

Chapter 1

**Summary, Policy Issues, and
Options for Congressional Action**

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Summary, Policy Issues, and Options for Congressional Action

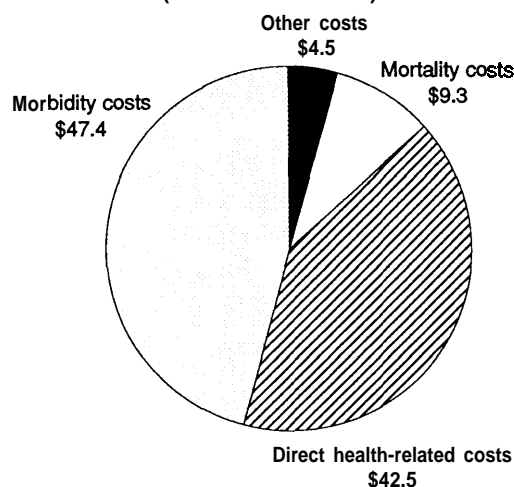
Mental disorders can strike with savage cruelty, producing nightmarish hallucinations, crippling paranoia, unrelenting depression, a choking sense of panic, or inescapable obsessions. The sheer number of Americans with mental disorders transforms this personal tragedy into a widespread public health problem. Nearly one in three American adults will experience a mental disorder during his or her lifetime, whether one of the disorders considered in this report [schizophrenia, bipolar disorder (commonly known as manic depression), major depression, obsessive-compulsive disorder, and panic disorder; table 1-1], or one of a variety of other conditions, including cognitive impairment (as in Alzheimer's disease), substance abuse or dependence, phobias, and antisocial personality disorder. Moreover, approximately 1.7 to 2.4 million Americans currently suffer from a persistent and severely disabling mental disorder, such as schizophrenia or bipolar disorder.

What are the costs of this public health problem? The most recent and comprehensive estimate of the total costs of mental disorders—for fiscal year 1985—added up to \$103.7 billion (figure 1-1) (box 1-A). When adjusted for inflation, this figure reaches \$136.1 billion in 1991. However, dollar figures alone, no matter how large, do not convey the toll mental disorders take. These disorders can be extremely disabling, significantly compromising productivity and the ability to work. It has been estimated that individuals with mental disorders fill 25 percent of all hospital beds and, further, that one-third of these persons suffer from schizophrenia. Mental disorders account for an even larger percent-

age of hospital beds in Department of Veterans Affairs (VA) hospitals: Fully 40 percent of all VA inpatient care is for persons with mental disorders. Perhaps most tragically, approximately one-third of homeless single adults and 10 to 15 percent of individuals who are incarcerated in jails and prisons have a severe mental disorder such as schizophrenia or bipolar disorder.

One of the most powerful factors affecting people with mental disorders and their families is the stigma often attached to these conditions. While the public's attitudes and knowledge about mental disorders have improved during the last 30 years, negative attitudes toward and ignorance of these disorders still abound. A sizable number of people continue to be frightened by the notion of mental illness. The public fears that people with mental disorders are violent and dangerous and perceives them to be dirty and unattractive, therefore often treating them with disrespect, if not rejecting them outright. Furthermore, despite gains in knowledge about specific

Figure 1-1—The Cost of Mental Disorders, 1985
(in billions of dollars)



In 1985, mental disorders cost the United States more than \$103 billion. Approximately 41 percent of that cost—\$42.5 billion—stemmed from hospital care, medication costs, and other treatment costs. Nearly half of the costs of mental disorders—\$47.4 billion—derives from lost productivity.

SOURCE: D.P. Rice, S. Keilman, L.S. Miller, et al., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness*, report submitted to the Office of Financing and Coverage Policy, Alcohol, Drug Abuse, and Mental Health Administration, U.S. Department of Health and Human Services (San Francisco, CA: Institute for Health and Aging, University of California, 1990).

Table 1-1—Prevalence of Severe Mental Disorders

Disorder	Adults diagnosed with disorder during their lifetimes (%)
Schizophrenia	1.0
Bipolar disorder	0.8
Major depression	4.9
Obsessive-compulsive disorder	2.6
Panic disorder	1.6

SOURCE: L.N. Robins and D.A. Regier, *Psychiatric Disorders in America, The Epidemiologic Catchment Area Study* (New York, NY: Free Press, 1991).

Box 1-A—The Cost of Mental Disorders

How big a problem do mental disorders present to our Nation? What priority should these disorders receive in the outlay of government funds for research and services? The answers to these questions are often sought in terms of a dollar figure. However, estimating the toll of mental disorders, or any illness, in economic terms is no easy or straightforward task. Everything from the cost of hospitalization, which is relatively easy to estimate, to the cost of reduced productivity, which is more difficult to assess, maybe evaluated. And while rarely included in studies, the psychological and social tolls on an individual's life are substantial, though not easily quantified.

During the last 40 years, studies have reported that mental disorders cost the Nation from \$3.6 billion to more than \$100 billion each year. The variation in estimates reflects changes over time as well as the use of different methods of calculation and sources of data. Dorothy Rice and colleagues have derived the most comprehensive estimate, based on the most recently available survey data. They estimate the total costs of mental disorders—including schizophrenia, major depression, bipolar disorder (manic-depressive illness), anxiety disorders, somatization disorder, antisocial personality disorder, and cognitive impairment—to be \$103.7 billion for the year 1985. When adjusted for inflation, this figure reaches \$136.1 billion in 1991.

These costs include health-related, or core, costs—that is, the expenditures made and resources lost as a consequence of having a mental disorder. Such costs makeup 96 percent of the total estimated costs for 1985, or \$99.2 billion. Health-related costs can be broken down further into direct and indirect costs.

Direct health-related costs—\$42.5 billion in 1985 and more than \$58 billion in 1991—include all expenditures related to the treatment and support of persons with mental disorders. The vast majority of these direct costs—92 percent—are related to treatment and involve expenditures on hospital and nursing home care, physician and other professional services, and drugs (figure 1-1). More than 50 percent of the treatment costs—almost \$22 billion in 1985—were spent on care in institutional or hospital settings, such as Department of Veterans Affairs (VA) hospitals, State and county psychiatric hospitals, private psychiatric hospitals, residential treatment centers for emotionally disturbed children, and short-stay (general) hospitals. The costs of care provided by office-based physicians, psychologists, and social workers amounted to approximately \$5.7 billion in 1985. Approximately \$1.5 billion was spent on prescription drugs, including minor tranquilizers, antidepressants, and antipsychotics. The estimate reached more than \$2.2 billion in 1991, when adjusted for inflation. Support costs, which equaled approximately \$3.2 billion in 1985, include expenditures for research, physician and nurse training, and program administration (as for health insurance).

Indirect health-related costs estimate the burden of increased morbidity and mortality that accompanies mental disorders. These estimates, which are based on the National Institute of Mental Health's Epidemiologic Catchment Area prevalence data, include the value of lost output caused by decreased productivity, lost workdays, or premature death. Rice and colleagues do not include measures of the psychological and social effects of mental disorders on the individual's life. Morbidity and mortality costs were estimated at \$47.4 billion and \$9.3 billion, respectively, in 1985. For 1991, estimates were \$60.0 billion for morbidity costs and \$11.7 billion for mortality costs. Thus, according to these data, lost or diminished productivity is the most costly outcome of mental disorders, with morbidity accounting for nearly 50 percent of the total costs of mental disorders. Furthermore, the cost of morbidity is not primarily due to institutionalization. Additional analysis, which considers such factors as the prevalence of mental disorders in various demographic groups, the type of disorder, and income levels, shows that a very large share of the morbidity costs—\$44.1 billion in 1985 and \$55.8 billion in 1991—derives from noninstitutionalized individuals.

