

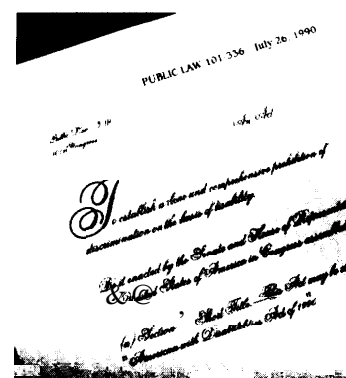
# The ADA and People With Disabilities: An Overview 2

**T**he Americans with Disabilities Act (ADA) is a watershed in the history of disability rights. It outlaws discrimination against people with disabilities in nearly every domain of public life: employment, transportation, communication, recreational activities, and other services (table 2-1 ). The Act's extension of employment provisions to many people with psychiatric disabilities has captured the attention of mental health advocates (24,32,33,35,42,44,47). Jobs are of particular concern to many people with mental disorders: For most people with severe mental disorders employment remains an elusive goal (see ch. 3). Many employees attempt to keep their current or past mental health problems a secret, for fear of stigma and discrimination. Reflecting the misperceptions, fears, and lack of information about mental disorders as well as the difficult issues sometimes raised by these conditions—subjectivity of claims, impact on behavior, and social interactions at work—some employers have expressed concerns about the ADA's provisions for employing people with psychiatric disabilities (27).

This chapter provides an overview of the ADA and some of the factors that led to its passage. First, it summarizes the ADA's provisions, highlighting issues of employment. Second, legal antecedents of the ADA are discussed, illuminating important forebears of the law and their impact on people with psychiatric disabilities. Third, the chapter describes how people with disabilities have influenced disability policy.

## THE ADA AND ITS LEGAL ANTECEDENTS

This OTA background paper has proclaimed the ADA “a watershed in the history of disability rights” and “the most far-reach-



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TABLE 2-1: Overview of the ADA

	Brief description	Law's enforcement date	Enforcement jurisdiction
<b>TITLE I</b> Employment	Provides that no covered entity shall discriminate against a qualified individual with a disability because of the disability in regard to job application procedures, hiring, advancement, employee compensation, job training, and other privileges of employment.	Effective July 26, 1992, for employers with 25 or more employees, and on July 26, 1994, for employers with 15 or more employees. Employers with fewer than 15 workers are not covered by ADA.	U.S. Equal Employment Opportunity Commission
<b>TITLE II</b> Public Services	Provides that no qualified individual with a disability shall be excluded from participation in or be denied the benefits of the services, programs, or activities of public entities, including transportation facilities.	As of Aug. 26, 1990, all new public buses and light and rapid rail vehicles ordered are to be accessible; one car per train must be accessible by July 26, 1995; key commuter stations must be retrofitted by July 26, 1993; all existing Amtrak stations must be retrofitted by July 26, 2010.	U.S. Department of Transportation; U.S. Department of Justice
<b>TITLE III</b> Public Accommodations	Provides that people with disabilities should have access to existing private businesses that serve the public, so long as required accommodations are "readily achievable." The list includes hotels, restaurants, theaters, laundromats, museums, zoos, private schools, and offices of health-care providers.	Effective Jan. 26, 1992, for businesses with more than 25 employees; on July 26, 1992, for businesses with 25 or fewer employees and annual revenue of \$1 million or less; and on Jan. 26, 1993, for companies with 10 or fewer employees and annual revenue not exceeding \$500,000.	U.S. Department of Justice
<b>TITLE IV</b> Telecommunications	Amends Title II of the Communications Act of 1934 by adding a section providing that the Federal Communications Commission shall ensure that interstate and intrastate telecommunications relay services are available, to the extent possible, to hearing-impaired and speech-impaired individuals.	By July 26, 1993, covered firms should have telecommunications services available 24 hours a day.	Federal Communications Commission

SOURCE: CQ Researcher, The Disabilities Act (Washington, DC: Congressional Quarterly, Inc., 1991).

ing legislation ever enacted against discrimination of people with disabilities.” But what exactly is the ADA? What are its specific provisions? Its history? Philosophical roots? This section considers the law and its forerunners. While not exhaustively detailing disability legislation—many other texts do so (e.g., 57)—the section will highlight information that specifically relates to people with psychiatric disabilities.

## I Overview of the ADA

The ADA intends sweeping and active antidiscrimination efforts and outcomes. Noting the high and increasing prevalence of disabilities, the lamentable socioeconomic straits of people with these conditions, and the exorbitant costs to society of disabilities, the law sets out:

1. *to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;*
2. *to provide clear, strong, consistent enforceable standards addressing discrimination against individuals with disabilities;*
3. *to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities; and*
4. *to invoke the sweep of congressional authority . . . in order to address the major areas of discrimination faced day-to-day by people with disabilities (42 U.S.C. 12101(b)).*

Drawing from the Rehabilitation Act of 1973, the ADA offers a three-pronged definition of disability:

- with respect to an individual,*
- (A) *a physical or mental impairment that substantially limits one or more of the major life activities of such individual;*
  - (B) *a record of such an impairment; or*
  - (C) *being regarded as having such an impairment (42 U.S.C. 12102(2)).*

While the definition of disability is discussed in detail in the following chapter, a few observations warrant mention here. Although specific conditions are explicitly excluded by the law, in-

cluding current illegal drug use (box 2-1), the definition is not simply a laundry list of disorders and conditions. Rather, the definition acknowledges the necessity of considering both impairment (e.g., symptoms of a mental disorder; see ch. 3) and functional sequelae. Furthermore, by defining disability in this way, flexibility is maintained, permitting the coverage of disabling conditions that are yet to appear (e.g., a new infectious disease).

The second and third prongs of the definition extend the protection of the law to those who have a history of a substantially limiting impairment or disability, or simply are regarded as such. This language recognizes the discriminatory use of such history or perceptions regardless of an individual’s abilities. Because negative attitudes are attached to mental disorders, these prongs of the definition are especially important to them.

Title I of the ADA focuses on employment. It forbids discrimination against qualified people with disabilities in every employment decision, including hiring, advancement, or discharge by employers with 25 or more employees. In July 1994, Title I extends to employers who have 15 or more employees. Key definitions of this section include:

- *Qualified Individual With a Disability.* An employer is not required to hire, promote, or retain any individual with a disability. Rather, the protection of the ADA is afforded to people with disabilities who are qualified for the job. Being qualified for a job often entails relevant training and work experience, factors that may prove problematic for people with psychiatric disabilities that emerged during their education or that disrupted work tenure (see ch. 3). The law defines “qualified individual with a disability” as “an individual with a disability who, with or without reasonable accommodation, can perform the essential functions of the employment position that such person holds or desires.” Embedded in this definition are two key terms: 1) “\*essential functions of the employ-

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### BOX 2-1: Substance Abuse, Psychiatric Disabilities, and the ADA

The ADA extends its reach to people with many different types of disabilities. While people with alcoholism and a history of illegal drug use maybe protected by the ADA, the act evidences congressional concern about current illegal drug use. Nearly 25 percent of Title I is devoted to the topic of drugs and alcohol, with the final Title of the act reinforcing much of the discussion. To quote the law itself (42 U. SC. 121 14):

*[T]he term "qualified individual with a disability" shall not include any employee or applicant who is currently engaging in the illegal use of drugs, when the covered entity acts on the basis of such use...*

*[furthermore] A covered entity.*

*(1) may prohibit the illegal use of drugs and the use of alcohol at the workplace by all employees;*

*(2) may require that employees shall not be under the influence of alcohol or be engaging in the illegal use of drugs at the workplace,*

*(3) may require that employees behave in conformance with the requirements established under the Drug-Free Workplace Act of 1988,*

*(4) may hold an employee who engages in the illegal use of drugs or who is an alcoholic to the same qualification standards for employment or job performance and behavior that such entity holds other employees, even if any unsatisfactory performance or behavior is related to the drug use or alcoholism of such employee; and*

*(5) may, with respect to Federal regulations regarding alcohol and the illegal use of drugs, require that employees comply with (various) standards established in such regulations of the Department of Defense... Nuclear Regulatory Commission,... (and the) Department of Transportation..*

*Nothing in this title shall be construed to encourage, prohibit, or authorize the conducting of drug testing for the illegal use of drugs by job applicants or employees or making employment decisions based on such test results.*

Thus, Title I of the ADA protects people substantially limited by alcoholism to the same extent that it protects persons with other disabilities. Additionally, a person who illegally used drugs in the past may be an individual with a disability under the law. However, regardless of performance, current illegal drug users find no haven in the ADA's protections; they are neither "qualified" nor "disabled" under the law. And use of alcohol or other drugs on the job can be restricted by employers.

