somewhat the same way the word *nigger* is used in the black community, or *disabled person*, which indicates pride in having a disability). Disability culture includes the rejection of some personality characteristics (passivity, dependence) in favor of others (assertiveness, control) as well as disability art and theater, which celebrate disability pride. There is even, some argue, (only partially tongue-in-cheek) disability food—fast food from drive-through windows (because there are no accessibility issues with the restaurant).

Gill (1995) notes that the concept of disability culture serves to unify people with disabilities and to recruit new people into the community. From the point of view of disability culture, disability can be something to celebrate (Brown, 1995). It has become a rallying cry, but, more than that, it sets up terms for the debate that are different from the way disability was perceived by the public, as well as by adherents, prior to the creation of this phrase.[10] The phrase highlights the demands to change the frame through which disability is perceived, from being a medical problem to being both nonmedical and not a problem.

IMPAIRMENT-SPECIFIC ISSUES

The demands discussed so far relate to cross-disability issues. But groups of people with specific types of impairments have specific demands that relate to the particulars of their own experiences.

Demands Related to Deafness

In recent years, a social movement has arisen within the deaf community. The movement goes by various names including the bilingual-bicultural (or bi-bi) movement, the Deaf Pride movement, and the Deaf Power movement (Rose and Kiger, 1995). Jankowski (1997) calls it the Deaf movement. The convention adopted by those within the movement is to use the uppercase "D" in *Deaf* to indicate adherence to their demands; a lowercase "d" simply indicates audiological status. That is, people who are "deaf" have hearing losses in the range known by audiologists as severe or profound (i.e., not hard-of-hearing) but do not identify themselves as part of the Deaf community (B. White, 1998) and do not support the demands made by that community.

Some of the issues for people with hearing impairments overlap those of people demanding disability rights; this is especially true in the area of discrimination. However, the specific demands for accessibility and equal opportunity differ. Deaf people are not concerned with getting into a building but with being able to communicate with the people in the building once they are inside. Whether it is a hotel, a movie theater, a court, a doctor's office, or a job interview, the issue is communication.

Deaf people are demanding the provision of interpreters in doctors' offices, courts, and hospitals; captioning of movies and videos; flashing light alerting systems in hotels; TDD-accessible 911 emergency telephone systems; and other types of communications accessibility. For deaf people, communications accessibility is the core of civil rights.

Employment discrimination issues for people with hearing impairments also revolve around communications accessibility. In a workplace, the provision of a TDD (about a $250 expense) or an interpreter, or restructuring a job so that nonessential telephoning duties are moved to another position, are ways in which employers can accommodate deaf workers. Deaf people feel discriminated against, for example, if they are not hired because employers refuse to make such accommodations or if they cannot attend a required training course or miss important information presented at a staff meeting because no interpreter or other communication facilitator was used.

There are, however, larger issues for many deaf people. Deaf culture and its recognition and acceptance as distinct from hearing culture is one of the major issues for those deaf people who consider themselves to be Deaf (White, 1998). This culture is seen to have its own norms or rules for behavior, values, symbols, language, and other components. Norms include, for example, tapping someone on the shoulder, stomping on the floor, or flashing the lights in a room to get someone's attention, introducing oneself by telling one's name and where one went to school before offering any other information, and assuming that gatherings in a house will take place in the kitchen (because it usually has the best lighting). Other norms include raising and shaking hands in the air instead of clapping and standing farther apart than hearing people do when communicating in order to utilize the entire upper body for sign communication (White, 1998). There are Deaf values, including the value on signing as opposed to speaking or lipreading, a strong positive regard for ASL, rejection of the clinical-medical perspective of deafness, and a high regard for deaf children, who symbolize the continuation of Deaf culture.[11] One of the most central values is that deaf people should identify with the Deaf movement and should demonstrate cultural pride. There are symbols, including the "I Love You" symbol and an ear with a slash through it. There are slogans, such as "Deaf people can do anything except hear," first said by Dr. I. King Jordan when he became president of Gallaudet University (Christiansen and Barnartt, 1995). There is a non-auditory language that contains all of the linguistic components found in auditory languages (Neisser, 1983). One demand is that ASL be recognized as the equivalent of other languages. There is a history of the Deaf community and Deaf people that is as separate from the history of hearing people as the history of blacks is separate from the history of whites. There is Deaf humor, including a corpus of jokes passed from one generation to the next. There is also Deaf art as well as Deaf poetry (which is meant to be signed, not read) and Deaf theater. There are also items of material culture that are different for deaf people than hearing people, such as TDDs, flashing light alerting systems (doorbells, baby monitors, smoke detectors, and alarm clocks), and vibrating bed alarms.