Mental disorders have other, nonhealth-related effects that impose a cost on society. Nonhealth effects lead to public and private expenditures on crime control and social welfare administration, the sum of which was estimated at \$1.7 billion by Rice and colleagues. Furthermore, the value of reductions or losses in productivity due to either incarceration for a criminal offense or time spent to care for a family member with a mental disorder exacts a price, estimated at approximately \$2.8 billion.

SOURCES: D.P. Rice, S. Kelman, L.S. Miller, et al., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness: 1985*, report submitted to the Office of Financing and Coverage Policy, Alcohol, Drug Abuse, and Mental Health Administration U.S. Department of Health and Human Services (San Francisco, CA: Institute for Health and Aging, University of California, 1990); The National Foundation for Brain Research, *The Costs of Disorders of the Brain* (Washington, DC: 1992).

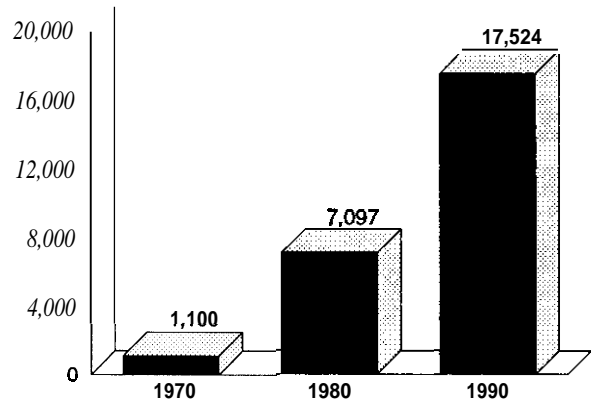
disorders and their treatment, considerable public ignorance about mental disorders persists. Although the stigma attached to mental disorders is complex in its makeup and effects, negative attitudes and ignorance have contributed to discrimination in research support, treatment availability, funding of mental health care, housing, and employment.

The reality of mental disorders—their symptoms, prevalence, costs, and associated stigma—commands the Federal Government’s attention. Despite the fact that Federal, State, and local governments spend more than \$20 billion each year on mental health services, with approximately 40 percent of these public funds derived from Federal sources, the consensus is that mental health policy is fragmented and mental health services often deficient. Fundamental to improving the Nation’s efforts on behalf of people with mental disorders is increasing public understanding of these conditions. More than a decade ago the President’s Commission on Mental Health wrote, “Expanding our understanding of the functioning of the mind, the causes of mental and emotional illness, and the efficacy of various treatments is crucial to future progress in mental health. This report from the Office of Technology Assessment (OTA) offers an appraisal of current knowledge about biological factors in severe mental disorders—schizophrenia, bipolar disorder, major depression, obsessive-compulsive disorder, and panic disorder.¹ It also reviews support for that research and considers some of the social implications of data from biological research into mental disorders.

DECADE OF THE BRAIN

An atmosphere of enthusiasm surrounds neuroscience—an area of interdisciplinary research focused on how the nervous system works and how it is affected by disease. Neuroscience is a rapidly growing field, as reflected in the membership of the Society for Neuroscience: This professional organization grew from 1,100 members at its inception in 1970 to more than 17,000 in 1990 (figure 1-2). The 1980s saw a nearly 70 percent increase in the number of papers published in neuroscience and behavioral research. At least 20 Federal organizations support research devoted to brain and behavioral research (figure 1-3), with total Federal expenditures just exceeding \$1 billion in 1990.

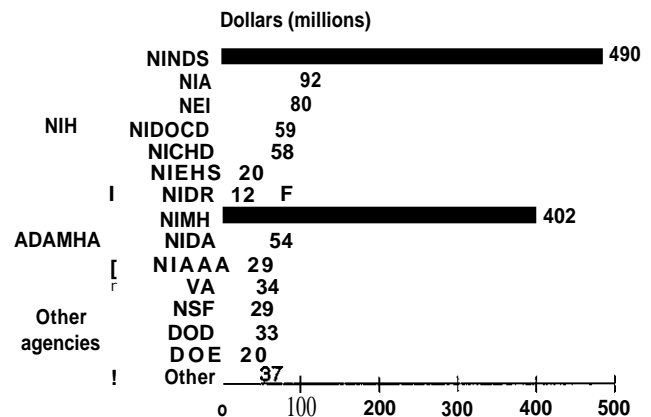
Figure 1-2—Membership in the Society for Neuroscience



Membership in the Society for Neuroscience has grown dramatically since its inception in 1970.

SOURCE: Society for Neuroscience, 1991.

Figure 1-3—Distribution of Federal Support of Neuroscience Research, Fiscal Year 1990



Funding of neuroscience research by various Federal agencies.

KEY: NIH = National Institutes of Health; ADAMHA = Alcohol, Drug Abuse, and Mental Health Administration; NINDS = National Institute of Neurological Disorders and Stroke; NIA = National Institute on Aging; NEI = National Eye Institute; NIDOC = National Institute on Deafness and Other Communication Disorders; NICHHD = National Institute on Child Health and Human Development; NIEHS = National Institute on Environmental Health Sciences; NIDR = National Institute of Dental Research; NIMH = National Institute of Mental Health; NIDA = National Institute on Drug Abuse; NIAAA = National Institute on Alcohol Abuse and Alcoholism; VA = U.S. Department of Veterans Affairs; NSF = National Science Foundation; DOD = U.S. Department of Defense; DOE = U.S. Department of Energy; Other = National Institute on Disability and Rehabilitation Research, National Aeronautics and Space Administration, Environmental Protection Agency, U.S. Department of Agriculture, Centers for Disease Control, and U.S. Food and Drug Administration.

^aFiscal year 1991.

SOURCE: Office of Technology Assessment, adapted from E. Pennisi and D. Morgan, “Brain Decade Scientists Court Support,” *The Scientist* 4:8, 1990.

¹Addictive disorders, Alzheimer’s disease, and developmental disorders such as autism have been or are being discussed in other OTA reports, and therefore are not considered in this report.

Advances in scientific methods and techniques have fueled the dramatic increase in neuroscience research during the last 15 years. Improved methods for staining nerve cells have made it possible to pinpoint their precise location in the brain. The electrical activity of a single channel in a nerve cell's membrane—less than one-trillionth of an inch in diameter—can be measured. Advances in computing, microscopy, and especially imaging technology underlie the spectacular ability to observe living brain tissue—from single nerve cells to the intact human brain. The development of psychological tests has enabled researchers to correlate observed brain activity with specific behaviors and thought processes. And molecular biology has revolutionized the study of the brain, producing monoclonal antibodies that allow labeling of specific nerve cells, the cloning of proteins involved in brain function, and the search for specific genes.

The rapid growth and productivity of neuroscience spearheads, in large measure, the general interest in the biology of mental disorders and Congress' request for this study. Modern neuroscience research is an important part of the contemporary effort to expose the causes of mental disorders. The National Institute of Mental Health (NIMH), the primary source of Federal funding for research into mental disorders, has focused a major portion of its research plan on the basis of developments in neuroscience. By strongly supporting neuroscience research, NIMH aims to "understand the workings of the human brain in sufficient detail to effectively treat or prevent the broad variety of behavioral disorders and mental illnesses." The spectacular growth of neuroscience also distinguishes the current focus on the biology of mental disorders from that of previous eras. While biological models of mental disorders have been emphasized time and again in the past, today's research into the brain's functions in mental disorders is supported in a qualitatively and quantitatively new way by an expanding base of knowledge about the brain and behavior.