The ADA's extensive discussion of substance abuse and the exclusion of current illegal drug users reflects the difficulty of rectifying distinct conceptualizations of drug abuse in making public policy. This difficulty in deciding whether drug abuse is a criminal justice problem, a medical or public health problem, or social issue is nothing new. For example, although the original Rehabilitation Act regulations defined illegal drug abuse as a protected disability, the issue met with considerable controversy. The 1978 Amendments to the Rehabilitation Act qualified the original regulations, protecting current drug and alcohol users only in the absence of poor work performance or threat to the property or safety of others. (The Rehabilitation Act Amendments of 1992 adopted the ADA's approach to coverage of current illegal users of drugs.)

The ADA reveals Congress' hope that employers will give drug abusers opportunities for rehabilitation. The law seeks to prevent the punishment of those who sought treatment in the past and are continuing to receive treatment, and no longer use drugs. The ADA states that it should not be construed:

*to exclude as a qualified individual with a disability an individual who: 1) has successfully completed a supervised drug rehabilitation program and is no longer engaging in the illegal use of drugs, or has otherwise been rehabilitated successfully and is no longer engaging in such use, 2) is participating in a supervised rehabilitation program and is no longer engaging in such use, or 3) is erroneously regarded as engaging in such use, but is not.*

## BOX 2-1: Substance Abuse, Psychiatric Disabilities, and the ADA (cont'd.)

Unfortunately, this language raises questions even as it attempts to answer them. For example, how long must an individual not take a drug to be considered successfully rehabilitated?

OTA has found no discussion of the impact of the ADA's substance abuse provisions on people with psychiatric disabilities. Data clearly have demonstrated that people with mental disorders often abuse alcohol and drugs. For example, information from a national survey indicated that nearly one-third of those with a diagnosable mental disorder will abuse alcohol or illegal drugs at some time in their lives. More severe diagnoses are associated with higher comorbidity. Nearly half of those with schizophrenia will abuse or be dependent on alcohol or other drugs, and over 60 percent of people with manic depression will abuse or become dependent on alcohol, other drugs, or both.

The fact that the ADA protects people with mental disorders but excludes those currently abusing illegal drugs also may raise difficulties. Analysts with the EEOC hold that distinctions between psychiatric disabilities and substance abuse can be dealt with in a fairly clean fashion.

If an individual is an alcoholic, then she could be protected under the ADA both for the psychiatric disability and the alcoholism. If the individual is a current illegal user of drugs, then she could be covered by the ADA for the psychiatric disability but not for the current illegal drug use. In other words, if an employer refused a reasonable accommodation for the psychiatric disability, the individual has grounds to file an ADA charge.

Given the high comorbidity between mental disorders and substance abuse, employer actions—permitted by the ADA—to restrict the use of alcohol or drugs may disparately affect people with psychiatric disabilities. Many people with psychiatric disabilities may refrain from seeking the protection of the ADA for fear of revealing a drug abuse problem. Another concern emerges from drug testing in the workplace. Tests for illegal drugs can register a false positive when an individual is taking some medications for mental disorders (as well as other conditions, such as epilepsy). At best, applicants or employees will be put in the position of disclosing their disability, perhaps against their desire.

SOURCES: P. R. Mastroianni, Assistant Legal Counsel, U.S. Equal Employment Opportunity Commission, Washington, DC, personal communication, Oct. 14, 1993; R. K. Scotch, from *Good Will to Civil Rights: Transforming Federal Disability Policy* (Philadelphia, PA: Temple University Press, 1984); R. J. Henderson, Jr., "Addiction As A Disability: The Protection of Alcoholics and Drug Addicts Under the Americans with Disabilities Act of 1990," *Vanderbilt Law Review* 44:713-740, 1991; N. L. Jones, "The Alcohol and Drug Provisions of the ADA: Implications for Employers and Employees," *Consulting Psychology Journal: Practice and Research* 45:37-45, 1993; L. K. Haggard, "Reasonable Accommodation of Individuals with Mental Disabilities and Psychoactive Substance Use Disorders Under Title I of the Americans with Disabilities Act," *Journal of Urban Contemporary Law* 43:343-390, 1993; W. F. Banta, and F. Tennant, Jr., *Complete Handbook for Combating Substance Abuse in the Workplace, Medical Facts, Legal Issues, and Practical Solutions*, 1989; U.S. Congress, Office of Technology Assessment, *The Biology of Mental Disorders*, OTA-BA-538 (Washington, DC: U.S. Government Printing Office, September 1992).

ment position," and 2) "reasonable accommodation."

- *Essential Functions of the Employment Position.* The term "essential functions" can be taken at its face value: essential functions of a job are those functions that are not marginal. Employers are vested with considerable, though not unassailable, power by the ADA in determining essential functions of the job. The Act itself says "consideration shall be given to the employer's judgment as to what functions of a

job are essential, and if an employer has prepared a written description before advertising or interviewing applicants for the job, this description shall be considered evidence of the essential functions of the job."

- *Reasonable Accommodation.* Providing a reasonable accommodation is the action required of employers by Title I of the ADA. Appropriate accommodation must be determined on an individual basis. However, the law lists some specific possibilities, including job restructuring-

ing, part-time or modified work schedules, or reassignment to a vacant position, all of which may prove useful to people with psychiatric disabilities. The ADA indicates that a reasonable accommodation is required unless it poses an “undue hardship” on the employer. Undue hardship “means an action requiring significant difficulty or expense.” Factors, specified by the law, that may make an accommodation an undue hardship include “the nature and cost of the accommodation. . . the overall financial resources of the facility. . . [and] the number of persons employed at such facility. . .” (42 U.S.C. 121 11(10)). Undue hardship is not limited to financial difficulty, however, a point especially relevant to psychiatric disabilities; it also refers to any accommodation that would be “unduly. . . extensive, substantial, or disruptive, or that would fundamentally alter the nature or operation of the business.”

What constitutes employment discrimination under the ADA? Section 102 of Title I enumerates a variety of practices forbidden by the law—a level of specificity that is uncommon in civil rights law (15). The ADA deems “not making reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability [42 U.S.C. 121 12(b)]” unless the employer can prove the accommodation is an undue hardship. Note that the employer’s obligation is to “known” limitations, a critical issue for such “hidden” conditions as psychiatric disabilities. Other expressly prohibited actions include discriminatory:

- limitation, segregation, or classification of job applicants or employees on the basis of disability;
- contractual arrangements, such as with an organization that provides training or facilities for a meeting; and
- use of employment tests or other qualification standards that “screen out” a person with a disability, unless the standard is “job-related and consistent with business necessity.”

Another common employment practice that is expressly forbidden by the ADA relates to medical examinations and inquiries. Employers can no longer inquire about the medical or disability status of a job applicant. This provision makes illegal such job application questions as: “Have you had a nervous breakdown?” Employers may require, however, medical exams and inquiries after a conditional job offer is made, provided such exams and inquiries are required of all applicants in the job category, and the information is kept confidential. A job offer may be rescinded only if the exclusionary criteria are job-related, consistent with business necessity and reveal that an applicant could not perform an essential function of the job or could not do the job without posing a direct threat to health or safety, even with a reasonable accommodation. In regards to current employees, employers can only require medical examinations or make medical inquiries if they are “job-related and consistent with business necessity.”

One qualification standard specifically permitted by the ADA is “the requirement that an individual shall not pose a direct threat to the health or safety of other individuals in the workplace” (42 U.S.C. 121 13(b)). This standard requires individualized and nonspeculative determinations of direct threat, not generalizations based on stereotypes or myths. Also, the law requires reasonable accommodation that may eliminate or sufficiently reduce a direct threat. Chapter 4 discusses in further detail the direct-threat standard, the regulations and technical guidance proffered by the Federal Government, as well as information on the relationship between mental disorders and violence.

