Politics and Policy in the History of the Disability Rights Movement

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In the past two decades, Americans with a broad array of physical and mental disabilities have formed a social movement seeking rights for disabled people—the disability rights movement. This movement has attempted to redefine the concept of disability through political and legal action and through public education. Rejecting the stigma, isolation, and dependency which have long characterized the social position of people with disabilities in Western nations, the disability rights movement has promoted the idea that prejudicial attitudes and exclusionary practices are far greater barriers to societal participation for many disabled people than are their physical or mental impairments.

The disability rights movement is made up of only a small number of the millions of Americans with disabilities, but these individuals have exerted claims on behalf of all people with disabilities. This article describes the history of the disability rights movement, focusing particularly on the major organizational components of the movement and the political and policy context within which they developed. The thesis of this article is that disability rights activists were able to create a social movement and achieve their early political, legal, and social goals, but that the disability rights movement faces an uncertain future.
Social Movement Theory and the Disability Rights Movement

Although sociologists use competing definitions of social movements, the disability rights movement meets most of their criteria for movements advocating social change. Turner and Killian (1987, 223), for example, define a social movement as "a collectivity acting with some continuity to promote or resist a change in the society or group of which it is a part." In their formulation, such collectivities have "shifting memberships" and leaderships whose position is determined largely through the "informal response of adherents." Moreover, social movements generally consist of an interrelated and coacting unity of persons, and have objectives which require sustained activity and continuity in strategy, leadership, and group identity.

An alternative way of conceptualizing social movements contrasts them with more ephemeral instances of collective behavior and with established interest groups (Freeman 1983). Social movements, which can be described on a continuum between these two types, possess both spontaneity and structure. As will be discussed, the disability rights movement has moved along this continuum as its structure has become institutionalized and articulated. Freeman also argues that social movements have members who share both a belief system which defines common grievances and goals and group self-consciousness.

Most theories which analyze social movements emphasize either beliefs and norms or organizational issues. The former emphasizes a social psychological perspective and is referred to by some of its proponents as emergent norm theory. This approach suggests research questions about the formation of collective perceptions of common grievances, the legitimation of opposition to existing institutions and power relationships, and how values and inducements influence different types of participation by individuals in movement activities (Turner and Killian 1987, 230–39).

A different set of questions has been raised by scholars who utilize the "resource mobilization" approach, which draws on recent work in organizational theory, emphasizing how social movements obtain and mobilize resources, the role of interpersonal and interorganizational networks in movement formation and expansion, and the structural characteristics of social movements which are associated with political success or failure (McCarthy and Zald 1977).
Proponents of these two perspectives have engaged in a lively debate for over a decade, but both suggest useful questions for the study of the disability rights movement. People with disabilities have been socially dispersed and have lacked both a common identity and the economic and political resources to coalesce into an active and effective movement capable of political action. A rights-oriented consciousness and an adequate organizational apparatus have both been essential to creating the disability rights movement, as this article describes.

The Disability Rights Movement

Because there are currently no aggregate data on individual or organizational participants in the disability rights movement, it is difficult to characterize movement adherents, or even say how many people are involved in it. Adherents who are active in national organizations are the most visible and thus easiest to study, and much of the discussion that follows focuses on them. Many adherents may participate in the movement, however, in relatively unobservable ways.

Not all people with disabilities are adherents of the disability rights movement, just as not all blacks consider themselves within the black civil rights movement and not all women identify with and participate in the feminist movement. A broad estimate would be that there are fewer than 100,000 people with disabilities who belong to organizations that work on behalf of rights for disabled people, and a somewhat larger number of nondisabled people who belong to such organizations, including many parents of disabled children. Many more support at least the broad movement goals of breaking down barriers to participation and promoting self-sufficiency and independence. A more accurate estimate of participation would be that far fewer disabled individuals, perhaps a few thousand, actively participate in movement activities on an ongoing basis.