SCHIZOPHRENIA

Schizophrenia "is arguably the worst disease affecting mankind." It is not, as commonly misconstrued, split personality. Although important questions remain about its classification, its characteris-



Credit: Copyright © 1992 Bill Lee. Reprinted with permission.

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

tic symptoms are well defined. Positive symptoms, which typify psychosis, include hallucinations and delusions, as well as bizarre behaviors and dissociated or fragmented thoughts. Negative symptoms include impaired emotional responsiveness, loss of motivation, general loss of interest, and social withdrawal.

Schizophrenia is a common disorder, with approximately one in every 100 persons developing it during the course of his or her lifetime; approximately 1.2 million people have schizophrenia in the United States at the present time. While schizophrenia does not invariably follow a deteriorating course, there are substantial and enduring consequences for many people with this condition. Its onset typically occurs during the late teens and early 20s, with a generally younger age of onset and worse prognosis in men. The expressed symptoms of schizophrenia may combine in various ways, their severity and duration fluctuating over time. Schizophrenia is associated with an increased risk of suicide; approx-

² *Nature*, editorial, 336:95, 1988.

Box 1-B—The Final Symptom: Mental Disorder and Suicide

In 1987, 11,7 people in every 100,000—more than 30,000 people—killed themselves in the United States, making it the eighth leading cause of death in the nation. While many factors are associated with suicide, including medical illness, availability of firearms, or stressful events such as a divorce or loss of a job, data indicate that mental disorders are a significant antecedent to many suicides in the United States. About 50 percent of all suicide victims may have suffered a mood disorder, and an estimated 5 to 10 percent of suicide victims suffered from schizophrenia.

Among people with schizophrenia, suicide is the number one cause of premature death, with the estimated age-adjusted suicide rate averaging 90 per 100,000 women with schizophrenia and 210 per 100,000 men with the disorder 10 to 15 percent of individuals with schizophrenia commit suicide. The higher rate of suicide among men versus women with schizophrenia not only mirrors the suicide statistics in the general population, but also reflects the more severe symptoms that men usually suffer. Some people with schizophrenia may commit suicide as a result of a psychotic episode—in response to a hallucinatory command. More commonly, however, people with this condition take their lives early in the course of the illness during a relatively stable period following a recent hospitalization.

Approximately 15 percent of people with mood disorders will commit suicide, with the suicide rates for men and women with major mood disorders averaging 400 and 180 per 100,000, respectively, 30 times higher than the rate in the general population. The link between mood disorders and suicide is well recognized, with recurrent thoughts of suicide or a suicide attempt being one diagnostic criterion for these conditions. Other mental disorders, such as panic disorder, also appear to be correlated with suicide. Although there is little information available concerning the number of people with panic disorder who actually commit suicide, survey data show that approximately 20 percent of people with this condition will attempt suicide during their lifetime.

High rates of suicide among individuals with major mental disorders like schizophrenia or major depression provide chilling evidence of the distressing nature of mental disorders. Furthermore, the strong correlation between mental disorders and suicide indicates that general suicide prevention efforts must include strategies to improve the treatment of mental disorders.

SOURCES: C.B. Caldwell and I.I. Gottesman, "Schizophrenics Kill Themselves Too: A Review of Risk Factors for Suicide," *Schizophrenia Bulletin* 16(4):571-589, 1990; F.K. Goodwin and K.R. Jamison, *Manic-Depressive Illness* (New York, NY: The Oxford University Press, 1990); J. Johnson, M.M. Weissman, and G.L. Klerman, "Panic Disorder, Comorbidity, and Suicide Attempts," *Archives of General Psychiatry* 47:805-808, 1990; E.K. Moscicki, chief, Prevention Research Branch, National Institute of Mental Health, U.S. Department of Health and Human Services, personal communication, Apr. 30, 1991; U.S. Department of Health and Human Services, Public Health Services, National Center for Health Statistics, *Monthly Vital Statistics Report* 40(8 suppl. 2), 1992.

imately 10 to 15 percent of individuals with this disorder take their own lives (box 1-B).

Currently, there is no way to prevent or cure schizophrenia; however, treatments that control some of its symptoms are available. The optimal treatment generally integrates antipsychotic drugs and supportive psychosocial treatment. Individuals acutely ill with schizophrenia may require hospitalization. Furthermore, rehabilitation is generally necessary to enhance social and occupational outcomes.

The complexity of expressed symptoms and the likelihood that the disorder encompasses various subtypes, which are not yet reliably distinguishable, have slowed progress in understanding schizophrenia. Nonetheless, converging research data point to the alteration of specific brain chemicals and regions as the biological substrate of the schizophrenias.

Investigators have examined the possible role of several brain chemicals in schizophrenia, including serotonin, norepinephrine, various neuropeptides, and, most recently, glutamate. The most venerable theory concerning the chemistry of schizophrenia implicates the brain chemical dopamine. Dopamine-releasing drugs, such as amphetamines, can induce a psychotic state, and drugs reducing dopamine function have antipsychotic effects. However, studies looking for simple changes in dopamine levels in the brain have provided inconsistent results. Thus, even though there is a consensus that dopamine plays a role in schizophrenia, the specifics of this brain chemical's action remain unknown.

Various studies of the function and structure of the brain in schizophrenia point to the involvement of two specific areas, namely, the frontal cortex and

the limbic system (figure 1-4). The limbic system seems to be involved in the positive symptoms and the frontal cortex in the negative symptoms of schizophrenia. The precise interaction between these specific brain regions, as well as the possible involvement of other areas of the brain, still need to be clarified.

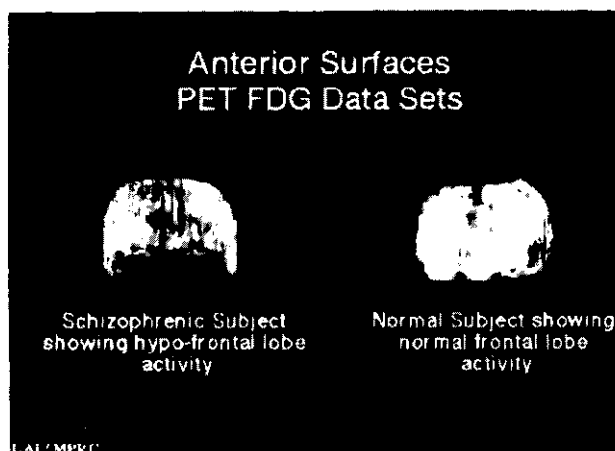
In addition to pinpointing the regions and chemicals in the brain that underlie the symptoms of schizophrenia, researchers have put forward several hypotheses concerning the cause or causes of this disorder. Information about the course of schizophrenia, its epidemiology, and specific biological measures suggests that a virus or immune system problem is a possible culprit. Another hypothesis asserts that injury to the brain early in life is the critical factor. Support for this viewpoint stems from various observations, including the higher rate of birth complications among individuals with schizophrenia and subtle deviations in neurological and psychological functions that sometimes precede the full expression of schizophrenia. Evaluation of the prevalence and pattern of schizophrenia among related individuals shows that genetic factors contribute to this disorder; however, the inheritance of schizophrenia is quite complicated, and nongenetic factors also play a role. The location of specific genes involved in schizophrenia remains unknown.