The ADA’s potential impact on employer-provided health insurance fuels much speculation, especially in the mental health field, where benefits are generally more limited (see ch. 4). Title I forbids contractual relationships, including those with “an organization providing fringe benefits to an employee” (42 U.S.C. 121 12(b))—that result in discrimination against employees with disabili-

ties; this provision applies to health benefits ( 15). In fact, the ADA and its legislative history directly assail discriminatory practices in the area of health care benefits. However, the Act permits “benefit plan(s) that are based on underwriting risks, classifying risks, or administering such risks. . .” (42 U.S.C. 12201 (c)) in accordance with State law (where insured plans are involved), so long as the practice “shall not be used as a subterfuge to evade the purposes of Title L” (See ch. 4 for further discussion of mental health benefits and the ADA.)

In addition to preparing regulations and providing technical guidance, the U.S. Equal Employment Opportunity Commission (EEOC) is responsible for enforcing Title I (see table 2-1). Administrative and judicial remedies are identical to those provided for under Title VII of the Civil Rights Act of 1964, as expanded in 1991 (P.L. 102- 166). After commencing the EEOC’s administrative process, an individual may file a private law suit. Upon proving “a discriminatory practice intentionally engaged in with malice or with reckless indifference to the rights of the aggrieved individual,” the accusing party may also recover punitive damages. The Civil Rights Act of 1991 limits the maximal compensatory and punitive damages of \$50,000 to \$300,000. An employer may avoid damages in an ADA reasonable accommodation case if it can show good faith efforts to accommodate the applicant or employee. Chapter 5 provides a detailed discussion of the EEOC’s role in implementing and enforcing Title I of the ADA.

Titles II, III, and IV of the ADA prohibit discrimination in public services (e.g., State-run services or programs, public transportation by commuter rail), privately owned public accommodations (e.g., hotels, theaters, restaurants, etc.), and telecommunications, respective] y.

These titles leave almost no aspect of public life untouched by the ADA. The ADA charges the U.S. Departments of Justice and Transportation with the enforcement of Title II. The U.S. Department of Justice (DOJ) also has enforcement jurisdiction for Title III. Telecommunications, as covered by Title IV, is in the purview of the Federal Communications Commission. Title II of the ADA also bans employment discrimination on the basis of disability by State and local governments; regulatory and enforcement jurisdiction for this provision lies with the DOJ.<sup>1</sup>

Several Federal authorities are responsible for the sometimes overlapping provisions of the ADA and the Rehabilitation Act. In order to avoid duplication of effort or conflicting standards, the ADA requires executive branch agencies to coordinate their activities. Specifically, the law charges the EEOC, DOJ, and Office of Federal Contract Compliance Programs (in the Department of Labor)\* to “establish such coordinating mechanisms. . . in regulations implementing this title and Rehabilitation Act of 1973 not later than 18 months after the date of enactment of this Act” (42 U.S.C. 121 17(b)). Similarly, DOJ, EEOC, and other agencies must coordinate technical assistance efforts. In addition, the Rehabilitation Act was amended in 1992 to provide that the standards of Title I of the ADA shall apply to complaints of nonaffirmative action employment discrimination under the Rehabilitation Act. Acknowledging the importance of technical assistance to the ADA’s success, Title V of the law (which includes “miscellaneous” provisions) also requires EEOC to provide technical assistance manuals and other support for implementation. Chapter 5 discusses technical assistance efforts and resources relevant to employment and psychiatric disabilities.

<sup>1</sup> When a State or local government employer meets the jurisdictional requirements of Title I regarding number of employees, the EEOC also has enforcement authority.

<sup>2</sup> The Office of Federal Contract Compliance Programs or OFCCP administers section 503 of the Rehabilitation Act.

## Federal Policy Antecedents

Federal disability policy<sup>3</sup> did not begin with the ADA. Many other policies and programs affect people with disabilities. Nor is the ADA the first law to offer protection to people with psychiatric disabilities. In fact, most disability efforts explicitly include this population. A review of the Federal building blocks of the ADA (as well as some disability programs in chapter 3) clarifies the legal precedents for this law and shows how people with psychiatric disabilities have fared under them. The analysis leads to the conclusion that psychiatric disabilities do not always have an easy fit with Federal disability policies that cover them.

Legislation attempting to chip away at discrimination against people with disabilities began with the Architectural Barriers Act of 1968 (46,57) (table 2-2). Title V of the Rehabilitation Act of 1973 formed the most important legal antecedent to the ADA. Sections 501 and 503 of the 1973 Act require affirmative action in the hiring and advancement of people with disabilities by the Federal Government and any of its contractors (and, under section 503, subcontractors) receiving over \$10,000. These sections forbid Federal executive agencies and Federal contractors and subcontractors from job discrimination against people with disabilities. Section 504 prohibits discrimination or exclusion because of disability in all programs or services offered by recipients of Federal funds and by executive agencies.

The Rehabilitation Act, however, was implemented slowly. Its regulations were finalized only after several years and a court challenge (49). Many commentators conclude that the impact of

the law on people with disabilities was not overwhelming. Studies that evaluated the level of employment of people with disabilities, the frequency of accommodations, and other measures, lead to the often cited conclusion that while the Act “has unlocked the door for handicapped persons to enter the mainstream of society, it has failed in its goal of opening the door wide” (51). Analysis argues that sections 503 and 504 have had even less effect on people with psychiatric disabilities, in terms of favorable employment outcomes and decisions stemming from complaints (2,5,36).

The existing research and analyses implicate several factors in the modest effect of the Rehabilitation Act, including: attitudinal barriers toward people with disabilities; less than vigorous enforcement; the relative obscurity of the law (51); its complexity and limited scope; and the lack of dedicated, Federal leadership (4). Nevertheless, legislative support for the ADA stemmed from its similarity to the Rehabilitation Act. The ADA was seen as an extension of the Rehabilitation Act to the private sector.<sup>4</sup>

What lessons emerge for ADA enforcement and implementation? Attitudes, especially toward people with psychiatric disabilities, are a formidable barrier (see next section). The law itself, as well as the nature of disability+ specially psychiatric disabilities—are complicated and obscure to many. And enforcement activities, at least of Title I by the EEOC, are limited by budgetary constraints (see ch. 5). Finally, ongoing evaluation of the ADA’s impact stands as a critical tool in adapting and improving enforcement and implementation efforts. Without attention to these is-

<sup>3</sup>States have also enacted a variety of policies that affect people with disabilities, including antidiscrimination and workers’ compensation laws. The limited scope of this report precludes a review of these policies. Such evaluation would, however, assist the continued implementation of the ADA, by illustrating successes and problems at the State level and distinguishing potential conflicts between laws at the State and Federal levels (45).

<sup>4</sup>While the language and experience with the Rehabilitation Act of 1973 form a template for the ADA, important distinctions exist (17,22). Most obviously, and as noted in the text, the Rehabilitation Act has a narrower scope, applying only to the Federal Government and those receiving Federal funds. Also, the Rehabilitation Act unambiguously requires affirmative action, not just the reasonable accommodations prescribed by Title I of the ADA. Also, the Rehabilitation Act was broader in its protection of current drug and alcohol users; the Rehabilitation Act Amendments of 1992 (P.L. 102-569) apply the substantive standards of Title I of the ADA to sections 501, 503, and 504 for nonaffirmative action employment discrimination cases.



