

**Chapter 7**

# **Public Attitudes and Policy**

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## Public Attitudes and Policy

Researchers have partially uncovered the biological substrates of the mental disorders considered in this report and have propounded testable hypotheses as to causation. These scientific advances portend increased research opportunities as well as the development of improved treatments. But as is true for science in general, this research interacts with broad social and political factors (56,58). Support—or lack thereof—reflects social attitudes and the efforts of advocacy groups. The results of biomedical research also affect society. Improved understanding of the cause of a disorder can influence the public's response to individuals with a particular disorder as well as the direction of public policy.

This chapter attempts to tease out some of the social effecters of biological research into mental disorders and some of the implications of data arising from these studies. What factors have led to enthusiasm for biological research into mental disorders? What are the limitations of this approach? How might information about the biology of mental disorders influence public attitudes and policy? The

chapter begins with a general description of public attitudes toward mental disorders.

### PUBLIC ATTITUDES TOWARD MENTAL DISORDERS

Mental disorders incur stigma, “a mark of disgrace or reproach” (72) (box 7-A). Surveys of 30 and more years ago showed that ‘the mentally ill are regarded with fear, distrust, and dislike by the general public’ (41) and that persons labeled as mental patients tended to be stigmatized and shunned (51). And negative attitudes toward and ignorance of these disorders still abound (33). A sizable number of people continue to be tightened by the notion of mental illness and believe that others are frightened also, although it is becoming less socially acceptable to say so (50). A recent survey conducted for the National Organization on Disability (40) found that only a minority of persons polled (19 percent) felt very comfortable with a person with a mental disorder (figure 7-1).<sup>1</sup> Despite gains in knowledge about specific disorders and

#### *Box 7-A—The Barriers Erected by Stigma: A Patient's Perspective*

We had met under the most unusual circumstances, in a place we came to call “The Funny Farm. . . .” We were initiated into a stigmatizing sorority. . . .

[Having] experienced the problems and barriers that lie before us in “normal” society. . . the scene has been repeated in many different settings: a supervisor who viewed my work and abilities as outstanding and my rate of productivity as very high before my illness, but who recommended disability retirement when I was depressed and less productive; a university that graduated me with high honors, admitted me into its graduate program with outstanding recommendations, and then sent me a form letter in response to my request for readmission (following my illness) saying, “You do not meet our admission requirements;” and community mental health agencies that rejected my offers to be of assistance because I “scared” mental health professionals. . . .

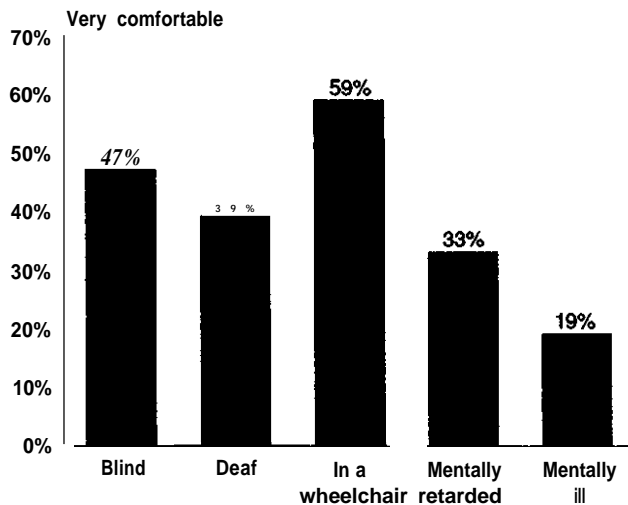
The literature says little about us individually. Most researchers group us, thereby reinforcing the stigma. Some lay odds on our recovery and predict high rates of suicide. Some experiment with us, offering convincing evidence that we can be trained-rehabilitated. Others raise ethical concerns about studying us, but justify their actions by noting that useful data can be obtained by following us. Some have tried to document that public attitudes toward the mentally ill have changed.

If my own research and experiences are representative, public attitudes have not changed. From my perspective, researchers continue to define stigma with statistics. Physicians continue to locate emotional pain points with questions. Families continue to treat mental illness as a silent, shameful disease. Clergymen continue to preach that mental illness is the result of satanic influence. The barriers remain. They are real. . . .

*SOURCE:* Anonymous, *Schizophrenia Bulletin* 6:544-546, 1980.

<sup>1</sup>The survey included a random sample of 1,257 people interviewed by telephone between May 15 and June 18, 1991. The estimated margin of error was \* 3 percent.

Figure 7-1—Level of Comfort With People With Mental Disorders



A survey conducted by Louis Harris & 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.

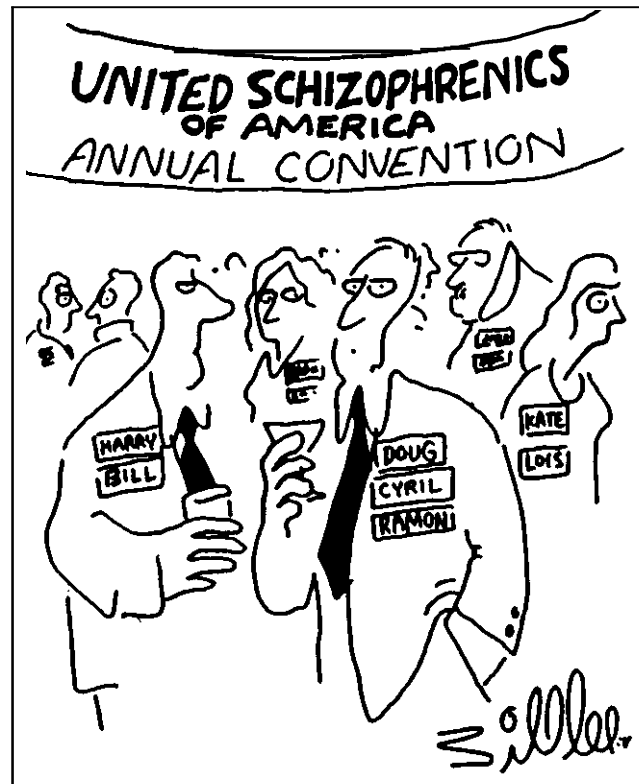
SOURCE: Adapted from National Organization on Disability, "Public Attitudes Toward People With Disabilities," survey conducted by Louis Harris and Associates, Inc., 1991.

their treatment, considerable ignorance about mental disorders persists: For instance, 64 percent of college freshmen thought schizophrenia referred to multiple personalities (68). Data from research also have indicated that some providers of mental health care are themselves inadequately informed as to the diagnosis and treatment of mental disorders (for example, see 44,61,73).