Jankowski (1997) argues that the most basic difference between the Deaf movement and the disability movement is that, although the disability movement has embraced the frame of civil rights in its discussions of access and discrimination and in its demands for change, the Deaf movement has not. Rather, it has embraced the frames of multiculturalism and diversity. Under this frame, Deaf people would fight not for integration but for respected segregation. She and other activists who embrace this perspective disavow the label of disability. They see themselves as being part of a linguistic minority rather than part of the disability community, a position the United Nations endorsed in 1987: "deaf and gravely hearing-impaired people [are] to be recognized as a linguistic minority, with the specific right to have their native and indigenous sign languages accepted as their first and official language and as the medium of conversation and instruction" (Wrigley, 1996: xiv). For activists who accept this position, being considered to be disabled is not a compliment, and it is not an option.[12]

The central issues for the Deaf movement are education, language, and culture—three issues that are intertwined. It is in the area of education that Deaf activists most strongly oppose the views of people with other types of impairments. Although some Deaf people do support the concept of mainstreaming, most suggest that it has problems. Deaf students in regular schools cannot just be put into a class with other students and be expected to succeed in the same way, perhaps, that a child who uses a wheelchair might. Deaf children need additional resources. They need teachers who know how to communicate in sign language, or because such teachers are so rare, they need interpreters. Because of issues about correct interpretation of advanced concepts at the high school and college levels, it is crucial that the interpreter and the teacher work together to make sure that the interpretation follows the meaning of the concept rather than be a word-for-word translation, which is almost never done.[13] In addition, because deaf students cannot watch an interpreter and take notes at the same time (and because few regular classrooms would be able to allow the additional time needed for them to take notes), students in higher grades and college classes need notetakers if they are to be on an equal footing with hearing students in those classes.

But even if competent, knowledgeable interpreters and diligent notetakers are provided, deaf students in hearing classrooms or schools are at a disadvantage in social interactions and extracurricular activities, for which interpreters are never provided. Because of this, deaf students who attend hearing schools will have more limited opportunities to participate on student councils, sports teams, or other extracurricular activities that are important to high school and college students, and they will have more limited communication in social interactions with their hearing peers. Thus, some deaf people and educators feel that a regular classroom does not constitute a "least restrictive" environment and, in fact, may constitute the *most* restrictive environment. Those who are adamant about this situation feel so strongly that they use terms such as "communication abuse," "communication violence," or "cultural genocide" when they discuss mainstreaming (Jankowski, 1997: 154; Foster, 2001). They favor the use of separate classrooms or, as the better alternative, separate schools where deaf students can interact with other deaf students and deaf, preferably native, signing teachers in environments that address their needs for communications accessibility.

In addition to supporting the use of separate classrooms or schools because of the communication accessibility, some deaf people favor the continuation of residential schools (even if many of the students are day pupils or pupils who go home for weekends) because they think that this is where Deaf culture is transmitted. In residential schools, Deaf culture is taught by osmosis, through role models, and sometimes explicitly, along with Deaf history, whereas in public schools with small numbers of other deaf children and no deaf adults, deaf children are not systematically exposed to either Deaf history or culture. If residential schools die out, it will be much more difficult to socialize young deaf people into Deaf culture, because they are likely to be isolated from other deaf people. Activists in the Deaf movement cite the demands of cultural continuation and equality in school situations in their opposition to mainstreaming.

Another reason that many Deaf activists oppose mainstreamed programs for deaf children is related to language. They feel that deaf children learn best if they learn ASL as their first, natural language and then learn written and perhaps spoken English as their second language. In that situation, English would be taught as a second language, and there would be no assumption that children would have learned it as a first language (Neisser, 1983). Deaf activists also demand that programs that teach ASL as a first language be recognized and supported. It follows then that they support the hiring of more deaf teachers and school administrators, or, failing that, the hiring of hearing people who are fluent ASL signers. They feel that native ASL ability is a qualification that must balance other types of academic qualifications or training when candidates for positions in residential schools are interviewed or hired.