TABLE 2-2: Federal Legislative Building Blocks to the ADA

<i>Law</i>	<i>Principle action</i>
<i>The Architectural Barriers Act of 1968</i>	Mandated that all buildings constructed, altered, or financed by the Federal Government after 1969 be accessible and usable by persons with physical disabilities.
<i>Urban Mass Transportation Act of 1970</i>	Required all public transportation services to be accessible to people with disabilities in order to qualify for Federal funding.
<i>Rehabilitation Act of 1973</i> • sections 501 and 503	Required affirmative action on plans for the hiring and advancement of persons with disabilities in the Federal Government and any contractors receiving Federal contracts over \$10,000 and covered employment discrimination.
• section 504	Prohibited discrimination against otherwise qualified persons with disabilities in any program or activity receiving Federal funds, or any program or activity of the Executive Branch agencies and the Postal Service.
<i>The Education of All Handicapped Children Act of 1975</i>	Now called the Individuals With Disabilities Education Act, this law mandated a free, appropriate public education for all children with disabilities.
<i>The Developmental Disabilities Assistance and Bill of Rights Act, 1975</i>	Included a small, Federal grant program administered by State Developmental Disabilities Councils and is intended to coordinate and fund services for persons with developmental or severe long-term disabilities.  The Bill of Rights declared that persons with developmental disabilities have a right to appropriate treatment, services, and rehabilitation that maximize the developmental potential of the person and take place in a setting least restrictive to personal liberty.  The Act also established in every State a system of protection and advocacy organizations that are independent of any service providing organization.
<i>Civil Rights of Institutionalized Persons Act, 1960</i>	Authorized the U.S. Department of Justice to sue States for alleged violations of the rights of institutionalized persons, including persons in mental hospitals.
<i>Voting Accessibility for the Elderly and Handicapped Act of 1984</i>	Required that registration and polling places for Federal elections be accessible to persons with disabilities.
<i>Air Carriers Access Act of 1986</i>	Overtaken a Supreme Court decision which held that air carriers operating at federally funded airports were not subject to section 504. The Act prohibits discrimination against persons with disabilities by all air carriers and provides for enforcement under the U.S. Department of Transportation.
<i>Fair Housing Act Amendments of 1986</i>	Added persons with disabilities as a group protected from discrimination in housing. First antidiscrimination mandate for persons with disabilities extended into private sector.
<i>Civil Rights Restoration Act of 1988</i>	Amended section 504 of Rehabilitation Act, as well as other civil rights statutes. Overturned Supreme Court's <i>Grove City College v. Bell</i> decision defining coverage of section 504 as broad rather than narrow when Federal funds were involved.
<i>Civil Rights Restoration Act of 1988</i>	The Humphrey-Harkin provision amended the Rehabilitation Act's definition of an individual with a disability and clarified that an individual with a contagious disease or infection who poses a direct threat to the health or safety of others was not covered by section 504.

SOURCE: Adapted from J. West, "The Social and Policy Context of the Act," *The Americans With Disabilities Act: From Policy to Practice*, J. West (ad.) (New York, NY: Milbank Memorial Fund, 1991).

sues, the ADA's ultimate effect, like the Rehabilitation Act's, may be limited.

The Fair Housing Act (FHA) Amendments of 1988 form another legislative building block for the ADA. The original FHA, passed in 1968, prohibits discrimination in public and private real estate transactions based on race, color, religion, sex, or national origin. After an abortive attempt in 1980, the U.S. Congress successfully extended FHA's coverage to people with disabilities in 1988 (46). This signaled the first time that an antidiscrimination mandate for people with disabilities was extended into the private sector, an important precedent for the ADA. Indeed, many of the features that appear in the ADA come directly from FHA.

Mental health advocates lauded the FHA amendments, mindful that many people with psychiatric disabilities desperately need housing and suffer considerable discrimination in this arena. However, problems soon arose (52). One resulted from the subsequent influx of young people with psychiatric disabilities into public housing for the elderly that prompted an outcry from public housing agencies (PHAs). Many of the PHAs urged lawmakers to exclude people with mental disabilities from public housing projects for the elderly. In response to their protests, Congress requested that the U.S. Department of Housing and Urban Development (HUD) reexamine the policies that require housing older people and people with mental disabilities together in public housing projects. Although HUD rejected suggestions to exclude people with mental disabilities from the housing projects, subsequent legislation (P.L. 102-550) did authorize separate housing, a reminder that legislative gains are not immutable. To the knowledge of OTA, people with psychiatric disabilities face no current effort to exclude them from the ADA's protection. However, given the stigma and misunderstanding attached to psychiatric disorders and the complex issues they sometimes raise, a backlash is always possible.

Efforts aimed at informing people about ADA implementation may be the best means to forestall exclusion of people with psychiatric disabilities.

## THE ROLE OF PEOPLE WITH DISABILITIES

The ADA is the culmination of more than two decades of effort to transform Federal disability policy from one fostering dependence and segregation, to one encouraging independence and integration (49,50,57). While not always the initial agents of public policy changes, people with disabilities, abroad coalition of groups, forced policy reforms by their advocacy, sustained attention, and forceful leadership. They can rightly call the ADA their victory. Without a doubt, people with disabilities will continue to play a pivotal role in the ADA's implementation as well as in disability policy in general.

The disability rights movement generally comprises people with physical disabilities. People with mental disabilities, and especially psychiatric disorders, normally stand apart from the larger disability rights community.<sup>5</sup> Given the disability rights movement's profound impact on public policy, the question emerges: What role do people with psychiatric disabilities play in policies, such as the ADA, that affect them? After summarizing the development and role of the disability rights movement, this section considers the alliances of people with psychiatric disabilities and their potential role in implementing the ADA.

## The Disability Rights Movement

The disability rights movement evolved slowly over the twentieth century (12,49,50,57). While some groups organized around a shared occupation-related illness (e.g., miners with black lung disease), specific disability (e.g., the National Federation of the Blind), or other common ties (e.g., war veteran status), the social isolation of in-

<sup>5</sup> This, of course, is not always the case, and may be changing. For example, commentators have noted the importance of the disability rights movement representatives standing with advocates for people with mental disorders to ensure their inclusion in the ADA (47) and major Federal financing programs (24).

dividuals with disabilities and their low socioeconomic status essentially barred them from organizing.

Social changes that began the 1960s inspired the vigorous growth of the disability rights movement. The disability rights movement embraced the values of equal opportunity and social integration advocated by people of color and women, and appropriated the political activism of the civil rights, women's, and consumer movements. The concepts of self-determination and freedom of choice also nurtured the concept of independent living (57). This model of coping with disability, in contrast to the medical dependence model, provided a framework for *living with* long-term disabilities. It emphasized the role of individuals with a disability in making decisions.

Changes in the populations of peoples with disabilities in America also helped foster the nascent disability rights movement. Many adolescents and young adults joined the ranks of people with disabilities after the epidemic of polio in the early 1950s and the Vietnam war in the 1960s and 1970s (49). More recently, an aging population (26) and the relative increase in chronic medical illness have added to the number of people with disabilities. Medical and technological advances lengthened life span and resulted in the survival of people with previously fatal diseases or congenital conditions. People with disabilities were no longer being instilled with a life-long experience of dependency and segregation. Thus discrimination, as opposed to physical impairment or personal attitude, assumed more importance in the lives of individuals with disabilities.

A leader of the disability rights movement, Patricia Wright, has noted that "(a)] disabled people share one common experience-discrimination" (12). The recognition of discrimination as a key problem for people with disabilities had an important result: Individuals with disabilities gained a common identity (18) which fostered their work together in the public policy arena. Advocates documented discrimination and developed an arsenal of information that fueled their advocacy efforts (18,41). The publicizing of problems that people with disabilities face in society as a result

of myths, stereotypes, and exclusionary practices was a driving force behind the ADA and is reflected in the language of the law itself:

• *The Congress finds that. . . individuals with disabilities. . . have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the ability of such individuals to participate in, and contribute to, society. . . (42 U.S.C. 12101(a)).*

Disability language also changed, moving away from "patronizing and stigmatizing descriptors to empowering and respectful terminology" (57). While differences exist in the disability community over appropriate language and its relative importance, in general "people first" language prevails: the phrase "people with disabilities" is used as opposed to "disabled people." The term "handicap" is generally rejected because of its negative connotations; it does not reflect how the environment contributes to producing disabilities.

Clearly, people with disabilities have made significant strides in the last 30 years. While still disproportionately poor and unemployed (21), they have formed a strong coalition, effectively and passionately advocating changes in public policy. They are increasingly at the helm of disability organizations, other interest groups, and Federal disability programs. The disability rights movement continues pressing for policy reform in health insurance, home health care, and personal assistants—and ADA implementation (37,38).