The disability rights movement is comprised of a wide variety of individuals and of national and local organizations, controlled by and acting on behalf of people with diverse physical and mental impairments. National and local interorganizational coalitions shift, dissolve, and are reestablished around varying issues. Thus, movement membership is fluid and subject to differing interpretations by different
participants. The name "disability rights movement" rather than sim­ply "disability movement" differentiates the loosely coupled network of organizations whose goals and objectives are focused on empower­ment and collective rights—human, civil, and legal—for disabled people from those groups seeking to assist individuals with disabilities in other ways, such as providing direct services or changing com­munity attitudes.

Dozens of national groups claim to speak for at least some number of disabled people. Some of these are essentially charitable or social service organizations whose leaders or members are primarily non­disabled. For most of the individuals who identify strongly with the disability rights movement, the issue of its control by disabled people is crucial. Many of the organizations discussed in this article have formal or informal requirements that a majority of their leaders have disabilities, and a distinction often made by disability rights activists is between organizations of disabled people and organizations for disabled people. The latter include professional associations of service providers, parent groups, philanthropic organizations, and other or­ganizations which may engage in advocacy on behalf of people with disabilities, but are not controlled by disabled people and thus are thought by some advocates to reflect inadequately the goals of self­help and independence of the movement.

Many groups are not a part of the disability rights movement, although ideologically and occasionally in practical politics they may be related. A number of organizations focus exclusively on people with particular disabilities or other characteristics, such as the National Federation of the Blind or the Disabled American Veterans, and do not typically identify with or work politically within a movement context. Alternatively, several other more focused organizations, such as the National Association for Retarded Citizens or the National Association of the Deaf, frequently work with other disability rights advocacy groups on lobbying and other political activities.

Other national organizations work within the disability rights movement but are not membership organizations, though they may claim all disabled people as their constituency. Examples include the Disability Rights Center or the Disability Rights Education and De­fense Fund. A number of such national advocacy organizations, often based in Washington or the San Francisco Bay area, are generally considered to be within the disability rights movement. Such groups
could be characterized as "professional movements" (McCarthy and Zald 1973), with full-time leadership, a small membership base, dependency on resources from outside their constituency, and activities that emphasize changes in public policy.

Most major cities have a number of organizations that work on behalf of rights for disabled people, and there are frequently coalitions at the metropolitan or state level which undertake such political activities as demonstrations or lobbying. Such coalitions are usually comprised of people with a variety of disabilities, although participation varies according to the particular issue involved.

One distinctive characteristic of the disability rights movement in the United States and similar movements in other Western nations is a focus on rights (on Great Britain, for example, see Scotch 1987). While American movement activists have been involved to some extent with the policy debates over disability benefits in the 1970s and 1980s, benefit issues appear to have had lower priority than issues about discrimination (including access to transportation, housing, and public services, accommodation in employment, and integration in education), the promotion of client control in rehabilitation services, and the development of independent living programs operated and governed by disabled people.

A rights issue orientation and participation in the identifiable disability rights movement network are the criteria used in this article for inclusion in the movement. Advocates of disability rights will not be considered to be part of the disability rights movement unless they are interacting with others in the movement in some direct or indirect way. Similarly, organizations concerned solely with disability issues other than rights will also be considered to be outside of the movement, although they have often overlapped organizationally and ideologically with disability rights groups. Some discussion of the independent living movement will also be presented.

Disability and the Capacity for Political Action

Disadvantaged status does not inevitably lead to political activity. Many barriers exist to both claiming the identity of "disabled person" and for people with such awareness joining collectively for political action (Scotch 1988). Disabled people, while disproportionately poor,
unemployed or underemployed, and undereducated, are dispersed socially; most disabled individuals outside of institutions live most of their lives with nondisabled family members, friends, and coworkers. Moreover, while many people with disabilities have had common experience in medical and rehabilitation facilities, such settings are typically dominated by service providers and may not offer the opportunity for extensive interaction with peers, or help to forge collective consciousness.

Furthermore, disability is hardly a unitary label. People who are deaf, blind, paraplegic, or mentally retarded may share similar problems of stigma and exclusion, but the practical accommodations they may require are varied, and in some case may even be inconsistent. Curb cuts needed for wheelchair users may make it more difficult for blind people to cross the street, for example. Despite these impediments, a broad social movement of disabled people in the United States developed around shared goals of independence and respect.