While widespread and incontrovertible, the stigma attached to mental disorders is a difficult concept to define. Many stress the deliberate nature of stigma:

Stigma refers to the process by which people who lack certain traits denigrate people who possess them, and it leads to individual differences in social interaction, prejudice, and discrimination (62).

Clearly, ignorance about mental disorders—their symptoms, treatability, or causes—can serve as a fertile breeding ground for negative attitudes. However, a lack of knowledge about mental disorders cannot explain all of the stigma that exists. For example, a 1990 national survey<sup>2</sup> of public attitudes toward people with chronic mental illness found



Credit: Copyright © Bill Lee. Reprinted with permission.

This cartoon, provided by O. Wahl, illustrates the commonly held misperception that schizophrenia is multiple personalities.

widespread evidence of the "not in my backyard" phenomenon, expressed as resistance to treatment and housing facilities in the community, with the incidence of opposition increasing with income and educational level (55). Even mental health care providers sometimes harbor negative attitudes toward individuals with mental disorders, especially those with severe and persistent conditions (8). In 1987, the American Psychiatric Association Task Force on the Chronic Mental Patient determined that

among professionals such as ourselves, and among paraprofessionals, there are prevailing attitudes—that working with [chronic] patients is unrewarding and dull, and that . . . prestige is not available for working in [chronic patient] programs (34).

While stigma is attached to many serious medical conditions, people with mental disorders are subject to much more rejection: Public attitudes toward mental disorders are more akin to those directed at drug addiction, prostitution, and ex-convict status

<sup>2</sup> Data from a telephone survey of approximately 1,300 Americans representative of the total population of adults 21 and older. In addition, four focus groups, two in Pennsylvania and two in Ohio, were conducted, as well as in-depth telephone interviews with 17 mental health opinion leaders.

than cancer, diabetes, and heart disease (2,33). The stigma reflects in part the fear or uneasiness evoked by individuals who display unusual or threatening behavior. Results from studies suggest that a sizable portion of the public harbors the belief that mental disorders are linked to violent behavior (35). As might be expected, the belief that people with mental disorders are more prone to violent acts leads to a strong rejection of people afflicted with these conditions (32).

The stigma attached to mental disorders, with all its variable expressions and sources, has important social implications. Afflicted individuals and their families suffer acutely from the stigma attached to mental disorders (28,71). Many family members feel uncomfortable talking about their problem and may feel responsible and isolated as a result (13, 29, 71). Ignorance and negative attitudes also interfere with successful treatment: Individuals with a mental disorder may avoid seeking treatment to avoid the associated stigma or simply because they are unaware of its availability. And as mentioned above, providers themselves may be inadequately informed about the recognition or treatment of mental disorders, or may harbor negative attitudes toward people with these conditions (5, 9, 43, 73). Finally, data show that people with mental disorders react in a negative fashion, in the belief that other people view them negatively (10, 31)

The stigma attached to and ignorance of mental disorders is mirrored in the discrimination in the financing of treatment, housing, employment, and the funding of research, a topic considered in this report. Previous studies (21, 49) and mental health advocates (for example, see 17) have demonstrated the underfunding of research into mental disorders compared to their social cost, attributing the deficiency to the low priority assigned to these conditions by the public and policymakers. The Office of Technology Assessment's (OTA) analysis also shows that, relative to their social costs, cancer and heart disease research receive substantially more funding than mental disorders research (see ch. 6). Thus, while the 1980s did witness a significant increase in Federal funding for research into mental disorders and new private sources of funding, support for research into mental disorders still fell short of that for other conditions in relation to their cost to society.



*Credit: Courtesy of the American Psychiatric Association, 1992*

**A recent public education campaign, sponsored by the American Psychiatric Association, highlighted the negative impact of stigma on treatment-seeking.**

**Thus, the impact of stigma on public policy is compelling and undeniable. This finding echoes the results of a recent report by the Interagency Task Force on Hopelessness and Severe Mental Illness (20):**

Stigmatization, fear, and mistrust regarding people with severe mental illnesses . . . are commonplace in our Nation. Such reactions influence both the direct responses of community members to these individuals as well as the development of local, State, and Federal policies affecting them.

A conclusion that OTA draws from this analysis is that the dissemination of accurate knowledge about mental disorders—to the public at large, families, consumers, care providers, and policymakers—is essential to improving the lives of individuals with mental disorders and fair and informed policymaking (box 7-B).

The negative influence of stigma and ignorance on public policy cannot be offered as a simple or complete explanation for failures in public policy. Attitudes toward mental disorders reflect the influence of a number of factors, ranging from beliefs about the origin of mental disorders, fear of individuals who are thought to be violent, and media portrayals. Furthermore, the way in which stigma contributes to policy formation is difficult, if not impossible, to distill precisely. The policy areas affected by negative public attitudes—research funding, treatment, housing, mental health care finance, and employment—are not influenced by stigma alone, but by other factors, such as the structure of

### **Box 7-13-Educating the Public About Depression**

Of the 15 million people who experience a major depressive disorder each year, four-fifths can be treated successfully; yet, only one-third of them seek treatment. Even when people seek treatment, symptoms of a depressive disorder are often unrecognized or inappropriately treated by health professionals. Given this level of ignorance, as well as the negative attitudes that surround mental disorders, the Federal Government sponsored its first major health education program about a specific mental disorder in 1986, with the initiation of the National Institute of Mental Health's (NIMH's) DEPRESSION Awareness, Recognition and Treatment (D/ART) program. The D/ART seeks to: 1) increase public knowledge of the symptoms of depressive disorders and the availability of effective treatment, 2) change public attitudes about depression so that there is greater acceptance of depression as a disorder rather than a weakness, 3) encourage changes in help-seeking behavior to reduce the number of untreated and inappropriately treated individuals, and 4) provide information to primary care physicians, mental health specialists, and medical students about advances in diagnosing and treating depressive disorders. The D/ART program will extend over a decade and consists of three components: a professional training program, a public education campaign, and a national worksite program.