## People With Psychiatric Disabilities and Their Family Members

The growing coalitions of people with psychiatric disabilities and their family members share some features with the broader disability rights movement, including social influences, an evolving sense of shared identity, and increasing involvement in public policy. People disabled by mental disorders often suffer lower socioeconomic status and unemployment. Medical advances contributed to social and public policy trends, such as

**deinstitutionalization (23).** The civil rights and consumer movements of the 1960s and 1970s motivated some individuals with psychiatric disabilities as they did the disability rights movement in general. Beginning in the early 1970s, small groups of former patients railed against institutionalization and mental hospital abuses, as well as the perceptions of mental illness held by mental health professionals and the public (6,7). These former patients and other advocates fought for and often won policy changes concerning involuntary commitment standards, patient civil rights, independent and community living, and treatment issues.

Changes in language were also a part of the movement of people with psychiatric disabilities. While all of the movement's members agree on the importance of destigmatizing, "people first" language, preferred designations for people with psychiatric disabilities include clients, consumers, ex-patients, patients, and psychiatric survivors (11 ). In this OTA report, people-first language will be used. Unless referring to a particular body of research in which there is a distinct and more specific designation (e.g., people with a particular diagnosis), the report will refer to *people with mental disorders or psychiatric or mental disorder-based disabilities*.<sup>6,7</sup>

Coalitions of people with psychiatric disabilities and their families, primary and secondary consumers,<sup>8</sup> are neither singular nor unified. Rather, various groups of people with psychiatric disabilities and mental health problems and their family members have joined together on the basis of need, treatment experience, types of disorders, and ideology (13,55). It is important to note that

while some leaders in the various groups have eloquently described the evolution and beliefs associated with their respective coalitions, little empirically based information (e.g., from surveys, ethnographic studies, etc.) documents these movements, or the experiences and beliefs of people involved in them (13,20,55).

Nevertheless, hundreds, perhaps thousands of local consumer groups have formed across the nation (13,55). At the national level, several groups figure prominently, including (in alphabetical order): Anxiety Disorders Association of America; National Association of Psychiatric Survivors; National Depressive and Manic-Depressive Association; and the National Mental Health Consumers' Association (20). An organization of family members as well as some primary consumers—the National Alliance for the Mentally Ill—also has a strong national voice. A brief description of each organization is provided below (and see table 2-3):

- Anxiety Disorders Association of America (ADAA): Between 2,000 and 4,000 professionals, consumers, and other interested parties form the membership of the ADAA (1,20). Founded in 1980, the ADAA has an annual budget of more than \$500,000 derived from membership fees, as well as individual and corporate contributions. Activities of the ADAA include: self-help/support groups, lobbying and public education efforts, and professional training seminars. When asked to describe its driving philosophy, the ADAA responded that "anxiety disorders are to be viewed on a par with physical illnesses which are currently

<sup>6</sup> The report focuses on mental disabilities, a broad rubric. However, some conditions are not discussed, including substance abuse disorders, developmental disabilities such as mental retardation, and other cognitive and neurological impairments. While these impairments and resulting disabilities raise important questions under the ADA—some similar and some distinct from the conditions considered in this study—they are beyond the scope of this report.

<sup>7</sup> The term psychiatric disabilities, as opposed to mental disabilities, is used because it is generally understood to refer to a narrower set of disabilities—those associated with mental disorders or mental health problems—that are the subject of this report. Also, the term psychiatric disabilities is commonly used in the rehabilitation community (32,40). Use of the term "psychiatric" is not intended to endorse a particular profession's role in treating or providing services for these conditions.

<sup>8</sup> Primary consumers refers to individuals with psychiatric disabilities themselves; secondary consumers indicate family members or others who care for people with disabilities.

TABLE 2–3: Coalitions of People With Psychiatric Disabilities and Their Families

Organization name	Year founded	Total number of members	Composition of membership	Total budget (1992)	Source of funds
Anxiety Disorders Association of America (ADAA)	1980	2,000	People with anxiety disorders, their families, and professionals.	\$500,000+	Membership fees, individual and Corporate contributions.
National Association of Psychiatric Survivors (NAPS)	1985	2,000	Current and former psychiatric patients, their families, friends, and others.	\$20,000	Membership dues and contributions.
National Depressive and Manic Depressive Association (NDMDA)	197a	30,000+	People with depressive and <i>manic</i> -depressive disorders and their families and friends.	\$780,000	Membership fees, private and public grants, fund-raisers.
National Mental Health Consumers' Association (NMHCA)	1985	1,000	Current and former consumers of mental health care services, professionals, and others.	\$2,000	Membership dues.
National Alliance for the Mentally Ill (NAMI)	1979	140,000+	Primarily parents and other family members of people with severe mental disorders.	\$2,000,000+	Membership fees, individual and corporate contributions.

SOURCE: Office of Technology Assessment, 1994.

most responsive to both medication and cognitive/behavioral therapy. No preference is expressed for either medication or therapy” (1).

- **National Association of Psychiatric Survivors (NAPS):** NAPS, which began as the National Alliance of Mental Patients in 1985, emerged as a national coalition of local groups (7,8,20). Individuals angry at their treatment by the mental health care system, including many of whom have experienced involuntary treatment and hospitalization, constitute the 2,000 active members of NAPS. The group shares some goals with other primary consumer organizations, such as the promotion of mutual support and self-help (see later discussion). But NAPS principles and tactics make it the most radical of consumer organizations. Members categorically oppose involuntary or forced treatment as well as the medical model of mental illness and treatment. They frequently adopt a confrontational approach in policy discussions and public forums.
- **National Depressive and Manic-Depressive Association (NDMDA):** The NDMDA, formed in 1978, identifies as its primary objectives self-help and support for people with serious mood disorders and their families, and education (20). With more than 30,000 members and an annual budget approaching **\$800,000**, NDMDA sponsors more than 200 local groups; forums and lectures for professionals, a semiannual national conference, several regional conferences, and publishes a quarterly newsletter, books, and other material. NDMDA views major depression and manic-depression as biological illnesses that can be treated with medication and therapy (39).
- **National Mental Health Consumers’ Association (NMHCA):** Most of the estimated 1,000 members of the NMHCA have serious psychiatric conditions, with many having experienced hospitalizations, involuntary treatment, and reliance on the public sector (7,10,28). Formed in 1985 as a network of local consumer groups, NMHCA engages in a variety of advocacy, technical assistance, and self-help activities. While sharing a strong commit-

ment to civil rights for people with mental disorders, self-representation, and self-help, the organization is less doctrinaire about the issue of forced treatment, and has worked for access to appropriate treatment, including medical interventions.

- **National Alliance for the Mentally Ill (NAMI):** NAMI was founded in 1979, as a national alliance of parents and family members of people with severe mental disorders. Most of the approximately 140,000 members are secondary consumers, with the “typical member (being). . . a mother in her sixties with a son in his twenties who has schizophrenia” (19). Increasingly, primary consumers are active although not dominant in NAMI. They are members of the Client Council and Board of Directors at the national level and leaders of some local groups. NAMI is the most influential of national mental health consumer groups, as reflected in its annual budget of more than \$2 million, large membership, and influence on public policy (20). The organization focuses on individuals with the most severe mental disorders and strongly advocates biomedical research and treatment.

Differences among these groups are real, and sometimes acrimonious. However, as they coalesce around shared goals, they also have much in common, including the experience and repudiation of stigma and discrimination, their insistence on the importance of empowerment and advocacy, and, notable for this report, the availability of jobs or meaningful activity (7).

While stigma and discrimination affect the lives of all people with disabilities, people with psychiatric disabilities suffer some of the harshest and cruelest attitudes (box 2-2). Although attitudes toward mental disorders may be improving (9), a recent national survey of public attitudes toward people with disabilities shows that, from the public’s perspective, mental illness is the most disturbing of all disabling conditions (41) (figure 2-1 ). This is not surprising given the exceedingly negative images of people with mental disorders—as incompetent, ineffectual, or violent—

## BOX 2-2: The Politics of Stigma

The public perception of an individual's stability, competence, and stamina is perhaps most important in the political arena. Indeed, the slightest hint of mental health problems can be the political kiss of death. Recent history shows that the stigma associated with mental illness is a formidable weapon when used to cast doubts on a candidate's fitness for political office. Although it was acknowledged among his peers that President Lincoln was plagued by "melancholy" throughout his life and his presidency, it wasn't until 1964 that a "mental illness" was first raised as a campaign issue. Since that attack on Republican presidential candidate Barry Goldwater's mental health, several other national candidates have had their mental stability attacked. A closer look at some of these political races corroborates the stigma of mental illness while hinting at an evolution in public attitudes.