MOOD DISORDERS: MAJOR DEPRESSION AND BIPOLAR DISORDER

Mood disorders, which are also referred to as affective disorders, are characterized by extreme or prolonged disturbances of mood, such as sadness, apathy, or elation. These disorders can be divided into two major groups: bipolar and depressive disorders. The occurrence of manic symptoms distinguishes bipolar disorders from depressive, or unipolar, disorders.

The most severe depressive disorder is major depression. While it has proven difficult to discern whether depression is a single disorder or a collection of disorders, its expression is well characterized. Box 1-C is a personal account of the symptoms of depression. Various psychological and somatic symptoms accompany episodes of depression, including profoundly depressed mood, the complete loss of interest or pleasure in activities, weight gain or loss, insomnia or excessive sleepiness, slowed or

Figure 1-4—PET Scan of an Individual With Schizophrenia



Brain activity in an individual who does not have schizophrenia (right) and a person who does (left). The frontal cortex shows more activity in schizophrenia (white areas).

SOURCE: W. Carpenter, Maryland Psychiatric Research Center and H. Loats, Loats Associates, Inc.

agitated movement, diminished energy, intense feelings of guilt or worthlessness, a diminished ability to concentrate, and recurrent thoughts of death or suicide (see box 1-B).

Major depression is a prevalent disorder: Nearly 5 percent of the population will develop it and the risk is twice as great for women as for men. Furthermore, its occurrence seems to be increasing among young people. Major depression typically has its onset in the late 20s, although it can emerge at any age. More than 50 percent of patients will have more than one bout of depression, the average being five or six episodes during a lifetime. Approximately 15 percent of persons suffering from the symptoms of depression will die by suicide.

Major advances have taken place in the pharmacological treatment of depression during the last decade. Various forms of psychotherapy—either alone or as an adjunct to medication—are also important to treatment. Severe cases may require hospitalization; electroconvulsive therapy may be used in severe cases. In depression that recurs each fall and winter, known as seasonal affective disorder, or SAD, light therapy can be useful.

Bipolar disorder is a severe mood disorder characterized by manic and depressive episodes. Although its symptoms are quite well known, questions remain about how it relates to other disorders, such

Box 1-C—Darkness Visible—A Personal Account of Depression

Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self—to the mediating intellect—as to verge close to being beyond description. It thus remains nearly incomprehensible to those who have not experienced it in its extreme mode, although the gloom, ‘the blues’ which people go through occasionally and associate with the general hassle of everyday existence are of such prevalence that they do give many individuals a hint of the illness in its catastrophic form. But at the time of which I write I had descended far past those familiar, manageable doldrums. . . .

It was not really alarming at first, since the change was subtle, but I did notice that my surroundings took on a different tone at certain times: the shadows of nightfall seemed more somber, my mornings were less buoyant, walks in the woods became less zestful, and there was a moment during my working hours in the late afternoon when a kind of panic and anxiety overtook me, just for a few minutes, accompanied by a visceral queasiness—such a seizure was at least slightly alarming, after all. . . .

I felt a kind of numbness, an enervation, but more particularly an odd fragility—as if my body had actually become frail, hypersensitive and somehow disjointed and clumsy, lacking normal coordination. And soon I was in the throes of a pervasive hypochondria. Nothing felt quite right with my corporeal self; there were twitches and pains, sometimes intermittent, often seemingly constant, that seemed to presage all sorts of dire infirmities. . . .

It was October, and one of the unforgettable features of this stage of my disorder was the way in which my own farmhouse, my beloved home for 30 years, took on for me at that point when my spirits regularly sank to their nadir an almost palpable quality of ominousness. The fading evening light—akin to that famous ‘slant of light’ of Emily Dickinson’s, which spoke to her of death, of chill extinction—had none of its familiar autumnal loveliness, but ensnared me in a suffocating gloom. . . . That fall, as the disorder gradually took full possession of my system, I began to conceive that my mind itself was like one of those outmoded small-town telephone exchanges, being gradually inundated by floodwaters: one by one, the normal circuits began to drown, causing some of the functions of the body and nearly all of those of instinct and intellect to slowly disconnect. . . .

What I had begun to discover is that, mysteriously and in ways that are totally remote from normal experience, the gray drizzle of horror induced by depression takes on the quality of physical pain. But it is not an immediately identifiable pain, like that of a broken limb. It may be more accurate to say that despair, owing to some evil trick played upon the sick brain by the inhabiting psyche, comes to resemble the diabolical discomfort of being imprisoned in a fiercely overheated room. And because no breeze stirs this cauldron, because there is no escape from this smothering confinement, it is entirely natural that the victim begins to think ceaselessly of oblivion.

SOURCE: Quoted from W. Styron, *Darkness Visible* (New York, NY: Random House, 1990). Copyright © 1990 by William Styron. Reprinted by permission of Random House, Inc.

as major depression and schizophrenia. The depressive episodes in bipolar disorder are similar to those seen in major depression. During a manic episode, an individual’s mood is extremely elevated, expansive, or even irritable, and his or her self-esteem is elevated. There is diminished need for sleep, energy abounds, and thoughts race. Individuals are extremely talkative and distractible and stereotypically indulge in unrestrained buying sprees or sexual activity. Psychotic features (i.e., delusions and hallucinations) are not uncommon during a manic episode.

Bipolar disorder afflicts approximately 0.8 percent of the population, with men and women being affected equally. It emerges relatively early in life, usually during the mid-20s. Episodes of mania or depression occur every several months to every year

or more, with periods of recovery typically separating the mood swings. This disorder continues throughout an individual’s lifetime.

Treatment for bipolar disorder is aimed at ending a manic or depressive episode and preventing its recurrence. Medication is typically required, and hospitalization may be required for acute episodes. The specific symptoms are treated: depressive episodes with antidepressant drugs; psychosis with antipsychotic medication; and manic symptoms and relapses with lithium, or, less frequently, carbamazepine. Supportive psychotherapy is generally required to help patients understand and deal with the symptoms of bipolar disorder.

The typical symptoms and course of major mood disorders have led to their being conceptualized as

biologically based conditions. Since the discovery of clinically useful mood-altering medications 30 to 40 years ago, research has focused intensely on the biology of these conditions. Although the causes of these disorders remain obscure, studies of brain chemistry and function, other physical correlates, and genetic research provide clues about the biology of major mood disorders. The most consistent of these observations are discussed below.

A number of different brain chemicals appear to be involved in mood disorders. The most prominent hypotheses have focused on a group of brain chemicals called monoamines, especially norepinephrine and serotonin, because clinically effective antidepressant medications influence the levels of these chemicals. While neither depression nor mania seems to result from a simple decrease or increase of these chemicals, there is sufficient evidence to implicate monoamines in mood disorders.

Hormonal abnormalities are common in depression. Many of the symptoms associated with mood disorders—changes in appetite, sleep patterns, and sex drive—may be related to these hormonal changes. One of the most consistent findings in this regard is an elevation of cortisol in severely depressed individuals. Also, altered mood sometimes accompanies reproductive events in women—menstruation, pregnancy, childbirth, menopause—suggesting an association between reproductive hormonal alterations and mood disorders.

Individuals with mood disorders typically have sleep disturbances. Insomnia or excessive sleeping often occurs in depression, with REM sleep, during which dreaming occurs, frequently disrupted. The sleep of individuals with bipolar disorder is often affected; during depressive episodes, people may sleep excessively, and when manic, little or not at all.

Other functions that cycle over time may be disrupted in mood disorders. For example, many people with depression exhibit daily and seasonal fluctuations in mood. Some data suggest that circadian rhythms—biological and behavioral functions that repeat roughly every 24 hours—are disrupted in mood disorders. Furthermore, animal studies indicate that some antidepressant medications have an effect on the organization of circadian rhythms.