The Basis for Disability Rights Activism

The formation of a broad cross-disability social movement, which began in the 1960s, was built upon local groups of people with diverse disabilities. In that era of political activism, grass-roots organizing among people with disabilities began on college campuses and in local communities, often with individuals receiving services from disabled student programs or other institutional networks which included people with diverse disabling conditions.

Since their initiation earlier in this century, special education classes and vocational rehabilitation agencies frequently have lumped people with all kinds of disabling conditions together for educational and social activities. As a result, it has not been unusual for students with communication impairments, those with mobility impairments, and those with cognitive impairments to be placed together in the same classroom or service site. Indiscriminate grouping of individuals across disability lines has obvious deficiencies as a service strategy, but it has had the consequence of promoting a collective identity.

Why did this claiming of a collective identity occur in the 1960s, when disabled people have been grouped together in institutions and service programs since the all-inclusive asylums of the middle ages?
A variety of social and technological factors were involved, but the most important influence may have been the other social movements of that era. The shape of the disability rights movement and perhaps its very existence has been the result of available models of these other movements, which have provided examples of political action and ideological frameworks, and which have also served as sources of cooperation and competition. Particularly important as models were other movements for equal rights, including the black civil rights movement and the women's movement. The student movement and the movement against the Vietnam War also were major influences, as they drew many mainstream Americans into a culture of protest, particularly on college campuses. A disability rights movement was much more likely to occur at a historical moment when protests were legitimate, widespread, and focused not only along lines of established economic conflicts but also around issues of identity and social roles.

Disability rights organizers may be individuals who accept their disability while denying the imposed social associations of incapacity (Scotch 1988, 162). The baby-boom generation was reared with high aspirations and a self-confident view of personal achievement. As Asch (1984, 551) wrote, "Many activists . . . had been in the mainstream and had never questioned their right to be there. So, when others questioned it, they were ready with armor and anger to fight to preserve their sense of themselves that the adult world was trying to shatter." Similarly, Judy Heumann, a long-time movement leader, has stated that "as long as you believe that your life is a tragedy, you can't do very many good things with your life. Once you believe that the tragedy isn't your fault, that it is the failure of the political system to acknowledge your rights as a human being, to be equal in society, that you can as an individual have a voice as part of a group, then you can make a difference" (Maddox 1987, 291).

Many of the leaders of the disability rights movement had been involved with other political activities as students on college campuses or in the earlier civil rights struggles. Ed Roberts, who helped to create the independent living movement at the first Center for Independent Living in 1972, attended the University of California at Berkeley as the free speech movement and the antiwar movement developed in the mid-1960s. Gerald Baptiste, the current associate director of the Berkeley Center for Independent Living, had been
active in the black civil rights movement, as were many other disability rights activists. Judy Heumann was involved with protests as a student at Long Island University in Brooklyn, New York, before she went on to organize Disabled in Action, one of the earliest disability advocacy groups that crossed disability lines.

Such leaders transferred political lessons from other movements to a disability context. The new organizations of the disability rights movement stressed the American values of independence and participation in ways that made such groups acceptable to public officials and the general public. At the same time, they borrowed concepts of inclusion from the protest culture of the 1960s which promoted the creation of cross-disability coalitions.

Activism for Disability Rights

A broadly based cross-disability movement advocating rights for disabled people began in the late 1960s with the local organizing activities of leaders such as Ed Roberts in Berkeley and Judy Heumann in New York City. College campuses were centers of activism for the new movement. Medical technologies and more generous public benefit programs had made it easier for people with disabilities, in some cases quite severe disabilities, to attend college. Many of them balked when recalcitrant rehabilitation professionals and educational administrators tried to deny them access to education and professional employment.