For fiscal years 1986 to 1991, the D/ART program expended \$4.5 million to train health professionals about recent advances in diagnosis and treatment of depressive disorders (table 7-1). Short-term training courses, developed for this purpose, have been used to train more than 11,000 primary care physicians, mental health professionals, and medical students about depressive disorders. In addition, the D/ART program sponsors continuing education programs in collaboration with professional associations.

In 1988, the D/ART program launched a two-part public education campaign consisting of a multimedia component to publicize messages about depressive disorders and a community partnership program to extend and reinforce the media messages at the local level. First, D/ART staff conducted 20 focus groups in nine geographically dispersed cities and contracted for a survey of 500 people in two cities (Indianapolis, IN and Sacramento, CA) to find out what people knew about depressive disorders. Furthermore, in the early stages of campaign development, the D/ART program organized a group of 45 campaign consultant organizations to advise about public education strategies. The group comprised of representatives from the major mental health and medical professional associations as well as health and mental health organizations, businesses, labor, religious, and educational groups, mental health advocacy groups, foundations, and other Federal agencies—continues to provide advice on campaign policy matters and to disseminate information on depression.

The D/ART Public Education Campaign has expended \$3.6 million in the past 5 years (table 7-1) to develop educational materials. For example, a total of 16 flyers, brochures, and booklets have been produced and distributed to more than 13 million people, with some of the publications geared toward the general audience and some to specific groups, such as teenagers, college students, young African-Americans, and older people; some have been published in Spanish and five Asian languages. Also, close to 1,000 television and 9,000 radio stations have broadcast public service announcements (PSAS) about depression to as many as two-thirds of households nationwide. A number of the initial PSAS featured celebrity spokespersons to introduce the campaign.

A critical component of the D/ART program is its community partnership strategy. The Community Partnership Program consists of 32 mental health groups, mostly "Mental Health Association" and "Alliance for the Mentally Ill" organizations, located in 24 States and the District of Columbia. Community partners reproduce and distribute copies of print materials on depression; conduct public forums, worksite programs, and professional

**Table 7-1—DEPRESSION Awareness, Recognition, and Treatment Program, Fiscal Years 1986-91**

Area	(\$ thousands)						Total
	FY 86	FY 87	FY 88	FY 89	FY 90	FY 91	FY 86-91
Training .....	142	520	646	824	1,146	1,260	4,528 (53%)
Public education .....	292	924	447	745	616	631	3,666 (43%)
Worksite .....	N/A	N/A	50	50	100	100	300 (4%)
<b>Total .....</b>	<b>434</b>	<b>1,444</b>	<b>1,143</b>	<b>1,619</b>	<b>1,862</b>	<b>1,881</b>	<b>8,483</b>

SOURCE: 1. Davidoff, Director, D/ART Campaign, National Institute of Mental Health, Rockville, MD, personal communication, Feb. 28, 1992.

seminars; develop videos; appear on television and radio talk shows; sponsor support groups and telephone hotlines, and carry out other varied educational activities, including brochure translations in five Asian languages. In 1990, the total dollar value of the programs that were offered and the partners' direct and in-kind contributions was estimated at nearly \$1.3 million, about ten times the Federal investment in the Community Partnership Program. D/ART also recently initiated a Professional Partnership program, through which depression-related community education activities similar to those offered by Community Partners will be developed by universities, foundations, and professional organizations.

In 1988, the D/ART program established a National Worksite Program as a collaborative effort between NIMH and the Washington Business Group on Health, a nonprofit health policy group composed of Fortune 500 employers. To date, \$300,000 has been expended on this program component. The purpose of the worksite initiative is to assist employers in reducing the impact of depression on productivity, on health and disability costs, and on employees and their families. The program disseminates information about depressive disorders to employers and encourages corporate policies and programs that promote early recognition, quality cost-effective care, and on-the-job support for individuals experiencing depressive illnesses. The program has developed a "Management of Depression" model program and published a report based on the experience of seven large U.S. companies that contributed to development of the model. In 1992, the program will produce a training program for management personnel and occupational health professionals to improve early recognition and referral to appropriate care for depression.

preliminary data suggest that the D/ART program has had some positive effects. For example, prior to the dissemination of any information, NIMH funded a 1987 telephone survey by the University of Michigan Institute of Social Research of 500 people (250 in Indianapolis, IN and 250 in Sacramento, CA) to determine the extent of their knowledge about depression. The survey found that most people believed that depressed persons could get better on their own rather than by seeking treatment. In 1990, the American Medical Association conducted a followup survey of the same group of 500 people. A total of 210 of the original group responded; 40 percent of the responders in Indianapolis and 25 percent of the responders in Sacramento said they knew more about depression because of the D/ART campaign. AMA also surveyed a new group of 500 people (250 people from each of the two cities). Of this group, 34 percent of those in Indianapolis and 30 percent of those in Sacramento said they were aware of the D/ART campaign and its messages. Another survey in North Dakota found that the number of adults treated for depressive disorders increased 1.5 times and the number of children treated increased 3 times in Human Service Centers (akin to Community Mental Health Centers) for fiscal years 1986 to 1991. The increase was attributed in part to the D/ART public and professional education programs and to a State program to develop treatment teams specifically for children within the Human Service Centers.

Has the D/ART program been a success? While the limited data on the effectiveness of the D/ART program preclude a quantitatively based answer to this question, several aspects of the program clearly deserve commendation. With limited resources and personnel (the entire D/ART program is managed by one- and one-half full-time Federal professional staff persons), the D/ART program established an educational campaign that is solidly rooted in research advances; the D/ART program carefully devises the messages to be relayed, uses diverse media to disseminate the messages, and coordinates its efforts with people in the community. D/ART has also trained substantial numbers of health and mental health care providers through its own efforts and through collaborations with public and private organizations. Advancement of this pioneering educational effort on a mental disorder by the Federal Government—via further study of its effect on the level of awareness, prevalence and treatment changes, expansion of the program into other communities, and adapting its techniques for educating the public about other conditions—will require some combination of increased funds and personnel, as well as highlighting this activity as a priority at the NIMH.