Episodes of mania and depression increase in frequency over time. And while environmental

factors appear to be important in triggering periods of altered mood in the early stages of bipolar disorder, mood swings become automatic later on. The increasingly frequent and spontaneous nature of mood cycling has led to the development of a hypothesis about the recurrent nature of bipolar disorder: the kindling and sensitization hypothesis. Kindling refers to an experimental model for epilepsy, in which spontaneous seizures occur after repeated stimulation of a particular region of the brain. Behavioral sensitization refers to an increasing behavioral response to the same dosage of a drug following repeated administration. It is possible that similar brain mechanisms underlie mood swings. While additional information is needed to confirm this hypothesis, it is interesting to note that the medications used to treat bipolar disorder—carbamazepine and lithium—can block kindling and behavioral sensitization.

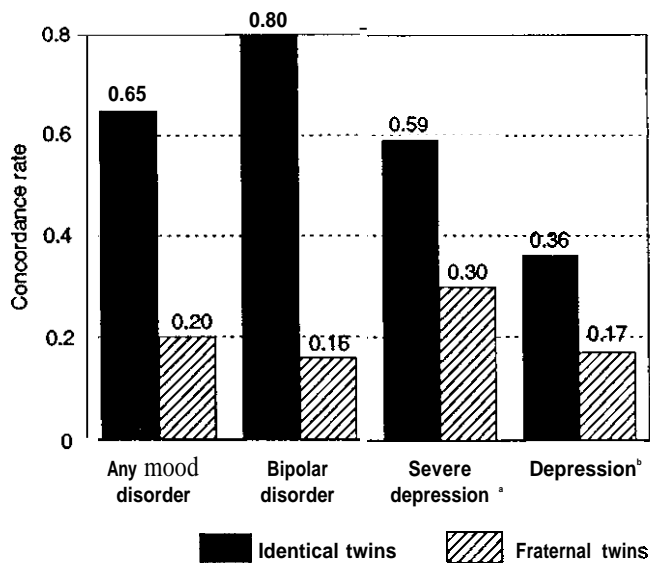
The most clearly established biological observation about mood disorders, and especially bipolar disorder, is that genetic factors play a role. Identical twins more frequently share mood disorders than do fraternal twins (figure 1-5). Also, parents, siblings, and children of individuals with bipolar disorder or major depression more commonly develop these conditions. Family and twin studies support a genetic link between depression and bipolar disorder, although the genetic overlap is not complete.

Clearly, genetic factors are important in both bipolar disorder and major depression. However, studies do not reveal a simple pattern of inheritance, nor do they necessarily implicate the action of a single gene. Data also indicate that nongenetic factors must play a role. While many studies have attempted to locate specific genes that lead to mood disorders, some with positive results, no strong evidence fixes a gene for mood disorders to a specific location.

ANXIETY DISORDERS: OBSESSIVE-COMPULSIVE DISORDER AND PANIC DISORDER

Anxiety is a normal human emotion, familiar to us all. However, anxiety can become extreme, leading to a disabling feeling of panic, a constant sense of apprehensiveness, or unrelenting worry about a possible mishap or accident. The current diagnostic system for mental disorders distinguishes several specific anxiety disorders, including panic disorder,

Figure 1-5—Mood Disorders Among Twins



Graphically depicted data were derived from evaluation of 110 pairs of twins. Identical twins shared mood disorders, and especially bipolar disorder, more frequently than fraternal twins.

^aThree or more episodes of depression.

^bLess than three episodes of depression.

SOURCE: Adapted from A. Bertelsen, B. Harvald, and M. Hauge, "A Danish Twin Study of Manic-Depressive Disorders," *British Journal of Psychiatry* 130:330-351, 1977.

phobias, obsessive-compulsive disorder, posttraumatic stress disorder, and generalized anxiety disorder. This report considers two of these conditions—obsessive-compulsive disorder and panic disorder—in which the role of biological factors has been more fully explored.

Obsessive-compulsive disorder (OCD) is characterized by the presence of recurrent and persistent thoughts, images, or ideas that are experienced by the afflicted individual as intrusive and senseless (obsessions) and stereotypical, repetitive, and purposeful actions perceived as unnecessary (compulsions) (table 1-2). A common manifestation of this disorder is the obsessional feeling of being dirty or contaminated, which leads to the compulsion of repeated hand washing. Many individuals with OCD have another diagnosis, most often depression. Other problems that may be associated with OCD include other anxiety disorders, eating disorders, alcohol abuse, and Tourette's syndrome.

Once thought to be quite rare, OCD has been found by more recent epidemiological studies to affect approximately 2 to 3 percent of the U.S.

population. Males and females appear to be afflicted equally. The symptoms of OCD begin in childhood or adolescence in one-third to one-half of all individuals who develop the disorder; the average age of onset is 20. Although the symptoms of OCD sometimes recede completely with time, most patients suffer chronically from OCD, with a waxing and waning course.

Currently there are two primary treatment approaches for OCD: behavioral therapy and medication. Behavioral therapy entails repeated exposure of the patient to the stimulus that sets off ritualistic acts. For example, if an individual has a compulsion that causes him to wash his hands 20 or 30 times a day, his hands may be deliberately dirtied, after which he is prevented from washing them. Medications affecting the brain chemical serotonin have proven effective, with clomipramine (Anafranil) being commonly used to treat OCD.

As with the other mental disorders considered in this report, biological factors appear to have a role in OCD. The fact that drugs which act on the brain chemical serotonin are sometimes effective in treating OCD implicates biological factors. Studies have not, however, uncovered a specific abnormality in serotonin metabolism or activity. Other studies implicate a genetic component in OCD.

Several lines of evidence indicate that a specific region of the brain—the basal ganglia—mediates the symptoms of OCD. Damage to the basal ganglia can lead to compulsive behavior. And OCD is sometimes associated with Tourette's syndrome, which also involves this region of the brain. These observations, coupled with data from studies that show increased activity in the basal ganglia and in another region of the brain, the orbital system in the frontal cortex, have led to the hypothesis that OCD results from the abnormal interaction of these two regions of the brain (figure 1-6). According to this hypothesis, the basal ganglia and frontal cortex, which normally modulate actions based on thoughts or impulses, do not work properly in OCD.

While controversy remains as to whether panic disorder is a distinct entity, clinicians have long recognized panic attacks and the extensive morbidity associated with them. The hallmark symptoms of a panic attack include a sudden and inexplicable bout of intense fear associated with strong bodily symptoms. A panic attack typically unfolds quite

Table 1-2—Obsessions and Compulsions

Obsessions	Reported symptom at initial interview	
	(no.)	(%)
Concern with dirt, germs, or environmental toxins	28	(40)
Something terrible happening (fire, death, or illness of self or loved one)	17	(24)
Symmetry, order, or exactness	12	(17)
Scrupulosity (religious obsessions)	9	(13)
Concern or disgust with bodily wastes or secretions (urine, stool, saliva)	6	(8)
Lucky or unlucky numbers	6	(8)
Forbidden, aggressive or perverse sexual thoughts, images, or impulses	3	(4)
Fear might harm others or oneself	3	(4)
Concern with household items	2	(3)
Intrusive nonsense sounds, words, or music	1	(1)

Compulsions	Reported symptom at initial interview	
	(no.)	(%)
Excessive or ritualized hand washing, showering bathing, tooth brushing, or grooming	60	(85)
Repeating rituals (going in or out of a door, up or down from a chair)	36	(51)
Checking (doors, locks, stove, appliances, emergency brake on car, paper route, homework)	32	(46)
Rituals to remove contact with contaminants	16	(23)
Touching	14	(20)
Measures to prevent harm to self or others	11	(16)
Ordering or arranging	12	(17)
Counting	13	(18)
Hoarding or collecting rituals	8	(11)
Rituals of cleaning household or inanimate objects	4	(6)
Miscellaneous rituals (such as writing, moving, speaking)	18	(26)

^aThe most frequent obsessions and compulsions among 70 children and adolescents who were diagnosed as having OCD by the author and her colleagues at the National Institute of Mental Health. The proportions total more than 100 percent because many sufferers have more than one symptom.