**The Political Kiss of Death**

In October 1964, in an effort to discredit presidential nominee Barry Goldwater, the publisher of the now defunct "Fact" magazine published the results of a survey he had commissioned in which more than 1,189 of the 2,417 psychiatrists answered "no" to the question, "Is Barry Goldwater psychologically fit to be President of the United States?" The American Psychiatric Association (APA) and the American Medical Association assailed the survey as "yellow journalism," with the APA noting that

By attaching the stigma of extreme political partisanship to the psychiatric profession as a whole in the heated climate of the current political campaign, *Fact* has in effect administered a low blow to all who would advance the treatment and care of the mentally ill of America.

Subsequently, the APA adopted what it called "the Goldwater Rule" which forbids doctors from offering a psychiatric opinion on a public figure unless the psychiatrist has personally treated the official and has authorization to break patient-doctor confidentiality. Although it is difficult to know with any certainty the effect of any one factor on a political campaign, it appears that the incident contributed to Mr. Goldwater's defeat in the presidential election. He did, however, successfully sue the magazine's publisher, becoming one of the few public figures to win such a libel suit.

Several days after Democratic presidential candidate George McGovern selected Senator Thomas Eagleton as his running mate, the national press revealed that Mr. Eagleton had withheld the fact that he had been hospitalized on three occasions for "nervous exhaustion and fatigue" and that he had undergone electroconvulsive therapy for depression on two of the three occasions. In this instance, the information was true. Mr. Eagleton had withheld the information from Mr. McGovern and his staff when asked if he had "any skeletons in the closet."

Perhaps Mr. Eagleton did not regard his medical history of depression as a "skeleton." It became clear, however, that the press and much of the public did. While some people praised Mr. Eagleton for his candor, most people criticized his judgment for failing to make the facts known before his nomination. Moreover, while some people found it reassuring that Mr. Eagleton recognized the need and sought treatment for depression and expressed confidence in his ability to be Vice President, others viewed him an unfit candidate for the office and urged him to withdraw from the race. After a painful and public debate, Mr. Eagleton was dropped from the ticket.

Sixteen years after Mr. Eagleton was forced to withdraw, rumors of mental illness were used against Michael Dukakis' bid for the presidency. During the 1988 presidential campaign, supporters of Lyndon LaRouche circulated the rumor that Michael Dukakis had been treated by a psychiatrist for depression. Initially, Mr. Dukakis dismissed the allegations with an assertion that there was no evidence to support the rumor and he refused to release his personal medical records. But then, President Reagan brought national attention to the rumor when he joked at a press conference that, "I am not going to pick on an invalid," when asked

(continued)

## BOX 2-2: The Politics of Stigma (cont'd.)

his opinion about Mr. Dukakis' refusal to release his medical records. Eventually, Mr. Dukakis' personal physician issued a statement assuring the public that the presidential candidate was in excellent health and had had no psychological symptoms, complaints, or treatment. While the ultimate outcome of the presidential race may not have hinged on this issue, it nonetheless underscores the potency of such allegations.

#### A New Age?

More recent experience suggests that voters' attitudes about mental illness may be changing. In 1990, former United States Senator Lawton Chiles had to deal with the mental health issue during his gubernatorial campaign in Florida. Mr. Chiles acknowledged that he was taking the widely prescribed drug Prozac for treatment of depression, which he had suffered since leaving the U.S. Senate, complaining of "burnout." During the gubernatorial primary campaign, his opponent's running mate suggested that Mr. Chiles could be suicidal. His allegation was based on newspaper accounts that the makers of Prozac were being sued because the drug induced suicidal tendencies.

Mr. Chiles was obliged to release medical records that said he did not contemplate suicide during his bouts with depression. The voters did not seem to consider Mr. Chiles' taking of Prozac to be a significant issue. Mr. Chiles said he thought the health issue was much more of a concern to the press and politicians than to average people. "I didn't realize how many people knew something about depression, had somebody in their family with it or whatever," he said. "People are always coming up to me, just kinda squeezing my arm and saying something." Mr. Chiles won the election.

Most recently, in 1992, Congresswoman Nydia Velazquez, former U.S. Secretary of the Department of Puerto Rican Community Affairs, won her bid to represent New York City's 12th Congressional District despite reports that she had attempted suicide in 1991. After hospital records revealing a bout with depression, pills, alcohol, and attempted suicide were anonymously leaked to news organizations, Ms. Velazquez held a news conference to assure voters that she had been receiving professional counseling that gave her "a whole new outlook on life." Apparently voters were convinced; she won the election with **77 percent** of the votes.

The experience of candidates for public office reflects what people in all walks of life know: Mental disorders trigger stigmatizing perceptions of incompetence, personal turpitude and weakness, endangering job prospects. Thus, even with the suggestion of diminishing negative attitudes, people with psychiatric disabilities clearly need protection from discrimination offered by the ADA.

SOURCES "Risks of Prying Into Mental Health Problems," *CQ Researcher* 2:346, 1992; J. Fuller, "Editorials Are Mixed on Eagleton," *Washington Post*, July 28, 1972, p. A13; J. LeMoine, "Polls Show Chiles Leading in Florida," *New York Times*, Sept. 2, 1990, p. A24, "IS Barry Goldwater Psychologically Fit to be President of the United States?" advertisement in *New York Times*, Sept. 12, 1964, p. L26; "Doctors Deplore Goldwater Poll," *New York Times*, Oct. 2, 1964; *New York Times*, "The 1992 Election: New York Stat" U.S. House Races: Green and Downey Lose as New York State Delegation Changes Dramatically," *New York Times*, Nov. 4, 1992, p. B11; C. Sandburg, *Abraham Lincoln: The Prairie Years and The War Years* (New York, NY: Harcourt, Brace, 1954); R. Toner, "Florida Governor Warily Fights Chiles Mystique," *New York Times*, Sept. 14, 1990, p. A14; "Ex-Senator Chiles Issues Health Data," *Washington Post*, Aug. 22, 1990, p. A3; "After Suicide Try, Candidate is 'Truly' Living," *Washington Post*, Oct. 9, 1992.

routinely projected by the news and entertainment media, the public primary source of information about mental illness (16,28,31,48,53) (see ch. 4 for discussion of mental disorders and violence).

The negative attitudes attached to mental disorders have profound implications for the imple-

mentation of the ADA. Fear, ignorance, and misperceptions about psychiatric disability undoubtedly contribute to employment discrimination (40,56). Furthermore, the education of employers and coworkers about mental disorders as well as employee willingness to disclose a psy -

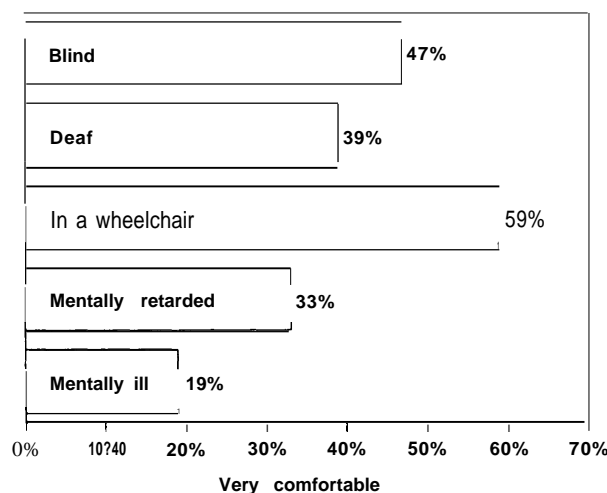


chiatric disability will be critical (see ch. 4). Stigma and discrimination also inspire the adoption of a principle that seems to be universally held by consumer groups: empowerment.

Before defining empowerment, it is important to explicate one of the most insidious results of stigma and discrimination. People with psychiatric disabilities often internalize the attitudes and practices of people who victimize them (7,28,40,43,56). Research findings support the observation that stigma and discrimination attached to mental illness undermine an individual's self-esteem and social interactions (31,56). For example, one study (30) correlated the expectation of rejection with demoralization and unemployment among people with mental disorders.