A somewhat more recent demand made by the Deaf movement involves an end to the use of cochlear implants in children. Advocates of this position say that "[t]he procedure is highly experimental, there is no evidence that children who receive cochlear implants learn English any better than they would with conventional hearing aids or with no aid at all, and the use of an implant could 'delay the family's acceptance of the child's deafness and their acquisition of sign communication' and thus have a negative impact on the child's future quality of life in the deaf community" (Christiansen, 1998: 1056).

The demands of Deaf activists, then, are very different than the demands of other disability activists. Although Deaf activists support the extension of the frame of civil rights to deaf people, their definition of civil rights is different than that of other groups. For them, "civil rights" includes the right to their own language, control over their own schools, their own teachers and other school personnel, and their own teaching methods. But their demands are not limited to civil rights; rather, they include issues relating to linguistic freedom, bilingualism, and being viewed as a linguistic minority group.

Demands Related to Blindness

Demands related to blindness fall into several areas, one of which is transportation accessibility. Blind passengers have been denied services completely or have been hassled, intimidated, and sometimes humiliated, especially on airplanes. Some blind passengers have been told they could not keep their white canes with them at their seats. One blind airline passenger was required to sit on a blanket in case she or he had an "accident." Blind passengers have been denied access to exit row seating, or, in some instances, were arrested for refusing to sit in an exit row seat. In 1988, the president of the National Federation of the Blind, Kenneth Jernigan, stated in several speeches and in Congressional testimony that "[t]oday the situation is such that no blind person anywhere in the country can board a plane without fear of harassment, public humiliation, and possibly arrest and bodily injury" (Matson 1990: 531). (Since that time, several laws were passed to attempt to clarify and ameliorate the situation.)

Another set of demands relates to wages and other conditions at sheltered workshops. The Fair Labor Standards Act of 1938 encouraged the growth of such workshops for blind people. In the early 1970s, there were approximately 160,000 workers in sheltered workshops, and we can assume that the majority of them were blind, as the law did not apply to workers with other types of impairments until it was amended in 1971. Even by the 1990s the majority of workers in these situations were not paid minimum wage rates (Pelka, 1997: 282). Blind workers in sheltered workshops began to demand that wages be raised to at least minimum wage, that unemployment compensation and worker's compensation be introduced, and that the possibility of collective bargaining be permitted (Matson, 1990: 755–57).

For a number of decades, a related concern was the accrediting of agencies that work with or for blind people. At issue are the operations and objectives of the Commission on Standards and Accreditation of Services for the Blind (COMSTAC), organized in 1965 and later renamed the National Accreditation Council for Agencies Serving the Blind and Visually Handicapped (NAC). Activists objected to the operations of this agency, which had little or no representation by blind people. NAC was perceived as having sympathies with organizations "for the blind," instead of organizations "of the blind," and many thought its outlook about blindness was paternalistic and condescending.

Finally, the blindness community has attempted to fight *against* paternalistic attitudes, discrimination, segregation, rejection, and a general sense that blind persons are inferior and *for* a recognition that they are competent and normal (Matson, 1990: 79).

Demands Related to Psychiatric Impairments

Activists have made a number of demands for changes in treatments and other aspects of psychiatric care. One set of demands is related to promoting empowered, positive, non-psychiatric identities; the goal is "relabeling" and shedding "ex-deviant" labels (Emerick, 1991). This may be the impairment group for whom the frame-stripping part of the frame extension process is the most important. Because stigma is attached to the label "ex-mental patient" (Goffman, 1963; Szasz, 1961), ex-patients seek to provide themselves with new, more positive, and less deviant identities. As former patients explain:

> the way society views us is all wrong. . . . They then disqualify us—throw us out with the trash. Mentals [sic] are shunned, ostracized, or treated with a lack of respect. We are discriminated against, just like other minorities.
>
> Ever since I joined this [activist] group, they have got me to think differently about myself. I am no longer ashamed. It's not my fault. (Herman and Musolf, 1998: 446)

Psychiatric survivor Judi Chamberlin, an early activist, is quoted as saying "all laws and practices which induce discrimination towards individuals who have been labeled 'mentally ill' need to be changed, so that a psychiatric diagnosis has no more impact on a person's citizenship rights and responsibilities than does a diagnosis of diabetes or heart disease" (Pelka, 1997: 252).