SOURCE: J.L. Rapoport, "The Biology of Obsessions and Compulsions" *Scientific American* 260(3):83-89, 1990.

rapidly; in just a few minutes an extreme sense of fear overtakes an individual, his or her heart begins racing, the individual begins to perspire, sometimes profusely, and he or she has trouble breathing. A single attack is short-lived, lasting 20 minutes to an hour, on average. These symptoms often leave a person believing that he or she is suffering from a heart attack or is losing his or her mind. In fact, many individuals with panic disorder seek general medical care at an increased rate. Panic attacks occur, on average, about two times a week, although the frequency varies considerably among individuals. People with panic disorder often exhibit other disorders as well. They may fear being in a public place from which escape is difficult—agoraphobia. Depression and substance abuse are also common among individuals with panic disorder.

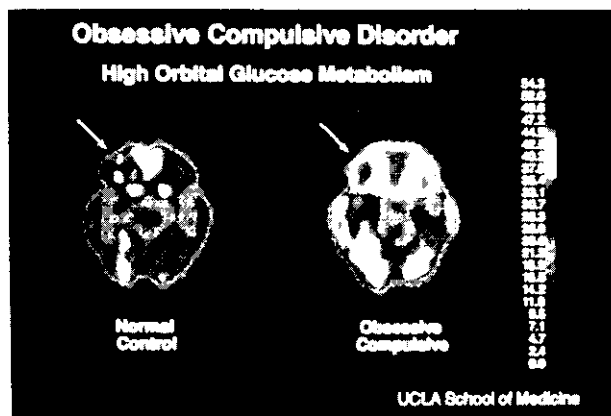
Data show that approximately one to two persons in every hundred will develop panic disorder during their lifetimes, with women being twice as likely as

men to develop the disorder. The disorder usually first appears during young adulthood, with an average age of onset of 24 years. Data suggest that many patients suffer chronically from this condition.

Panic disorder is treated with medication and/or psychotherapy. Antidepressant drugs and anti-anxiety agents, such as the benzodiazepine alprazolam, are used with some effectiveness in panic disorder; behavioral or cognitive therapy may prove useful in diminishing the severity or frequency, or both, of panic attacks.

There are several psychological and biological theories about the origin of panic disorder. For example, one cognitive theory posits that individuals may misinterpret normal physiological changes, such as an increase in heart rate, as dangerous, thus inducing anxiety and precipitating a panic attack. Several observations are consistent with a role for biological factors in panic disorder. Data from

Figure 1-6—PET Scan of an Individual With Obsessive-Compulsive Disorder



Brain activity in the brain of a person with OCD (right) and the brain of a person without OCD (left). In OCD, there is increased activity in a region of the brain called the frontal cortex.

SOURCE: L. Baxter, UCLA Center for Health Sciences, Los Angeles, CA.

genetic studies indicate that panic disorder may, in part, be inherited. The action of antianxiety medications has led to hypotheses that naturally occurring anxiety-provoking chemicals underlie panic disorder or, conversely, that a deficit of natural anxiety-blockers is at the root of the disorder. To date, however, no such substances have been identified. Research data have also implicated a particular region of the brain, the limbic system, in anxiety and possibly panic disorder.

Whatever the cause, several lines of evidence point to the role of a particular brain region (the locus ceruleus) and a specific chemical (norepinephrine) in mediating panic attacks. Antidepressant drugs, which act on norepinephrine, are an effective treatment for panic disorder. Various drugs and other substances that stimulate the locus ceruleus and increase norepinephrine production can also trigger panic attacks. Continuing research is aimed at clarifying what role the locus ceruleus plays in panic disorder, how it might relate to the limbic system (which is involved in anxiety), and what other chemicals and regions of the brain may be involved.

A SYNTHESIS: UNDERSTANDING THE ROLE OF BIOLOGY

What can we conclude about the role of biology in mental disorders? In its review of research, OTA found the following evidence that biological factors

are involved in schizophrenia, bipolar disorder, major depression, OCD, and panic disorder:

- Medications can suppress symptoms associated with these disorders.
- Specific mental disorders can often be typified by distinguishable clinical features, such as age of onset, symptoms, and course.
- These disorders may have associated “physical” symptoms, such as altered sleep patterns in depression.
- Known physical agents and drugs can produce some symptoms of mental disorders, demonstrating that biological factors can in fact be causative.
- Genetic studies show that the disorders are influenced by inheritance.
- Other areas of research provide evidence about correlated biological factors and suggest testable hypotheses as to causation.

Some researchers and advocates conclude from this evidence that biological factors are the predominant cause of severe mental disorders and that the medical model is the best way to conceive of them. In contrast, others deplore the talk of “brain disease,” citing the incomplete state of our knowledge about what causes these conditions and even how best to categorize them. The majority of experts and interested parties—and OTA—recognize that research data increasingly show that biological factors play an important role in these disorders. Furthermore, OTA concludes that advances in biological research will serve as the linchpin in improving our understanding of these conditions.

Biological research has not ruled out a role for psychosocial factors in the mental disorders considered in this report. In fact, it is clear that mental disorders cannot be understood or treated in biological terms only. Nor does biological research necessarily implicate biological treatments. Environment, education, and culture exert powerful influences, and psychological interventions are important for treatment. Experts increasingly recognize the essential error of discussions that pit biology against psychosocial factors: The two are obviously and inextricably interrelated. Sorting out their relative roles and how they interact in different conditions will be critical for the development of research and treatment strategies.

Many questions remain about the biology of mental disorders. In fact, research has yet to identify

specific biological causes for any of these disorders. Why do we not know more about the biological causes and correlates of these conditions? One reason stems from the complexity of these disorders and the difficulty of categorizing them. Individuals often exhibit symptoms that reach across categories of disorders. And a single diagnostic category may encompass multiple conditions. Furthermore, we do not completely understand the relationship among different disorders.

Another reason is our incomplete understanding of the brain. The brain and behavior are immensely complicated, and our knowledge of them is still scant in comparison to what we have yet to learn. With advancing knowledge about the brain, more sophisticated hypotheses about mental disorders— involving how the many chemicals in the brain work, and how nerve cells and discrete regions of the brain interact—will be propounded. Given our nascent understanding of the brain, it will be necessary to stay the course in what is likely to be a slow unveiling of the biology of mental disorders.

The search for specific genes involved in mental disorders has also proven a difficult task. Attempts to locate specific genes have alternately produced acclaimed reports of success and contradictory data followed by the withdrawal of results. While these events impugn the theory of a simple relationship between one gene and a particular mental disorder, they do not rule out the need for further genetic studies: Evidence from many sources clearly indicates that mental disorders have a genetic component. Nor do past problems necessarily rule out the action of a major gene in the development of a mental disorder, at least in some cases. Like the investigations of other common diseases with complex genetics (e.g., Alzheimer's disease, diabetes mellitus), future studies must take into account the complicated pattern of inheritance, the likely role of more than one gene operating within different families and individuals, questions as to what is inherited, and the undeniable role of nongenetic factors.