To counter these crippling effects, many people with psychiatric disabilities and their family members hold empowerment as a fundamental goal (5,34,55). While the term may suffer from overuse and some ambiguity (34), empowerment connotes a sense of personal and social potency. "Empowerment means acquiring the ability to make decisions that affect an individual's life" (55). Government officials at the Federal and State level increasingly endorse the principle of empowerment and have legislated consumer involvement in policy making and the delivery of mental health care (55). For example, the statement from the Federal consensus conference on "Strategies to Secure and Maintain Employment for Persons with Long-Term Mental Illness" prominently highlights consumer involvement (40): "It is important to promote the active participation of people with psychiatric disabilities at all levels of research development, implementation, and evaluation." Similarly, the National Association of State Mental Health Program Directors asserts in a position paper that "former mental patients/mental health consumers have a unique contribution to make to the improvement of the quality of mental health services in many arenas of the service delivery system. . . Their contribu-

FIGURE 2-1: Public Attitudes Attached to Mental Disorders



*A survey conducted by Louis Harris and Associates, Inc., for the National Organization on Disability indicated that of all the disabilities asked about, people felt least comfortable with people with mental illness.*

SOURCE Adapted from National Organization on Disability, "Public Attitudes Toward People With Disabilities," survey conducted by Louis Harris and Associates, Inc., 1991

tion should be valued and sought in areas of program development, policy formation, program evaluation, quality assurance, system designs, education of mental health service providers, and the provision of direct services" (43). Federal legislation also has required the involvement of people with psychiatric disabilities and their family members in mental health services and policy. The Mental Health Planning Act (P.L. 99-660) and the Protection and Advocacy for Mentally Ill Individuals Act (P.L. 99-319) require the formal involvement of consumers on State advisory bodies. A more recent development is the establishment of the Consumer/Survivor Mental Health Research Policy Work Group by the Center for Mental Health Services<sup>9</sup> (CMHS). The group, which includes several people with psychiatric

<sup>9</sup>The Center for Mental Health Services is part of a newly organized Federal agency, Substance Abuse and Mental Health Services Administration (SAMHSA), in the U.S. Department of Health and Human Services (P. L. 102-321). See chapter 5 for complete description.

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disabilities, identifies roles for consumers in mental health policy and research (3).

The Community Support Program (CSP) in CMHS is among the most prominent governmental supports for groups of people with psychiatric disabilities and their families (8; see ch. 5). Since its inception in 1977 as the first national program to promote consumer involvement in mental health care, CSP has funded several national conferences, two national technical assistance centers, a self-help clearinghouse, a national monthly teleconference, and various model programs for self-help and consumer service involvement (see ch. 5). In fiscal year 1993, CSP provided \$4.4 million (about 35 percent of the CSP budget) in grants to 31 States to support family and consumer initiatives. In addition, the CSP funds research into the consumer movement (55).<sup>10</sup>

Two activities commonly performed by consumer groups could effect better ADA implementation. First, these groups may offer technical assistance to businesses. Because people with psychiatric disabilities and their family members have a long involvement in rehabilitation, job clubs, and consumer-run businesses, they have first-hand knowledge of the issues that arise in employment (55). For example, Fountain House, founded in 1957 in New York, pioneered “club houses,” an approach to psychosocial rehabilitation that provides for transitional employment services. The club houses place individuals in temporary jobs with on-site support and training. Second, many groups have considerable experience educating outside groups about mental disorders, a service that many employers may find helpful. Thus, many consumer organizations can help employers devise accommodations and sensitize them to the issues associated with psychiatric disabilities. As mentioned, the CSP supports two consumer-run national technical assistance centers—Project Share in Philadelphia, Pennsylvania, and the National Empowerment Center in

Lawrence, Massachusetts—as well as the National Mental Health Consumer Self-Help Clearinghouse. These centers can assist employees and employers in finding local groups and employment/ADA related information.

Consumer self-help groups form another potential resource during ADA implementation. Such groups, in operation since the late 1970s, offer empowerment, inspiration, education, and support (7,8, 14,34,55). Self-help group functions range from support services to advocacy (25,55). Recently published data detail the nature of these services and provide evidence that many people with psychiatric disabilities and their family members utilize them (55). While empirical proof of performance is yet to come, new and ongoing studies suggest that self-help groups can provide effective services (25,55). Given their apparent wide use and the support that they provide, self-help groups may be useful in helping people with psychiatric disabilities address ADA employment issues.

The above discussion asserts that consumer groups may advance ADA implementation by serving as a source of information and support to employers and employees. Three caveats warrant notice, however: First, in general, employers have not tapped into the experience and expertise of people with disabilities; people with psychiatric disabilities and their family members may be even more underutilized. Second, characterization and evaluation of consumer-provided services to identify the groups that are most effective are at a very early stage (25,29,34,55). Third, to be effective agents of information and support for the ADA, people with psychiatric disabilities and their family members need to understand the law.

## SUMMARY AND CONCLUSIONS

This chapter summarizes the ADA’s provisions, highlighting issues of employment. While not an

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<sup>10</sup> According to an informal survey by the U.S. Department of Health and Human Services Inspector General, while CSP is rightly credited with fostering the mental health consumer movement, it “has become overidentified with . . . certain consumers over others.” (54).

in-depth analysis of the ADA's legislative history or requirements, the overview points out the importance of this legislative mandate for people with psychiatric disabilities. The overview also points out some potential problems. Chapters 3 and 4 consider these areas in greater detail.

The ADA stems from a 25-year history of anti-discrimination laws. Review of the policy antecedents of the ADA in this chapter and in the next led OTA to the conclusion that psychiatric disabilities do not always have an easy fit with Federal disability policies. This reflects the stigma attached to mental disorders and the complexity of psychiatric disability. This history has important implications for the ADA: Federal leadership, public education about the law's goals, and understanding of psychiatric disabilities will be critical for fair and effective implementation.

This chapter also outlines the history of people with disabilities in making public policy. Individuals with physical disabilities organized over the last three decades; they worked to invest disability policy with values of self-determination, equal opportunity, and full participation in society. United against discrimination, the disability rights movement passionately worked to win the ADA's passage. In addition, people with physical disabilities have achieved important policy goals, political clout, and leadership.

Although not yet at the same level of leadership and political influence as those with physical disabilities, people with psychiatric disabilities and their families have founded several national organizations and have gained a voice in public policy over the last 10 to 20 years. While often divided over priorities and ideologies, these groups express common concerns over the need for employment and the problems of discrimination. Their experience with employment, technical assistance, support groups, and public education has the potential to inform and promote ADA implementation.

## CHAPTER 2 REFERENCES

1. Anxiety Disorders Association of America, Rockville, MD, personal communication, June 1993.
2. Berkeley Planning Associates, *A Study of Accommodations Provided to Handicapped Employees by Federal Contractors, Vol. 1: Study Findings* (Washington, DC: U.S. Department of Labor, 1982).
3. Bevilacqua, J.J., "Consumerism Is Not a Fad," *Resources* 5: 1-6, 1993.
4. Bevilacqua, J.J., Director of Mental Health, South Carolina Department of Mental Health, Columbia, SC, personal communication, Sept. 17, 1993.
5. Brakel, S.J., Parry, J., and Weiner, B. A., *The Mentally Disabled and the Law*, 3d ed. (Chicago, IL: American Bar Foundation, 1985).
6. Brown, P., "The Mental Patients' Rights Movement, and Mental Health Institutional Change," *International Journal of Health Services* 11:523-40, 1981.
7. Chamberlain, J., "The Ex-Patients' Movement: Where We've Been and Where We're Going," *The Journal of Mind and Behavior* 11:323-336, 1990.
8. Chamberlain, J., Rogers, J. A., and Sneed, C. S., "Consumers, Families, and Community Support Systems," *Psychosocial Rehabilitation Journal* 12:93-106, 1989.
9. Clements, M., "What We Say About Mental Illness," *Parade Magazine*, Oct. 31, 1993, pp. 4-6.
10. Community Support Network News, "National Mental Health Consumers' Association," *Community Support Network News* 5:2-3, 1988.
11. Consumer/Ex-Patient/Survivor Advisory Committee, remarks at the conference, "Rehabilitation of Children, Youth, and Adults With Psychiatric Disabilities," Tampa, FL, January 1993.