Ed Roberts, who is a post-polio quadriplegic who uses a wheelchair, was one of the first severely disabled persons to attend the University of California at Berkeley. As a student, he pressed the university into accommodating his disability. Because of the lack of accessible housing, Roberts resided at a university health facility, along with several other students with severe disabilities. In 1970, with the assistance of federal funding, these students initiated a program on the Berkeley campus to provide disabled students with peer counseling and support in gaining access to university programs, housing, and personal attendant services. Roberts and the other disabled student leaders insisted that people with disabilities knew their own needs best, that
therefore programs to meet those needs must be controlled by disabled people, and that people with disabilities must integrate themselves into the broader community in order to avoid dependency.

Throughout the late 1960s and early 1970s, the number of students at Berkeley who had disabilities increased dramatically, in large part because of the increasing accessibility to the campus and the university's programs. People from outside the university community sought assistance from the disabled students' program. In 1972, Roberts and others, taking the model of the university program into the community, established the Berkeley Center for Independent Living (CIL) in an apartment near campus. Within a few months, with a federal grant, CIL was firmly established as the first independent living center in the United States. Roberts later directed California's Department of Rehabilitation under Governor Jerry Brown, and subsequently helped to establish the World Institute on Disability, a "think tank" in Berkeley.

Similar events occurred elsewhere. In 1970, Judy Heumann, a graduate of Long Island University and a post-polio paraplegic, filed a widely publicized lawsuit when she was denied teaching certification because of her disability. Heumann used a network of peers with diverse disabilities, many of whom she had met as a participant and staff member in summer recreational programs for disabled children, as the organizational core for Disabled in Action (DIA), a group of about eighty people which sought to break down barriers to disabled people's full societal participation.

By the spring of 1972, DIA had 1,500 members in several cities, predominantly on the East Coast. Its protests were targeted at inaccessible public buildings, the Jerry Lewis telethon which disability rights activists accused of perpetuating demeaning stereotypes, and media organizations which were believed to neglect or provide prejudicial coverage of disability issues. The group also blocked traffic in front of Richard Nixon's 1972 New York campaign headquarters to protest his vetoing of the Rehabilitation Act, and held a march of 150 disability rights activists in Washington when Nixon vetoed the act again after Congress had passed a revised version. Such demonstrations received major media attention and widespread expressions of popular support, in part because they were conducted by people using canes or wheelchairs. Many more people with disabilities were consequently prompted to political action, and newly organized groups
in communities across the country often modelled themselves after DIA and other prominent organizations.

Building a Movement

Until the mid-1970s, the disability rights movement was a loosely structured grass-roots movement, with leadership by example. Disabled in Action, for instance, consisted of virtually autonomous local groups which kept in touch and sometimes acted in concert. Disabled people generally lacked economic resources and did not control an institutional network. In response to occasional focusing events, such as blatant publicized instances of discrimination or legislative decisions, temporary local or state coalitions sometimes took coordinated action. Nationally, informal ties among individuals were promoted, in part, by common attendance at the annual meeting of the President's Committee on Employment of the Handicapped (PCEH) in Washington. At the 1972 and 1973 PCEH meetings, friendships had formed among those attending who identified with the new movement. One participant, Eunice Fiorito of Disabled in Action of New York, described the emerging group as "rabble-rousing kids" who "had begun to reach out to other young people or people of like-mindedness" (Scotch 1982, 186).

The demonstration against the 1973 veto of the Rehabilitation Act was organized through this "alternative" network. Fiorito recalls "that we had to become articulate for ourselves, that we had to become more political, that we had to pull ourselves together" (Scotch 1982, 187). Another participant, Reese Robrahm of the American Council of the Blind, remembered that "we had to not only get together in order to agree upon what we could support, but also because it would give us a much louder, stronger voice" (Scotch 1982, 188).

Within a year this informal network of about 150 people became the American Coalition of Citizens with Disabilities (ACCD), with about 65 national and local affiliated organizations. For its first year, ACCD operated out of the office of Fiorito, who had become director of the New York Mayor's Office for the Handicapped. In order to establish a Washington office and a federal lobbying presence, the ACCD board obtained an organizing grant from the sympathetic head of the federal Rehabilitative Services Administration, Andrew Adams.
It was also in 1975 that Judy Heumann, who had left New York to attend graduate school in Berkeley, worked as an intern for the Senate Labor and Public Welfare Committee.