The other category relating to psychiatric impairment demands is patients' rights. The most radical of the groups use terms such as "compulsory psychiatry" and call themselves "the psychiatric survivor liberation movement." These rights, they say, include an end to forced medication, which they call "chemical restraints" or "chemical straitjackets" (Pelka, 1997: 63), an end to forced (some groups would say, *all*) electroshock treatments, an end to forced psychosurgery (i.e., lobotomies), which they call "surgical mutilation", and, overall, an end to the violation of civil rights that occurs in an involuntary commitment to mental hospitals. The demands related to ending forced medication have increased with the passage of laws in some states, such as "Kendra's Law" in New York State, which permit the practice.[14] Some groups demand an end to the use of all psychotropic medication, although others think that such medicines are overprescribed but sometimes still necessary. Many groups demand an end to what they see as being tortures, including solitary confinement and tying a person to a bed, which are done in the name of treatment. Activists want mental illnesses to be considered equivalent to physical illnesses for purposes of rights and health insurance, with the end result that American culture would destigmatize mental illness.

To some extent, the demands of activists in the psychiatric survivors' movement do not seem to overlap with either the disability rights movement or the independent living movement. And it is true that, in some specifics, they do not. Disability rights activists are not always attuned to the specific issues that face psychiatric survivors. And this movement sees the specific demands made by the independent living movement as having little to offer to it, since the latter's concerns are with issues of physical survival and assistance, not labeling or rights to refuse treatment.

But there are similarities. Stigmas apply to all people with visible disabilities and to those with invisible disabilities when or if those become known (Goffman, 1963). In addition, activists within the psychiatric survivors' movement applaud the extension of the frame of civil rights to people with mental as well as physical impairments. Despite the lack of overlap in specific demands, there are survivor activists who see themselves as part of the disability rights movement, and disability activists who see the psychiatric survivors' movement as part of the movement toward disability rights.

Demands Related to Developmental Disabilities

The earliest demands relating to developmental disabilities (which used to be called mental retardation), primarily made by parents, were related to the flagrant and severe abuses that occurred in the institutional settings in which their children lived. Some of these abuses even caused deaths. Some of the most egregious problems have been reduced, if not solved, as a result of lawsuits and other actions brought by parents as part of the parents' movement described in chapter 1. But abuses and deaths of adults with mental retardation continue to this day (see, for example, Vobejda, 2000). Policy changes that favored deinstitutionalization and "normalization" reduced the numbers of children who live in institutional settings, but approximately 60,000 people with developmental disabilities still live in large state institutions, with another 40,000 living in large private facilities (Ferguson, personal communication, 1998). Thus, demands are still made for appropriate education and state support for people with developmental disabilities. Ferguson (1987) notes, however, that some of the demands made by the disability community have bypassed people with severe retardation, especially those for whom independent living is not, and never will be, possible. He notes that "disability," when used in the context of disability rights, has come to mean physical disability, not cognitive disability, and the minority group model, which reduces the limitations that accompany physical impairments to societal (i.e., discriminatory) practices, cannot deal with the situation of people who have severe mental retardation. As he notes, this has occurred partly because the policy reforms being sought by the independent living movement are being justified on economic grounds—if people with impairments could become self-reliant, they could cease to be dependent upon society's handouts. People with severe cognitive impairments will not cease to be dependent and will never live independently.

CONCLUSION

A collective consciousness has driven contentious political action by people with impairments. We have attempted to define the ideas that form this consciousness, spell out the grievances that have led to action, and suggest some of the remedies. The problems identified are diverse and deeply rooted in our society. They range from the ways deafness and disability are perceived to concrete problems of accessibility, discrimination, and, some would contend, human rights violations (see any issue of the journal *Dendron*).

The solutions are also diverse. They involve a cultural recategorization in which disability would be reframed. This reframing would include viewing people with impairments as a minority group lacking in civil rights, and would call for rethinking of disability policies so that they are not based upon an automatic equating of "disabled" with "unable to work." The recategorization would involve new rules, new roles, and sometimes new construction.

In the next chapters, we show how various demands have been translated into contentious political action. We show how members of a powerless, politically almost invisible community took the ideas that form the collective consciousness of a social movement and translated those ideas into action. We examine the ways in which the rhetoric of the protests fits with the actions that have been taken.