SOURCES: J.E. Barham, Mental Health Consultant personal communications May 4, 1992; R. Brown Senior Scientist Department of Mental Health American Medical Association personal communication June 23, 1992; I. Davidoff, director, D/ART Campaign, National Institute of Mental Health, Rockville, MD, personal communication, June 1992; R. Kessler, Institute for Social Research University of Michigan, personal communication, June 23, 1992; A. Koss, coordinator of State D/ART Program Division of Mental Health, Department of Human Services, Bismark ND, personal communication June 22, 1992; D.A. Regier, M.A. Hirschfeld, F.K. Goodwin, et al., "The NIMH Depression Awareness, Recognition, and Treatment Program: Structure, Aims, and Scientific Basis," *American Journal of Psychiatry* 145:1351-1357, 1988; D. Regier, Director, Division of Clinical Research, National Institute of Mental Health, personal communication May 1992; U.S. Department of Health and Human Services, Public Health Service, Alcohol Drug Abuse and Mental Health Administration National Institute of Mental Health, *Depression, Awareness, Recognition, and Treatment (D/ART) Fact Sheet*, DHHS Pub. No. (ADM) 90-1680 (Rockville, MD: U.S. DHHS, 1990).

service delivery, available treatments, economic constraints, and existing laws. Thus, influencing mental health policy requires not only dispelling the myths and negative attributes surrounding mental disorders but also paying attention to the other factors that affect these issues. For example, efforts to fight employment discrimination were focused on the inclusion of individuals with mental disorders in the recently passed Americans With Disabilities Act (ADA) (box 7-C). It is hoped that the ADA will have a profound effect on individuals with mental disorders by opening options in employment now unavailable to them.

## THE IMPACT OF BIOLOGICAL RESEARCH

The ongoing revolution in neuroscience has invigorated research into mental disorders, leading to new discoveries about and increased emphasis on the biological underpinning of these conditions. This is not the first time that the biological component of mental disorders has been emphasized—concepts of mental illness historically have been cyclic in nature (15,16,59). Nor have previous hopes concerning the curability or biological basis of mental disorders always correlated with improved public attitudes or care for those with these disorders. Current biological research into mental disorders is different from that done in previous eras, however. It is set on the stage of what has been called a new age of neuroscience (1).

The research that is possible, or is already taking place, represents not just an extension of earlier efforts but a qualitative change. From a base of knowledge about the brain in general, neuroscience is now making the first exploratory inroads into the features that characterize us as humans: the ability to create and to calculate, to empathize, to recall and plan (Enoch Gordis quoted in 1).

General developments in brain research, complete with rapid technological advances and the contribution of a host of scientific areas, distinguish current biological research into mental disorders.

Most experts in the mental health field appreciate the fact that biological factors play an important role in the mental disorders considered in this report. Furthermore, advocates who focus on the biological

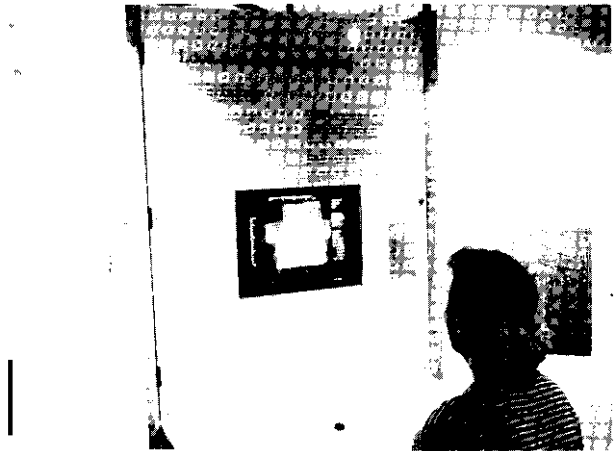


Photo credit: M. Catherine Sargent, 1992

Developments in neuroscience have received increasing attention, as illustrated in this exhibit of the American Psychological Association at the Smithsonian Institution.

aspects of mental disorders are an increasing force, joining and shaping the debate of policy issues. This section considers some of the social impacts of the biology of mental disorders—that is, how the gains from neuroscience research and the perception that mental disorders have a biological basis influence public attitudes toward mental disorders and mental health policy. The discussion is organized under two broad titles: *Perceptions of Responsibility* and *The Link Between Mental Disorders and Medicine*.

### *Perceptions of Responsibility*

Despite the regular reemergence of biological explanations for mental disorders since the classical Greek period (48,57,59), these conditions have often been perceived as a sign of moral weakness or the manifestation of evil. The view that the antisocial, irrational, withdrawn, or unpredictable behavior sometimes produced by mental disorders stems from moral turpitude persists to this day, even among some medical researchers and caregivers (23). A key finding of a 1991 survey of public attitudes by the National Mental Health Association evidences these social beliefs or judgments: 43 percent of American adults see depression as a personal weakness (39).<sup>3</sup> Also, a 1988 survey by the Utah Division of Mental Health and the Alliance for the Mentally Ill found that 71 percent of respondents thought severe mental

<sup>3</sup>The National Mental Health Association poll is based on a nationwide telephone interview of 1,022 adults age 18 and older conducted between October 18 and 23, 1991.



### **Box 7-C—Americans With Disabilities Act: Employing People With Mental Disorders**

The Americans With Disabilities Act of 1990 (ADA), which received the President's signature on July 26, 1990, is the most expansive civil rights legislation passed since the 1964 Civil Rights Act. Under the ADA, the estimated 43 million Americans with disabilities, including those with mental disorders, will be afforded protections from discrimination similar to those prohibiting discrimination based on race, sex, national origin, and religious affiliation. Equality of opportunity and protection from discrimination for individuals with disabilities is guaranteed in the areas of employment (Title I), public transportation and other State and local government services (Title II), public accommodations (Title III), and telecommunications (Title IV).

The ADA definition of a person with a disability applies to individuals meeting one of the following criteria: 1) having a physical or mental impairment that substantially limits one or more of the person's major life activities; 2) having a record of such an impairment; or 3) being regarded as having such an impairment. While the law refrains from delineating specific disabilities, it does define "major life activities": caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. Thus, the act applies only to mental disorders that are severe enough to significantly affect a major life activity. Also, the law affords protection from discrimination based on health or treatment history to persons who have recovered from a physical or mental illness or have at some point been inappropriately diagnosed or misclassified as having a mental or physical disorder. Finally, the ADA directly addresses the negative impacts of the stigma associated with mental disorders, since it protects individuals from being denied employment on the basis of negative attitudes and misperceptions concerning mental disorders in the absence of a legitimate, job-related reason.