Given the need for resources and linkages which theorists of resource mobilization regard as essential for a movement, the decision by disability rights leaders to develop a national institutionalized presence in Washington made sense. Advocacy groups promoting a variety of causes had burgeoned in Washington since the 1960s. Many former activists, who now had staff positions in Congress and federal agencies, were sympathetic to the cause of disability rights and helped to direct governmental resources to outside advocates. Moreover, receptiveness within the federal government to advocacy for progressive causes grew in the 1960s and continued through the Carter administration. The disability rights movement capitalized on such government support to build a broader national movement (Scotch 1984).

Relating to the Federal Government

The leaders of the disability rights movement adopted many of their policy goals from other movements. Local, state, and national statutes prohibiting discrimination on the basis of handicapping condition frequently borrowed language from laws concerning racial, religious, or gender discrimination. Existing antidiscrimination statutes were amended to add disability as a category. The first major attempt to protect disabled people from bias occurred in 1972 when Representative Charles Vanik and Senator Hubert Humphrey proposed to amend the Civil Rights Act of 1964 to include handicapping conditions. Their bills were defeated in committee, partly because of opposition from supporters of black civil rights, who feared that attention and resources would be diverted from their cause.

The following year, several Senate liberals led by Harrison Williams successfully used a different strategy. They added Title V to the reauthorized Rehabilitation Act to prohibit discrimination on the basis of handicap by recipients of federal grants and contracts and in federally operated programs, using legislative language from Title IV of the 1964 Civil Rights Act and Title IX of the Education Amendments of 1972 (Scotch 1984).

These changes in the Rehabilitation Act were made without major
involvement of the new disability rights movement. The major lobbying groups involved with the drafting of the 1973 Rehabilitation Act were service providers, particularly the National Rehabilitation Association which represented vocational rehabilitation counselors. Such disability rights groups as Disabled In Action were more concerned with broadening the act to expand benefits and to extend eligibility for services to include severely disabled people than they were with its civil rights provisions.

Two other major federal laws passed in the mid-1970s attracted more attention from other advocates for the disabled than from the movement. One statute was the Education for All Handicapped Children Act of 1975, on which Judy Heumann had worked as a legislative intern. This law (P.L. 94-142) guaranteed a free and appropriate public education and related services to all children with disabilities, many of whom previously were segregated in ineffective special education programs or excluded from any public schooling.

The other major law, the Developmental Disabilities Amendments of 1975, expanded services for individuals with such problems as mental retardation and cerebral palsy, and mandated a network of state protection and advocacy agencies to monitor and protect their rights. Organizations representing service providers and parents of disabled children were more prominent in promoting these laws than the emerging disability rights movement, which did not have a significant Washington presence in 1974 and 1975, nor a broad base of community support.

The implementation of this legislation by the federal government had, however, a profound effect on the emerging movement. Federal agencies paid movement organizations to provide technical assistance and organize public education campaigns at the same time that the movement was organizing disabled people to influence the government.

Rule-making for the antidiscrimination measures in Title V of the Rehabilitation Act of 1973 was the responsibility of government agencies charged with enforcing other civil rights laws, including the Office of Civil Rights in the Department of Health, Education, and Welfare (HEW), the Office of Federal Contract Compliance Programs in the Department of Labor, and, later on, the Department of Justice. The lawyers who staffed these agencies perceived the disability rights cause as analogous to other civil rights movements with which they
identified. Thus, they regularly consulted with leaders of organizations representing disabled individuals, and used advocacy organizations both to educate disabled people in the community about their newly enacted rights and to assist people who believed they had been victims of discrimination in obtaining relief (Scotch 1984).

Federal legislation and regulations thus established a minority group definition of the position of disabled people. Consequently, disability rights groups were able to take a role in the Washington scene which had been established by other civil rights advocates. As this role became institutionalized, disability rights leaders were accepted into formal and informal associations of civil rights lobbyists.