NOTES

1. This concept is similar to other concepts that have linked beliefs to contentious action, including "political culture," used by political scientists, and "mentalities," used by historians (Tarrow, 1992).

2. New social movements are not really new, either empirically or conceptually. The revitalization movements that Wallace (1956) discussed more than forty years ago resemble new social movements, although they did not grow out of a postmodern context. In addition, new social movement issues surfaced in the American countercultural movements of the 1960s (Turner, 1968; Westhaus, 1972).

3. For example, articles by Hacker (1951) and Streib (1963) aided in extensions of the frame of civil rights to women and to the elderly, respectively.

4. Although sociologists disagree about the defining aspects of a minority group, they tend to agree that it applies to people who differ physically or culturally from the dominant group in a society; who experience economic and political discrimination, and powerlessness; for whom membership in the group is ascribed rather than achieved; and for whom intramarriage is common (Stroman, 1982).

5. Cost is one area in which the types of accessibilities differ. Most of the costs of achieving accessibility in the built or natural environment involve one-time costs, either for removing barriers or for adding accessibility features. Usually these are accommodations that, once made, will not require additional expenditures, except for maintenance or replacement of equipment. Some aspects of communications accessibility can be achieved for free or for minimal cost. Chairs can be rearranged into a circle in classrooms; professors can learn not to speak while they are writing on the blackboard; walls can be repainted. But communications accessibility more often involves both one-time and ongoing costs. One-time costs can include the installation of visual fire alarm systems, loop or infrared listening systems, electronic signs or platform safety lights, telephone amplification devices, or built-in TDDs. They could also include purchasing equipment such as TDDs, FM systems, or hearing aids. Ongoing expenditures in addition to maintenance can include costs for closed or real time (live) captioning, note-takers, or sign language or oral interpreters (Barnartt, Seelman, and Gracer, 1990).

6. A related demand, which does not fall under the frame of civil rights, asks that support payments that are given to people with impairments under some circumstances, through Supplemental Security Insurance (SSI) or Social Security Disability Income (SSDI), be restructured so that they do not include work disincentives. That is, they demand that these programs be structured so people do not automatically lose medical assistance through Medicaid, an important benefit carried by these programs, in addition to losing the support payments, when they earn above the minimum amount. If people also lose their medical insurance when they start to earn money, they may be much less inclined to try to look for work because the fear of losing health insurance coverage is greater than the desire to work, especially if it is likely that the job would not carry health benefits. This is not an issue for all people with impairments. People with some types of impairments may have no more health concerns than an average person (Pfeiffer, 1997). But for people with types of impairments that do require extensive or specialized medical care, health insurance that covers their needs is a very large worry.

7. Burgdorf (1984) argues that the goal for racial and ethnic groups (as well as for women) was to make the laws as neutral as possible—to force the laws to disregard race (or sex) as a relevant classification. For people with impairments, however, neutrality may not be the most appropriate legal goal: The goal may be to remove barriers rather than simply ignoring them.

8. Other words are used in other countries. In Australia, for example, the word used is *integrated* and its opposite is *segregated* (Byrnes, 1998). In Zimbabwe the word *mainstreaming* is sometimes mixed up with the word *streaming*, or tracking (Barnartt and Kabzems, 1992).

9. See, for example, John Hockenberry's (1995) description of life in a rehabilitation facility.

10. It may also be setting up terms that are different from those used in other countries. For

example, some of the radical writings about disability from England, such as Oliver (1990), do not use the concept at all.

11. Some deaf parents surprise their doctors by being pleased with a diagnosis of deafness in their babies (White, 1998).

12. As Wrigley (1996: 8) notes, however, some Deaf activists "are willing to accept the label's inherent limitations in exchange for shorter-term payoffs in social welfare privileges," such as support by SSI, vocational rehabilitation, or coverage under the ADA.

13. An example of this was observed by the first author relating to the use of the word *waiver* in the context of the juvenile justice system. In that context, if people are waived from the juvenile system, they are in effect "bumped up" to the adult system. Thus, the word *waiver* in this situation should be signed "promoted." If the word is signed, as it frequently is, using the sign for "excused," students are likely to misunderstand the concept.

14. The issue is also becoming one that links the psychiatric treatment system and the criminal justice system with arguments about whether defendants can be forced to take medicine that may make them lucid enough to stand trial and, in some cases, to face the death penalty (e.g., Miller, 2001).