While the ADA covers almost every aspect of life in which people with disabilities might encounter discrimination, the employment provisions are likely to have the most profound impact on the lives of individuals with mental disorders. Title I of the ADA prohibits discrimination

... against a qualified individual with disability. . . in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.

Title I requires employers to provide reasonable accommodation to qualified employees, including physical modifications in order to make existing facilities used by employees readily accessible to and usable by individuals with disabilities. Alternatively, it may require nonphysical adjustments including job restructuring, part-time or modified work schedules, and other such modifications. Such nonphysical modifications may be especially important for people with mental disorders. Employers are required to make reasonable accommodations unless it can be demonstrated that the accommodation would impose an undue hardship on the operation of the business. This safeguards the viability of businesses and organizations by protecting employers from incurring unreasonable burden in the provision of needed accommodations. Such a burden may include the disruption of business as well as excessive financial expense.

Ironically, while the provisions of the ADA may serve to combat the stigma of mental disorders, they may also raise the specter of stigma--because coverage under ADA is dependent upon disclosure of disability. Persons with "hidden disabilities" --those not apparent to an observer, such as mental disorders--are covered only if the disability is revealed. Individuals with a severe mental disorder or a history of mental disorder are often reluctant to disclose their disability, and the provisions of the ADA preclude preemployment inquiry into mental health history; however, employers are required to make reasonable accommodations only if the disability is known.

While this landmark act has the potential to benefit individuals with mental disorders greatly, hurdles remain in the ADA's implementation phase. Certain issues have yet to be resolved, including the determination of who exactly is covered, the precise definition of reasonable accommodation for individuals with mental disorders, the provision of an adequate definition of the role of medication in reasonable accommodation for individuals with mental disorders, and the promulgation of such information to both covered individuals and employers.

**SOURCES:** Americans With Disabilities Act of 1990, Public Law No. 101-336, 1990; House Report No. 101-585, Pt. 1 (Committee on Public Works and Transportation), Pt. 2 (Committee on Education and Labor), Pt. 3 (Committee on the Judiciary), and Pt. 4 (Committee on Energy and Commerce), all accompanying H.R. 2273; LL. Mancuso, "Reasonable Accommodation for Workers With Psychiatric Disabilities," *Psychosocial Rehabilitation Journal* 14(2):3-19, 1990; LL. Mancuso, Director, Path project, National Association of State Mental Health Directors, Alexandria, VA personal communication, Feb. 21, 1992; National Mental Health Association *ADA: Americans With Disabilities Act of 1990 (Public Law 101-336)*, 1991; L.J. Scallet and C.F. Rohrer, *Analysis: Americans With Disabilities Act and Mental Health (Washington DC: Policy Resource Center, 1990)*.

illness was due to emotional weakness, 65 percent thought bad parenting was to blame, 35 percent cited sinful behavior, and 45 percent believed that the mentally ill bring on their illness and could will it away if they wished (67). These beliefs have contributed to the public condemnation of unusual or frightening behavior produced by mental disorders, as well as to the shame and guilt experienced by patients and their families.

A biological explanation of the unusual, erratic, or tightening behavior sometimes associated with mental disorders challenges the notion of moral turpitude directly. When atypical behavior is attributed to biological factors, an individual with a mental disorder is less likely to be perceived as the perpetrator of immoral actions than as the victim of forces beyond his or her control. Thus, a biological understanding of severe mental disorders may remove the blame for antisocial or atypical behavior from a person with the disorder.

While biological explanations may absolve individuals of some of the blame for their illness, such theories are not always associated with more benevolent treatment by society. Biological theories have led to abuses in the past, such as eugenic practices (see ch. 5). And other theories as to the origin of mental disorders—such as early childhood experiences—have been used to exculpate individuals from responsibility for their behavior. Furthermore, biological explanations may not be sufficient to overcome society's fear of violent or very bizarre individuals with mental disorders or the stereotype of the 'berserk madman.' The media spotlight on a hideous crime committed by an "ex-mental patient" reinforces the link in the public's mind between mental disorders and violence (box 7-D)<sup>4</sup>

Attributing behavior to biological, and especially genetic, factors may lead to the perception that human actions are predetermined. Biological explanations of behavior encroach uncomfortably on our sense of free will and moral agency (11).

[M]ost of us aren't comfortable with genetic explanations for our own or anyone else's behavior. We are proud of our freedom, individuality, and powers of self-determination (53).

American psychologist and philosopher William James struggled with this dilemma more than 100 years ago. James felt that our sense of self, needed to lend meaning to our existence, maybe incompatible with the necessary assumption of psychology and neuroscience that the "prediction of all things without exception (including human behavior) must be . . . possible" (quoted in 11). Thus, neuroscience's exploration of the human brain challenges the way in which we think about the mind in general.

Individuals with mental disorders may be especially vulnerable when society is seduced by notions of biological reductionism and determinism. These notions can cause individuals with mental disorders to feel dehumanized, with less control over their minds. Insensitively labeling the way a person feels, thinks, or behaves as diseased can diminish his or her sense of "personhood" (36,60), as revealed in the following passage (37):

I have discussed the diagnostic label '*schizophrenia*' with a number of patients. Interestingly, they often say that they do not mind the label itself, but it is the inaccurate attributions made to them because of it that they find objectionable. They know quite well when they are manifestly schizophrenic. They know it from their personal phenomenology at a point in time. They object to being *seen* as schizophrenic when they are not; they object to being treated as dependent children when it is not necessary; they object to having to lie to obtain work for which they are qualified; and they object to their not being listened to and taken seriously because they are, after all, 'schizophrenic.'

The extent to which persons are responsible for their actions—even if there is a biological underpinning—is far from resolved; it requires the consideration of social, philosophical, legal, and moral issues that are beyond the scope of this report. However, it is important to debunk the myth that modern neuroscience necessarily leads us to conclusions of biological reductionism and determinism. Recent advances in neuroscience do not suggest that our brains are biologically fixed or immutable; rather, results increasingly show the dynamic nature of nervous tissue and its responsiveness to environmental cues throughout life. And as Owen Flanagan

<sup>4</sup> While most individuals with a severe mental disorder are not violent, the question, "Are mental disorders linked to violence?" is a complex one. A psychotic episode can lead to a violent act. However, the relationship between mental disorders and violent acts is a complex one, being influenced by various factors, among other things the nature of the disorder, the availability of adequate treatment, and the law (35).