Between 1976 and 1980, ACCD and its constituent organizations were heavily involved in these efforts. ACCD leaders talked frequently with officials in the Departments of HEW, Labor, and Transportation. Centers were founded and funded, conferences were organized, handbooks were published. Movement representatives testified on Capitol Hill and commented on proposed regulations. The federal government provided a massive infusion of resources, including legitimacy, for the movement.

The movement continued to grow. Local groups organized around issues of implementation and enforcement of requirements for accessibility of mass transit, public facilities, and education. Legal advocacy expanded as the result of claims under the new statutory protections. Public interest law centers and individual attorneys developed expertise in litigating disability rights cases.

By the late 1970s, the disability rights movement had most of the ideological and structural attributes that sociologists associate with a social movement. It had developed a coherent set of beliefs and values about the problems faced by disabled people in American society and a network of national and local organizations which were linked together structurally and ideologically. The new movement demonstrated its power in 1977, when it held sit-ins in federal offices across the country to protest inaction by the Department of Health, Education, and Welfare in issuing the regulations prohibiting discrimination in federally supported programs. After statements of support from elected officials and community leaders and sympathetic media coverage, the government released the regulations within a few days.

Some movement leaders believe, however, that the energies of many in the disability rights movement became directed toward national
political and legal advocacy at the expense of grass-roots organizing. Although the movement continued to expand slowly at the local level, it could not exert much effective political power when government support waned after 1978. The insider strategy that had served the movement well in the 1970s became a liability when the nation and its political leaders increasingly avowed a less active role for government.

Political decision makers continued to work with disability rights advocates, but they did not have to take a "disabled vote" into account, despite the millions of disabled people nationwide. The membership base of the disability rights movement was sufficiently broad for it to survive, but not as broad nor as institutionalized at the local level as, for example, the black civil rights movement which had an important role in effectively mobilizing blacks in electoral politics in some jurisdictions, nor the senior citizens organizations, which have made the Social Security retirement system virtually unassailable politically.

The Independent Living Movement

Civil rights was not, however, the only focus for the disability rights movement. Independent living programs which had begun at the CIL in Berkeley and a few other cities in the early 1970s became models for a network of hundreds of centers providing support services for disabled people living in the community and controlled by disabled consumers. Independent living centers provide a range of services, which may include wheelchair repair and ramp construction, screening and training personal attendants, information and referral on accessible housing and employment, and peer counseling and political advocacy. Heumann and Wilkie (1987, 2–3) have described the concept of independent living as "the ability of disabled people to participate actively in society: to work, have a home, raise a family if they wish, in sum to decide their own futures according to the cultural context within which they live."

The federal government also played a crucial role in the proliferation of independent living centers. In the 1978 Amendments to the Rehabilitation Act, Congress established a program of "Comprehensive Services for Independent Living" which allowed funds previously des-
igned for use in employment-related training to be utilized to pro-
mote independent living by individuals whose severe disabilities might
preclude employment. Centers receiving those funds had to involve
disabled persons in policy direction and management.

By the late 1980s, over 300 centers had been established in the
United States. Independent living centers were an expression and a
consequence of the disability rights movement. They were also a major
resource for it, a site for consciousness raising and political organizing,
although not all have been unambiguously controlled by disabled
people.

A notable product of the independent living movement is the
Disability Rag, which has become the unofficial newspaper of the
disability rights movement. The Rag, as it is known within the move-
ment, began in 1980 as a newsletter about disability issues from
the Center for Accessible Living in Louisville, Kentucky. Its purpose
was to "shake people out of complacency," according to the founding
editor Mary Johnson (personal communication June 4, 1988). Since
1982 the paper has sought and attracted a national readership as a
forum for discussion and debate within the movement. A 1985 article
on the front page of the Wall Street Journal helped increase its sub-
scription list to 6,000, which translates into approximately 30,000
readers. While the Rag received some grants for specific projects, it
carries no advertisements and 80 percent of its funds come from
subscriptions and subscriber donations.