THE RESEARCH ENTERPRISE

The pursuit of knowledge about the biological aspects of mental disorders rests upon an adequate research capacity, which in turn is subserved by a complex enterprise that makes funds available, sets research priorities, attends to relevant ethical and policy issues, outfits researchers with equipment and other resource needs, and provides for education and training. The answers to three questions shed light on factors that influence this research enterprise: What level of public concern motivates research into mental disorders? What is the level of research support? What factors form barriers to research?

What Level of Public Concern Motivates Research Into Mental Disorders?

Several studies and mental health advocates have claimed that research into mental disorders is underfunded, attributing the deficiency to the low priority assigned to these conditions by the public and policymakers. This assertion stems from three observations: 1) the Federal investment, as reflected in the NIMH budgets, declined significantly between the late 1960s and early 1980s; 2) Federal support for research on mental disorders is comparatively less than its support of other areas of health research; and 3) there are limited non-Federal sources of funding, especially from private foundations.

A seminal report from the Institute of Medicine concluded in 1984 that the:

... real buying power of research funding for mental disorders has dropped sharply during the past 15 years, even as available personnel and basic knowledge about brain function have expanded dramatically.³

OTA evaluated the NIMH research budget since 1980, to gauge recent Federal support (figure 1-7). Between 1980 and 1992,⁴ NIMH funding of research, including funding of extramural basic and clinical research, intramural research, and research training, increased by 6.7 percent annually.⁵ The rate of growth from 1986 to 1992 was substantially higher, at 11.5 percent.⁶

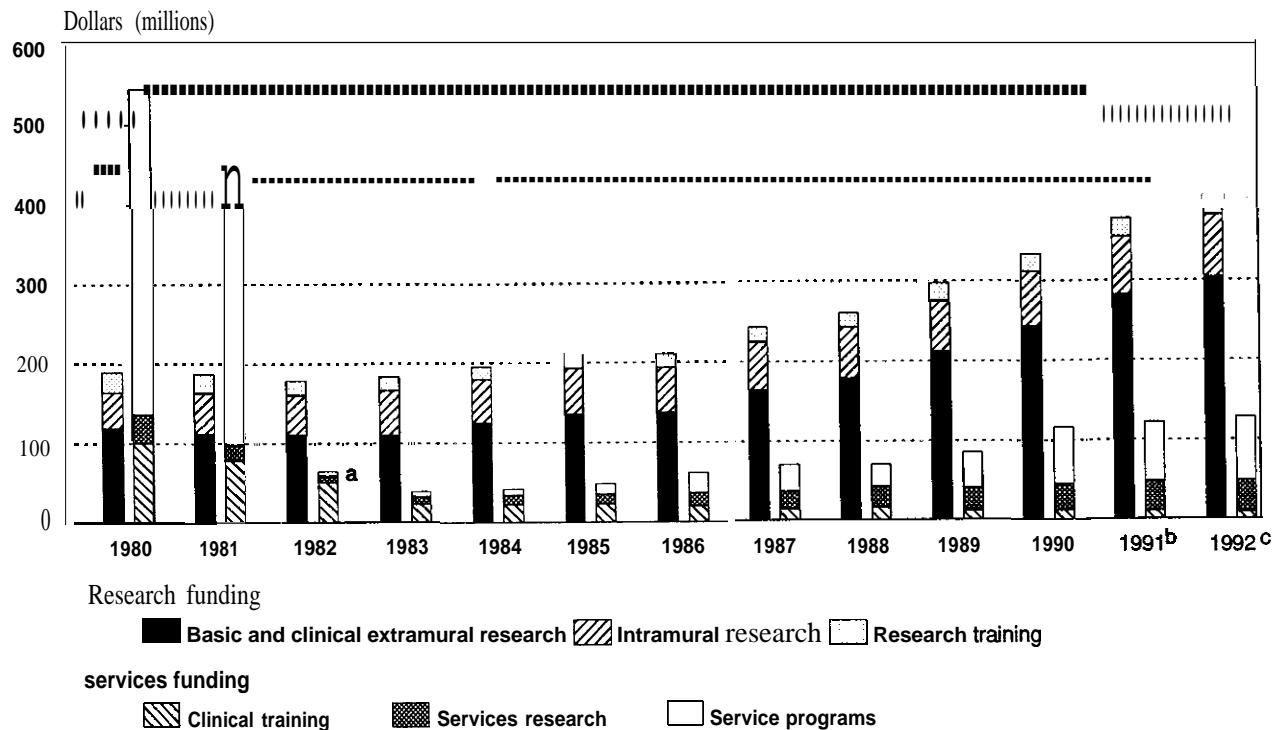
³ Institute of Medicine, *Research on Mental Illness and Addictive Disorders: Progress and Prospects* (Washington, DC: National Academy Press, 1984).

⁴ Fiscal years are indicated.

⁵ This is the average annual real rate of increase, determined by converting the NIMH budget in current dollars into constant 1987 dollars, using the gross domestic product deflator as the price index.

⁶ Based on estimates, the increase in NIMH's research budget slowed to 7.7 percent between 1991 and 1992.

Figure 1-7—NIMH Budget, Fiscal Years 1980-92



Funding of the components of the research and services budgets of NIMH.

NOTE: Figures converted to constant 1987 dollars using the 1992 gross domestic product deflator.

^aDecrease reflects initiation of State block grants.

^b1991 and 1992 figures are estimates.

^c1992 figures based on assumption of constant price index.

SOURCE: Office of Technology Assessment from figures supplied by National Institute of Mental Health, 1992.

Despite the increases, various measures indicate that during the 1980s the relative investment in research on mental disorders was considerably less than that for other diseases. OTA compared the relative support for research to the total costs of mental disorders, cancer, and heart disease (table 1-3).⁷ For every \$100 of costs imposed by mental disorders, \$0.30 was spent on research. In comparison, for every \$100 of costs of heart disease and cancer, \$0.73 and \$1.63, respectively, were spent on research. It is of interest to note, however, that the Federal Government's purchasing power for mental disorders research increased faster in the 1980s than did its purchasing power for cancer research.

Previous studies have also called attention to the historic neglect of research into mental disorders by private foundations and voluntary health agencies,

which currently form a relatively small, but important source of support for biomedical research. The 1980s did witness new sources of private support for research into the biology of severe mental disorders, with the formation of the National Alliance for Research on Schizophrenia and Depression (NARSAD) in 1986 and the establishment of the National Alliance for the Mentally Ill's (NAMI's) Stanley Awards Program. Still, support from such organizations for mental disorder-related research stands at a much lower level than private foundation support for other diseases. For example, in fiscal year 1991, the American Cancer Society spent nearly \$91 million dollars on research, compared to NARSAD's \$3.3 million.

What can we conclude about the level of public concern that surrounds mental disorders, as meas-

⁷ The analysis used the most comparable and recent data, which stemmed from 1985.

Table 1-3—Comparison of Costs and Research Funding, Fiscal Year 1985

Illness	costs' (\$ millions)	Total budget of principal Federal institution (\$ millions)	Dollars spent on research per \$100 of cost to society
Mental disorders	103,69f	310 ^a	0.30
Cancer (malignant neoplasms only) . .	72,494	1,184	1.63
Heart disease	69,000	501	0.73

^aD.P. Rice, S. Kelman, L.S. Miller, et al., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness: 1985*, report submitted to the Office of Financing and Coverage Policy, Alcohol, Drug Abuse, and Mental Health Administration, U.S. Department of Health and Human Services (San Francisco, CA: Institute for Health and Aging, University of California, 1990); D.P. Rice, T.A. Hodgson, and F. Capell, "The Economic Burden of Cancer, 1985: United States and California," *Cancer Care and Cost: DRGs and Beyond*, R.M. Scheffler and N.C. Andrews (eds.) (Ann Arbor, MI: Health Administration Press Perspectives, 1989); T. Thorn, Health Statistician, Division of Epidemiology and Clinical Application, National Heart, Lung, and Blood Institute, National Institutes of Health, personal communication, 1991.