### Box 7-D—Media Portrayals of Mental Disorders

Since the late 1950s and early 1960s, studies have consistently revealed a high incidence of media attention to mental disorders. While media attention contributed significantly to the end of mass warehousing of patients, often in cruel conditions, much of the information it provided about mental disorders was negative and inaccurate. Recent studies have shown that although there has been an increase in the frequency of portrayals of individuals with mental disorders, there has not necessarily been an increase in the accuracy of such portrayals. Surveys of images of mental disorders on prime-time television conducted in the 1980s found that between 17 and 29 percent of the shows had some portrayal of mental disorders. Unfortunately, much of that information concerning mental disorders is inaccurate and stigmatizing.

One of the most persistent and damaging inaccuracies conveyed by the media is the characterization of individuals with severe mental disorders as violent despite the fact that individuals with severe mental disorders are more likely to be withdrawn and frightened than violent and are more frequently victims than perpetrators of violent acts. Violence occurs on television at the rate of approximately six incidents per hour in prime time and 25 incidents per hour in children's daytime programming; a disproportionate number of these occurrences are either perpetrated by or against individuals identified as mentally disordered. In fact, characters labeled mentally disordered in television dramas are almost twice as likely as other characters to kill or be killed, to be violent or fall victim to violence. Efforts to combat this image are confounded by the fact that some individuals with mental disorders—particularly when untreated—are at risk of committing violent acts against themselves or others, or both. Perhaps more troubling is the fact that the stigmatizing equation of severe mental disorder with violence is not limited to fictional entertainment media. News stories and headlines identifying violent criminals on the basis of their mental health history, such as the recent Associated Press headline “Woman Who Shot at Restaurant Previously Committed to Mental Hospital,” saturate the news media, while stories of successful recovery are rare. Such news stories are damaging to individuals with mental disorders because they suggest both an inescapable connection between mental disorders and violence and the incurability of mental disorder (that is, even former, treated mental patients remain prone to violence).

Do these inaccurate and negative depictions of individuals with mental disorders adversely affect public attitudes? Research has shown that television is able to influence viewers' attitudes in subtle ways, through the repetition of images not necessarily labeled as factual. Knowledge specifically concerning the impact of media depictions of mental disorders on public opinions is limited. Some studies have revealed that programming intended to increase knowledge of and improve attitudes toward individuals with mental disorders has a positive impact. However, data indicate that the damaging effects of negative portrayals overwhelm the benefits of the media's positive efforts. Negative mass media portrayals of persons with mental disorders generate negative attitudes among viewers, and corrective information, or disclaimers, has been shown to be largely ineffectual.

Advocacy groups are working to reduce inaccurate and stigmatizing depictions of individuals with mental disorders in the mass media. For example, the Alliance for the Mentally Ill of New York State operates a Stigma Clearinghouse that records and responds to inaccurate or stigmatizing media depictions of individuals with mental disorders, and the National Alliance for the Mentally Ill may soon launch a similar program nationwide. In addition, the Carter Center in Atlanta, Georgia, has held two conferences addressing the problems of stigma and mental disorders and the role of the mass media and has subsequently launched a media initiative to address these issues.

SOURCES: *Stigma and the Mentally Ill: Proceedings of the First International Rosalynn Carter Symposium on Mental Health Policy*, Nov. 15, 1985 (Atlanta, GA: Carter Center, 1985); L.R. Marcos, “Media Power and Public Mental Health Policy,” *American Journal of Psychiatry* 146:1185-1189, 1989; A. Mayer and D. Barry, “Working With the Media To Destigmatize Mental Illness,” *Hospital and Community Psychiatry* 43:77-78, 1992; Robert Wood Johnson Foundation Program on Chronic Mental Illness, “Public Attitudes Toward People With Chronic Mental Illness,” April 1990; O. Wahl, “Mental Illness in the Media: An Unhealthy Condition,” *The Community Imperative*, R.C. Baron, I.D. Rutman, and B. Klaczynska (eds.) (Philadelphia, PA: Horizon House Institute, 1980); O. Wahl, Professor, George Mason University, personal communication, February 1992; O. Wahl and J.Y. Lefkowitz, “Impact of a Television Film on Attitudes Toward Mental Illness,” *American Journal of Community Psychology* 17(4):521-528, 1989; O. Wahl and R. Roth, “Television Images of Mental Illness: Results of a Metropolitan Washington Media Watch,” *Journal of Broadcasting* 28:599-605, 1982.

# Blaming the Brain



*Credit: Illustration by Robin Applestein, reprinted by permission of R. Applestein and the Washington Times*

**Findings that biological factors underpin certain mental disorders help relieve individuals and their families from feelings of guilt.**

(11) observes in his recent book, *The Science of the Mind*, science permits:

... a model for conceiving of the mind that allows for the beliefs: that actions can be done on purpose; that action can be rational; that deliberation can result in free choice; that such choices can go against

very powerful desires and inclinations; that we can think of humans as responsible—all this without the paradoxical requirement that some actions, namely those of our free will, be totally uncaused.

The assertion that biological factors contribute to the development of mental disorders challenges the once reigning theory that they are caused by bad parenting. For example, psychoanalytic thought posited that psychic damage during early childhood produced schizophrenia and other mental disorders. This concept evolved into the focus on the “schizophrenogenic” mother—that is, a mother with overbearing tendencies, warped psychosexual development, and near-psychotic behavior who produces schizophrenia in her offspring (12). Since little or no scientific evidence supports these theories as sufficient or necessary causes of the severe mental disorders considered in this report, most experts reject them (14,25). However, the message that mental disorders are a response to cruel social and family conditions nonetheless continues to shape the attitudes of the public and even some experts (28). For example, data from a 1989 study showed that textbooks in abnormal psychology implicitly support the concept of the schizophrenogenic parent (69).