Although the independent living movement is extremely decen-
tralized, a Washington-based group, the National Coalition for In-
dependent Living (NCIL), organizes testimony at congressional hear-
ings and responds to federal regulations. The NCIL has been effective
at representing the movement in the federal policy-making world,
but it is much more of a voice than a leader of the movement.

Policy Advocacy in a Conservative Era

By the late 1970s, the disability rights movement had become an
established player in the liberal sector of the Washington lobbying
world, and disability rights and independent-living advocacy orga-
nizations were receiving substantial portions of their budgets from
the federal government. This favorable situation began to change in
1978, as interests such as mass transit agencies, local governments, and other federal fund recipients began to protest the new federal antidiscrimination laws. The 1978 Rehabilitation Act Amendments were virtually the last major legislative expansion of disability rights for a decade. Following the election of Ronald Reagan in 1980, federal funds available to movement organizations became severely limited. Debates over disability rights in the 1980s were generally about proposals for weakened federal requirements, reduced budgets, deregulation, and judicial decisions that threatened previously established guarantees. Relations between government officials and leaders of the movement became more distant and adversarial.

Disability advocates have had mixed success in the past decade (Percy 1989). They were successful in organizing opposition to Reagan administration attempts to weaken the requirements of the Education for All Handicapped Children Act and several other previously enacted laws. They experienced defeat, however, when the Reagan administration rescinded a Carter administration requirement that all new transit systems and newly acquired buses be wheelchair accessible, allowing local transit operators discretion in determining how to serve disabled transit patrons. In most communities, some form of limited paratransit was substituted for accessibility, under which people with disabilities could arrange with public or private vans or taxis for individual service. American Disabled for Accessible Public Transit (ADAPT), which evolved out of the Atlantis Community in Denver, has been the major movement organization involved with the issue of access to urban mass transit. Since the early 1980s, ADAPT has organized demonstrations in cities across the country demanding fully accessible public transportation, so far with only limited success.

Disability rights advocates have also joined with a number of other groups in fighting budget cuts and conservative civil rights policies. The Disability Rights Education and Defense Fund (DREDF), a spin-off of the Berkeley Center for Independent Living with offices in California and Washington, worked effectively with the Leadership Conference on Civil Rights and a number of ad hoc coalitions concerned with social policy. Disability rights groups also participated in such coalitions in several states.

An important policy debate in which such coalitions played a key role occurred in the aftermath of a 1984 Supreme Court decision (Grove City College v. Bell, 465 U.S. 555 [1984]) which considerably
narrowed the coverage of several federal antidiscrimination statutes. Groups concerned with the rights of racial minorities, women, and disabled people worked together to secure the passage in 1988 of the Civil Rights Restoration Act, which explicitly returned statutory coverage to what had been intended by civil rights activists in Congress and the lobbies prior to the court's decision.

From 1982 to 1984, an altogether different coalition was formed over the issue of medical treatment for disabled infants, in response to the *Baby Doe* and *Baby Jane Doe* cases. Several leading disability rights advocates, representing such groups as the Disability Rights Center and the National Association for Retarded Citizens joined with politically conservative right-to-life groups in seeking government protection for newborns whose disabilities might lead parents or physicians to order conservative medical treatment or to withhold it entirely.

This was the first attempt by two movements with substantially divergent ideologies to broaden their base of support. As discussed by Paige and Karnofsky (1986), the alliance was difficult to put together and difficult to sustain. Right-to-life groups were adamantly opposed to abortion, and many in these groups opposed most federal social programs and any broadening of civil rights protections except in the particular instance of handicapped newborns. Conversely, many disability rights organizations were pro-choice, and favored expanding government social programs and strengthened civil rights laws.

Despite these differences, disability rights and right-to-life advocates jointly issued statements, lobbied government officials, and filed court briefs in support of policies of government intervention on behalf of disabled newborns. While there was much debate within the disability rights movement about the desirability of such a coalition, there was also strong overall agreement about the specific issue of protecting disabled newborns. Parents and physicians alike were considered to be misinformed about disability and the "quality of life" of people with conditions such as Down's syndrome and spina bifida.