### 3 8 Psychiatric Disabilities, Employment, and the Americans With Disabilities Act

12. CQ Researcher, *The Disabilities Act* (Washington, DC: Congressional Quarterly, Inc., 1991).
13. Emerick, R.E., "Group Demographics in the Mental Patient Movement: Group Location, Age, and Size as Structural Factors," *Community Mental Health Journal* 25:277-300, 1989.
14. Emerick, R. E., "The Politics of Psychiatric Self-Help: Political Factions, Interfactual Support, and Group Longevity in a Social Movement," *Social Science* 32:1 121-1128, 1991.
15. Feldblum, C. R., "Employment Protections," *Milbank Quarterly* 55:81-106, 1991.
16. Gerbner, G., Gross, L., Morgan, M. et al., "Health and Medicine on Television," *New England Journal of Medicine* 305:901-904, 1981.
17. Haggard, L. K., "Reasonable Accommodation of Individuals With Mental Disabilities and Psychoactive Substance Use Disorders Under Title I of the Americans With Disabilities Act," *Journal of Urban and Contemporary Law* 43:343-390, 1993.
18. Harris, L. and Associates, *The ICD Survey of Disabled Americans: Bringing Disabled Americans Into the Mainstream* (New York, NY: International Center for the Disabled, 1986).
19. Hatfield, A. B., "The National Alliance for the Mentally 111: A Decade Later," *Community Mental Health Journal* 27:95-103, 1991.
20. Have], J.T., "Associations and Public Interest Groups as Advocates," *Administration and Policy in Mental Health* 20:27-44, 1992.
21. Institute of Medicine, *Disability in America: Toward A National Agenda for Prevention*, A.M. Pope and A.R. Tarlov (eds.) (Washington, DC: National Academy Press, 1991).
22. Jones, N. L., "The Alcohol and Drug Provisions of the ADA: Implications for Employers and Employ ees," *Consulting Psychology Journal: Practice and Research* 45:37-45, 1993.
23. Klerman, G.L., "Better But Not Well: Social and Ethical Issues in the Deinstitutionalization of the Mentally Ill," *Schizophrenia Bulletin* 3:617-631, 1977.
24. Koyanagi, C., and Goldman, H., *Inching Forward: A Report on Progress Made in Federal Mental Health Policy in the 1980s* (Alexandria, VA: National Mental Health Association, 1991).
25. Kurtz, L.F., "The Self-Help Movement: Review of the Past Decade of Research," *Social Work With Groups* 13: 101-115, 1990.
26. LaPlante, M. P., "The Demographics of Disability," *Milbank Quarterly* 55:60-63, 1991.
27. Lechner, W., Manager, Research and Policy, National Federation of Independent Business, Washington, DC, personal communication, May 25, 1993.
28. Leete, E., "The Role of the Consumer Movement and Persons With a Mental Illness," *Switzer Seminar* 12:65-73, June 1988.
29. Lieberman, M., "Self-Help Groups and Psychiatry," *Psychiatry Update: American Psychiatry Association Review* 5:744-760, 1986.
30. Link, B.G., "Understanding Labelling Effects in the Area of Mental Disorders: An Assessment of the Effects of Expectations of Rejection," *American Sociological Reviews* 52:96-112, 1987.
31. Link, B.G., Cullen, F.T., Mirotznik, J. et al., "The Consequences of Stigma for Persons With Mental Illness: Evidence From the Social Sciences," *Stigma and Mental Illness*, P.J. Fink and A. Tasman (eds.) (Washington, DC: American Psychiatric Press, Inc., 1992).
32. Mancuso, L. L., "The ADA and Employment Accommodations: What Now?" *American Rehabilitation* 32: 15-17, 1990-1991.
33. Mancuso, L. L., *Case Studies on Reasonable Accommodations for Workers With Psychiatric Disabilities* (Sacramento, CA: California Department of Mental Health, 1993).
34. McLean, A., "Empowerment and the Psychiatric Consumer Movement: Contradic-

- tions in Consumer-Run Alternate,” *Social Science and Medicine*, in press.
35. Milstein, B., Rubenstein, L., and Cyr, R., “The Americans With Disabilities Act: A Breathtaking Promise for People With Mental Disabilities,” *Clearinghouse Review*, March 1991, pp. 1240-1249.
36. Moss, K., *Implications of Employment Complaints Filed by People With Mental Disabilities* (Washington, DC: Mental Health Policy Resource Center, 1992).
37. National Council on Disability, *A Study on the Financing of Assistive Technology Devices and Services for Individuals With Disabilities* (Washington, DC: 1993).
38. National Council on Disability, *ADA Watch-Year One: A Report to the President and the Congress on Progress in Implementing the Americans With Disabilities Act* (Washington, DC: Apr. 5, 1993).
39. National Depressive and Manic-Depressive Association (NDMDA), Chicago, IL, personal communication, June 1993.
40. National Institute on Disability and Rehabilitation Research, “Strategies To Secure and Maintain Employment for Persons With Long-Term Mental Illness,” Consensus Validation Conference, Washington, DC, September 1992.
41. National Organization on Disability, “Public Attitude Toward People With Disabilities,” survey conducted by Louis Harris and Associates, Inc. (Washington, DC: 1991).
42. O’Keeffe, J., “Disability, Discrimination and the Americans With Disabilities Act,” *Consulting Psychology Journal: Practice and Research* 45:3-9, 1993.
43. Parrish, J., “The Long Journey Home: Accomplishing the Mission of the Community Support Movement,” *Psychosocial Rehabilitation Journal* 12: 107-124, 1989.
44. Parry, J. W., “Mental Disabilities Under the ADA: A Difficult Path to Follow,” *Mental and Physical Disability Law Reporter* 17: 100-112, 1993.
45. Percy, S., *Disability Rights Mandates: Federal and State Compliance With Employment Protections and Architectural Barrier Removal* (Washington, DC: Advisory Commission on Intergovernmental Relations, 1989).
46. Rubenstein, L. S., “Mental Disorder and the ADA,” *Implementing the Americans With Disabilities Act: Rights and Responsibilities of All Americans*, L.O. Gustin and H.A. Beyer (eds.) (Baltimore, MD: Paul H. Brookes Publishing Co., 1993).
47. Scallet, L.J., and Rohrer, C. F., *Analysis: Americans With Disabilities Act and Mental Health* (Washington, DC: Mental Health Policy Resource Center, 1990).
48. Scheff, T.J., *Being Mentally Ill: A Sociological Theory*, 2nd ed. (Chicago, IL: Aldine, 1984).
49. Scotch, R. K., *From Good Will to Civil Rights: Transforming Federal Disability Policy* (Philadelphia, PA: Temple University Press, 1984).
50. Shapiro, J. P., *No Pity* (New York, NY: Random House Inc., 1993).
51. Tucker, B. P., “Section 504 of the Rehabilitation Act after Ten Years of Enforcement: The Past and the Future,” *University of Illinois Law Review* 4:845-921, 1989.
52. U.S. Congress, Government Accounting Office, Report to the Chairman, Subcommittee on Housing and Urban Affairs, Committee on Banking, Housing, and Urban Affairs, U.S. Senate, *Public Housing: Housing Persons With Mental Disabilities With the Elderly*, GAO/RCED-92-81 (Washington, DC: August 1992).
53. U.S. Congress, Office of Technology Assessment, *The Biology of Mental Disorders*, OTA-BA-538 (Washington, DC: Government Printing Office, September 1992).
54. U.S. Department of Health and Human Services, Office of the Inspector General, *Revitalizing the Community Support Program* (Washington, DC: June 1993).

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55. Van Tosh, L., "Consumer/Survivor-Operated Self-Help Programs," in preparation.
56. Wahl, O. F., and Harman, C. R., "Family Views of Stigma," *Schizophrenia Bulletin* 15: 131-139, 1989.
57. West, J. (cd.), *The Americans With Disabilities Act: From Policy to Practice* (New York, NY: Milbank Memorial Fund, 1991).