Given that family members are often viewed as the agents of mental illness, it is understandable that they embrace biological theories of mental disorders. When families belonging to the National Alliance for the Mentally Ill (NAMI) were asked what had helped them to cope with stigma, 73.2 percent indicated that “research findings which establish a biological basis for mental illness helped much or very much in dealing with stigma” (71). The concept that a biological defect causes a mental disorder largely exonerates family members and the individuals themselves from blame, placing it instead on a disease process (22). The solace found by families in biological explanations of mental disorders is revealed in this passage, written by the father of a son with obsessive-compulsive disorder (52):

*It May Not Be Your Fault That You or Your Child Has Obsessive-Compulsive Disorder!* Early toilet training, a rigorously disciplined home environment, an unresolved Oedipal complex, and endless demands that your child clean up her “disgusting” room may not be and is probably not the cause of this illness.

Obsessive-Compulsive Disorder, the flu, and diabetes may have at least one thing in common—

the cause. The disease is possibly biological; it may even be inherited from one generation to another, as suggested in my family's case. However, OCD manifests itself as strange behavior while the other two show up as physical illnesses. To my wife and me this understanding that there might be a physical cause was a great relief. . . .

At the same time, strict adherence to biological theories may impair psychosocial research into the development, relapse, and treatment of mental disorders. While beyond the scope of this report, it is important to note that some data suggest that psychosocial factors play a role in mental disorders. For example, research findings point out the role of what is called disruptive emotional expression (DEE), in schizophrenia. Studies suggest that with schizophrenia who spend time in a stressful environment (that is, an environment with high EE) are more likely to suffer a relapse (24,27,64). The message from such studies is not a return to the cruel and stigmatizing concepts of family causation, but rather an acknowledgment that the emergence, symptoms, and course of mental disorders are multifactorial.

Genetic models of mental disorders may unintentionally recast the stigma and discrimination experienced by individuals with mental disorders and their families. With increased knowledge about the genetics of mental disorders, new questions emerge. Will individuals who pass on a gene or several genes predisposing their offspring to a mental disorder be viewed as blameworthy for having children? Will insurance coverage or employment be denied on the basis of a "positive" genetic test in the future?

Some groups and individuals interested in or afflicted by genetic diseases voice concerns about potential genetic discrimination—'the denial of rights, privileges, or opportunities on the basis of information gathered via genetic tests' (65). Eugenic policies in the past (see ch. 5) and popular support of prenatal testing for genetic diseases (and termination of the pregnancy in the event of a positive test) foster concern about possible genetic discrimination (47). It may be premature to raise concerns about genetic testing for mental disorders, given their complex and poorly understood genetic underpinnings (see ch. 5). However, that some mental disorders have a genetic component is strongly supported by research data. Therefore, tests for a genetic predisposition to some mental disorders may well be technically feasible in the future. Given

the stigma attached to individuals with mental disorders and their families, the chronic nature of disorders, and the current barriers to insurance and employment, genetic testing—even the perception that genetics accounts for these conditions—could become a tool for discriminating against individuals with mental disorders and their families.

### ***The Link Between Mental Disorders and Medicine***

Intimately linked to the emphasis on biological aspects of severe mental disorders is the hope that biomedical research will lead to new treatments and, ultimately, cures for these disorders (19). As stated on NAMI's platform (38):

For the purposes of research, the National Alliance has defined serious mental illnesses as those brain diseases that are at the present time neither preventable nor curable but are controllable with proper medication and support services. . . . Biomedical research will yield better treatment and a cure for these diseases.

Hope for a cure has accompanied many eras of mental health policy. In addition to the desire to eliminate the complicated problems associated with severe mental disorders, the current hopes for a cure spring from general optimism for biomedical research, the track record of biomedical research in finding treatment and cures for disease in general, the past and continuing development of drugs used to treat many individuals with mental disorders, and the neuroscience revolution. In light of the considerable advances of neuroscience research in general, it is hard not to be infected by this hope. A realistic viewpoint is necessary, however, to stay the course of what is likely to be a slow unraveling of the secrets of the brain. Furthermore, policymakers and advocates must also be wary of the danger, not always resisted in the past, of emphasizing research at the expense of providing adequate care for people with mental disorders.

Biological research on mental disorders has entered into the issue of mental health care finance. Currently, financial barriers limit access to treatment. Insurance coverage for mental health care is generally inferior to coverage for "physical" illnesses (3,42,54,66). Recently, advocates have lobbied for the designation of certain mental disorders as biological, or brain-based, in order to gain parity in insurance coverage (6,19,46). In the first case of

its type, a father sued Arkansas Blue Cross and Blue Shield for increased coverage for the care of his daughter, who was hospitalized for bipolar disorder. His insurance policy provided for extensive coverage for physical conditions but limited coverage for “mental, psychiatric, or nervous” disorders. The plaintiff argued that bipolar disorder is a biological disorder and therefore should be considered “physical” under the terms of the policy. In this case, *Arkansas Blue Cross and Blue Shield v. Doe (4)*, the courts ruled that bipolar disorder “is a physical condition within the meaning of the Blue Cross contract.

State legislatures also have begun to address the issue of providing equal treatment for biologically based mental disorders. For example, a bill that became law in Maine in 1992 requires group insurers that offer coverage for disorders of the brain to offer the same coverage for biologically based severe mental disorders. The law specifies all of the conditions included in this report: schizophrenia, bipolar disorder, major depression, panic disorder, and obsessive-compulsive disorder.

Advocates who would identify specific mental disorders as “brain-based” invoke the traditional medical model of illness as the most appropriate one for treatment in order to tap into society’s perceived responsibility for providing health care. Will discovery that certain mental disorders are “brain-based” — or renaming them as such — achieve insurance parity? Clearly, pinpointing a diagnostic entity with a biological marker—coupled with treatment—can be useful for third-party payers, as expressed by William S. Custer, director of research at the Employee Benefit Research Institute (7):

One underlying problem with mental health benefits is the difficulty in defining an insurable event. An insurable event is whatever triggers benefit payment. Ideally that event should be out of the control of the insured individual or the individual’s agent (in this case, the provider). The difficulty in insurance plan design for mental health benefits is that for at least some conditions, the need for mental health care is subjectively determined. More importantly, individuals seeking treatment must choose between several types of providers (psychologists, psychiatrist, social workers, etc.) and settings (hospitals, halfway houses, clinics, etc.), and more than **150**

different modalities (45), with little information about the efficacy of treatment or quality of care. . . .