The coalition experienced limited success. Congress and the courts were reluctant to establish a strong federal government role in medical decision making about disabled infants, although an amendment to the Child Abuse and Neglect Act of 1984 directed states to establish procedures for reporting and investigating cases where treatment was denied on the basis of disability (Brown 1986). The association be-
between right-to-life and disability rights groups appears to have been an ad hoc alliance. Several disability rights leaders established connections to Republican candidates in the 1988 election campaigns, but there has been no apparent alignment with the New Right on a long-term basis.

**Entering the Nineties: The Prospects for Disability Rights**

The disability rights movement has begun to fashion a more positive agenda for the future. One focus for the movement has been on building broader coalitions around issues of concern to disabled people. An obvious partner in many issues would be the organized senior citizens lobby, which has tremendous political power. Many older people have disabilities, and their concerns about noninstitutional support services and access to affordable health care are often shared by the working-age disabled people who for the most part constitute the disability rights movement. While disabled people and the elderly have many common concerns, many older people reject identification with the disability community. Attempts have been made, however, to explore the connections between disability and aging, including a conference sponsored by the University of California, San Francisco's Institute for Health and Aging, and the World Institute on Disability (Mahoney, Estes, and Heumann, 1986). In several states, coalitions have formed around human service issues affecting both seniors and people with disabilities which include representatives from both groups.

Another potential ally is the gay rights movement. People with HIV infection and related diseases are covered by laws protecting disabled people from discrimination, but there are few signs of a coalition between the disability rights and gay rights movements. Gay and lesbian groups within the disability rights movement may serve in a liaison role between these two movements. The awareness that such a potential alliance carries with it political risks, however, has made many disability rights groups wary of associating with people who may be subject to much greater stigma than disabled people.

Much of the ongoing advocacy by the disability rights movement is likely to be at the federal level, although efforts in several states
are also underway. A comprehensive legislative agenda reviewing federal laws and programs and making farreaching recommendations was published in 1986 by the National Council on the Handicapped (1986) (NCH), an independent federal agency that reflects the views of advocates from around the country. In a follow-up report issued in January 1988, NCH reported a number of incremental legislative changes in federal disability programs (National Council on the Handicapped 1988).

The most significant legislative goal for the disability rights movement and a test of its ability to enter coalitions has become enactment of the Americans with Disabilities Act (ADA). Proposed in 1986 by the NCH, it was introduced into the 100th Congress with nearly a hundred cosponsors in the House and Senate. ADA would extend broad protections against discrimination on the basis of disability—which now apply only to federal agencies, contractors, and grant recipients—into the private sector. The bill has been reintroduced in 1989, and its supporters include groups concerned about AIDS.

In the summer of 1988, Congress passed the Fair Housing Amendments Act, which prohibits discrimination against both families with children and people with disabilities. This law, the most significant housing discrimination measure since the Civil Rights Act of 1968, is also the broadest antidiscrimination protection for disabled people enacted in a decade. In the midst of hotly contested presidential and congressional election campaigns, both Congress and the president were eager to demonstrate their support for families and people with disabilities.

Another event of 1988 suggests that a new period of expansion for disability rights may be under way. The board of Gallaudet University, a federally chartered university in Washington which serves deaf and hearing-impaired students, chose as the new president a hearing person, as has been the institution's practice since it was founded. Students responded by blockading the campus and demanding that a deaf president be appointed. The faculty overwhelmingly supported the student demands, as did members of Congress and presidential candidates George Bush and Robert Dole (Bruske 1988). A week later, the deaf dean of Gallaudet's school of arts and sciences was appointed president, and a deaf IBM executive was named board chair.

The social movement created by people with disabilities has not faded away, as many of its supporters feared it would in the early
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1980s. It has not developed complete autonomy or self-sufficiency, however; many movement organizations still rely heavily on government grants and contracts for their political activities. While grassroots groups continue to spread, they have only involved a tiny proportion of Americans with physical or mental impairments. Nevertheless, the disability rights movement has become a presence in the politics of the American welfare state.

References


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