These problems could potentially be alleviated for those with mental disorders that have a biological cause and for which effective treatments can be found. For those illnesses, the detection of the biological cause would define an insurable event, for which an insurance plan could be designed which would more closely resemble those for other physical ailments.

In fact, since the mid-1970s, the treatment of severe mental disorders has increasingly reflected the medical model, with short-term hospitalization, the use of prescription drugs, and the development of a more reliable diagnostic classification system (63).

As indicated in this report, data point increasingly to the importance of biological factors in certain mental disorders. However, some mental health policy experts and advocates question whether labeling as such is necessary or appropriate, asserting that emphasizing the underlying causes of mental disorders is not necessary to gain care and will not guarantee adequate care; rather, what is needed is political will.

To accomplish some form of parity for insurance reimbursement of mental disorders requires no reliance on the brain disease theory or, indeed, on any theory of the cause or nature of mental disorders (60).

While the general view of what causes a disorder or problem can impact on policy approaches in dealing with it (58), simply renaming a condition may not be adequate for achieving such a goal. The court case previously described is illustrative: After the court ordered Arkansas Blue Cross and Blue Shield to pay for treatment of the daughter’s bipolar disorder, the company rewrote its contract so that this disorder was specifically identified as a mental disorder, subject to the usual coverage limitations (42).

Another factor in this debate is the heightened concern about the cost of health care in general (30), which has led to an environment of restricting, not expanding, insurance benefits. For example, during the 1980s, the States began to mandate some type of mental health insurance coverage; the more recent trend in State legislatures is to waive mandates requiring such coverage (18). Concern also exists about what will happen to coverage of the other “nonphysical” disorders (26). Increased coverage

of biological disorders could reduce even further coverage of psychological disorders that cannot demonstrate a clear biological foundation. Preventive efforts and stress-related disorders, for example, might be neglected (70). Another concern focuses on the definition of medical management, even for biologically based mental disorders.

Skeptics view it as a prelude to eliminating insurance coverage for psychotherapy and fear that it will encourage unnecessary drug treatment and create an incentive to diminish the time spent talking to patients (63).

Although researchers are developing more effective biological approaches, psychosocial interventions are an important component of treatment and rehabilitation. Given the problems faced in obtaining adequate coverage for the care of severe mental disorders, as well as the complexities of the issues impacting on the health care and mental health care finance debate, a full consideration of these issues, which is beyond the scope of this report, is warranted.

## SUMMARY AND CONCLUSIONS

While the last 30 years have seen an improvement in the public's knowledge of and attitudes toward mental disorders, stigma still abounds. People with mental disorders and their family members suffer acutely from that stigma. And negative public attitudes contribute to discrimination in research support, treatment availability, financing of care, housing, and employment.

The stigma attached to mental disorders, while compelling and undeniable, has manifold aspects. The notion of stigma embraces everything from willful denigration of those who are different to fear and ignorance. The social and public policy effects of stigma are also complex, being influenced by many different factors, including laws, the structure of service delivery, and economic constraints. Because of the complex nature of the stigma attached to mental disorders and the many relevant areas of public policy, OTA finds that a wide-ranging strategy will be necessary to bring about public policies that benefit persons with severe mental disorders. Educating the public about the nature of these conditions is one important tactic; vigilance in relevant policy areas, such as that evidenced in the passage of the Americans With Disabilities of Act, is another.

Concepts of what causes mental disorders influence public attitudes and policy. Modern neuroscience, which is undergoing revolutionary and rapid advances, is the primary influence on current understanding of the mental disorders considered in this report. Some skeptics point out that this trend is but another reincarnation of biological psychiatry, which historically has wielded influence from time to time—not always to the advantage of those with mental disorders. While many factors play a role, including professional self-interest, the perennial hope for a cure, and the optimism traditionally attached to biomedical research, the broad base of research into the function of the human brain distinguishes today's search for biological factors associated with mental disorders.

OTA identified several ways in which the data from biological research into mental disorders and perceptions of that data can affect public attitudes and policy. Biological explanations of mental disorders are used to counter the view that these conditions result from moral turpitude, thus exculpating individuals whose disorders may lead to unusual, erratic, or tightening behavior. Also, the assertion that biological factors contribute to the development of mental disorders debunks the stigmatizing notion that bad parenting is the essential cause. Biological data have been viewed as exonerating family members from blame and thus helping them to deal with stigma.

The increased emphasis on biological aspects of mental disorders, while helpful in dismantling some negative attitudes, is not without its limitations. As mentioned, perceptions of what causes mental disorders are not the sole reason for stigma. For example, fear of violent behavior, a simplistic image of mental disorders reinforced by the media, also shapes public attitudes. Furthermore, publicized data may be misinterpreted. The specious notion that a biological, especially a genetic, substrate for human behavior dissolves moral agency can be especially dehumanizing to persons with mental disorders. Also, while reproachful theories of causation, such as the schizophrenogenic mother, have been largely refuted, it is important to note that biological research has not ruled out the role of psychosocial factors in the development, course, and treatment of mental disorders. Finally, with rapid advances in molecular genetics, some sort of genetic test for mental disorders may become possible in the future; such a test—or simply the perception that these conditions

are inherited--could prove to be a powerful tool for discrimination.

The emphasis on biological aspects of severe mental disorders is intimately linked to the hope that biomedical research will lead to new treatments and, ultimately, cures. While hopes for a cure have long accompanied new eras of mental health policy, this period bears the distinctive mark of the new age of brain research. A realistic viewpoint requires that we be patient and stay the course of what is likely to be a slow unraveling of the secrets of the brain. Similarly, policymakers must not be seduced into simplifying their consideration of mental disorders and focusing solely on research while ignoring the care needs of those currently afflicted with these disorders.

By highlighting the biological components of mental disorders, advocates seek more than treatment advances. As exemplified by recent court cases and State laws, attempts to obtain increased financial support for care also drive this trend. Identification of biological markers for certain mental disorders, along with effective treatments, can assist third-party payers for health care by enabling them to identify objectively an insurable event. However, other questions are raised by this trend, including concerns about the coverage of "nonbiological" disorders or interventions. A full consideration of mental health care and its finance is required to answer this issue.

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