^bNational Institute of Mental Health, National Cancer Institute, and National Heart, Lung, and Blood Institute budgets.

^cCosts of mental disorders include costs of dementia.

^dFi₉₈₅ includes \$29 million for funding of dementia research by the National Institute on Aging.

SOURCE: Office of Technology Assessment, 1992.

ured by research support? As others have noted, the historical lack of support for this research was reversed somewhat in the 1980s: Federal funding for research into mental disorders increased significantly, and new private sources of funding developed. Even with the increased funding of the 1980s, however, support for research into mental disorders falls short of that for other conditions in relation to their cost to society.

What Is the Level of Research Support?

How much of NIMH's increasing funding goes to support the areas of research considered in this report? OTA examined extramural research funding in two major divisions of NIMH: the Division of Basic Brain and Behavioral Sciences (DBBBS) and the Division of Clinical Research (DCR). In 1991, these divisions accounted for 74 percent of the extramural research budget—some \$287.2 million.

As indicated by its name, DBBBS supports basic research aimed at furthering the understanding of basic brain mechanisms and behavior related to mental disorders. Over the last few years, DBBBS has received increasing support, with its research budget reaching \$117.6 million in 1991 (figure 1-8). Specific areas of neuroscience, including molecular and cellular biology, cognitive neuroscience, neuroimaging, and psychopharmacology research, have been particularly favored. The annual rate of increase in its budget was 14.5 percent between 1988 and 1992.

DCR consists of six research-oriented branches; its total research budget in 1991 was \$169.6 million.

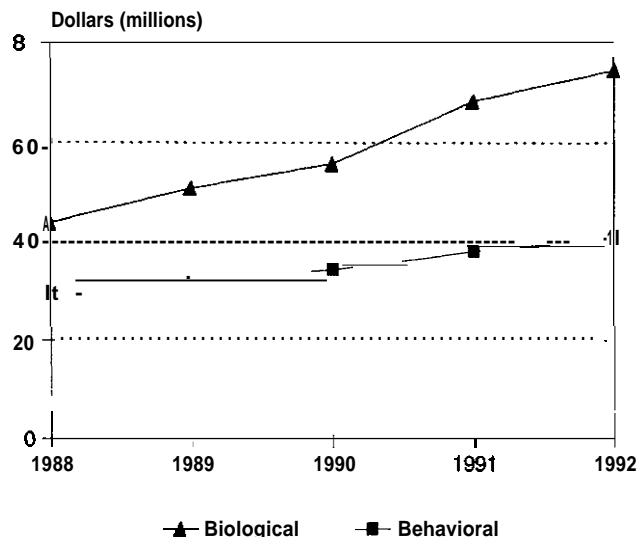
Two branches—the Schizophrenia Research Branch and the Mood, Anxiety, and Personality Disorders Research Branch—target the disorders considered in this report and receive 50.3 percent of DCR's research budget. Between 1986 and 1992, both of these branches experienced above average funding increases (figure 1-9). The DCR's emphasis on schizophrenia and mood disorders is further reflected in the fact that 16 of its 23 research centers focus on these disorders.

What Factors Create Barriers to Research?

Funding is not the sole determinant of research capacity. Various other factors, ranging from the availability of animals to the number of trained researchers, influence the success of the research enterprise. OTA has identified several areas that, if neglected, can create barriers to research.

Several issues common to all biomedical research come to bear on research into mental disorders. For instance, support for facilities and equipment affects mental disorders research. Efforts to contain health-care costs also affect clinical research, since third-party payers typically cover the costs of clinical care in research. Another general issue for mental disorders research centers around the representation of all members of society in research, regardless of age, sex, race, or ethnic group; concerns about fairness and the ultimate implications for health and the advancement of knowledge have driven congressional and executive branch action. Finally, because the use of animals, especially nonhuman primates, is critical for neuroscience and research into mental

Figure 1-8—Funding of the Division of Basic Brain and Behavioral Sciences, Fiscal Years 1988-92



The funding of the Division of Basic Brain and Behavioral Sciences broken down into biological and behavioral research (see text).

NOTE: Figures converted to constant 1987 dollars using the 1992 gross domestic product deflator.

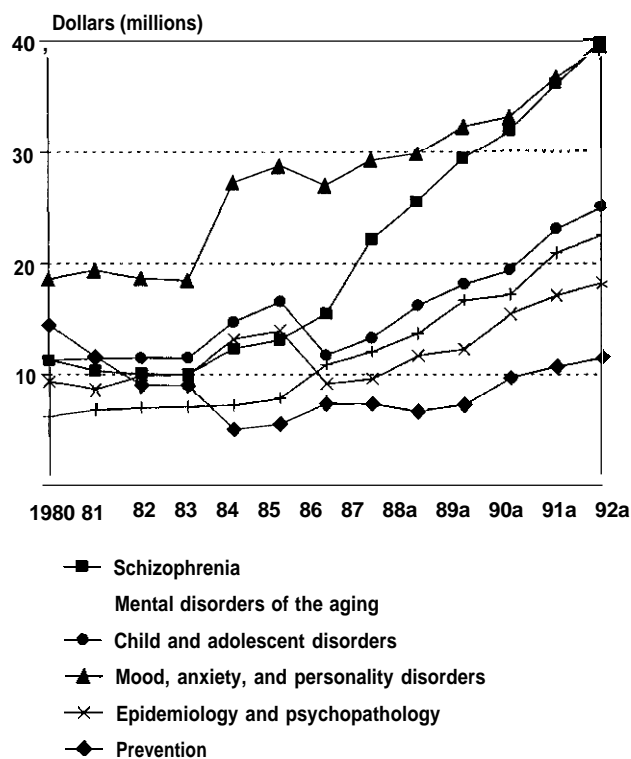
SOURCE: Office of Technology Assessment from figures supplied by National Institute of Mental Health, 1992.

disorders, developments concerning the use of animals in research, including tightening regulations and increased cost, raise concern.

The fact that mental disorders disrupt human cognitive, emotional, and social capabilities presents special challenges for researchers. For example, how can these complicated effects be studied or modeled in animals? Also, the unique nature of mental disorders raises ethical concerns in clinical research, requiring a careful balancing of individuals' needs and interests and the need for continued research. While these issues cannot be eliminated, investigators can devise ways of dealing with them effectively. Finally, the stigma attached to and the ignorance surrounding mental disorders influence research in a variety of ways, from hindering recruitment of subjects to amplying privacy concerns.

OTA considered, in some detail, three issues identified as significant obstacles to research on mental disorders: the difficulty of obtaining post-mortem brain tissue, the cost of hospitalization, and the number of clinician-researchers.

Figure 1-9—Funding of the Division of Clinical Research, Fiscal Years 1980-92



Funding of the six research branches of the Division of Clinical Research.

NOTE: Figures converted to constant 1987 dollars using the 1992 gross domestic product deflator. aFigures include research training.

SOURCE: Office of Technology Assessment from figures supplied by National Institute of Mental Health, 1992.

The expansion of biological research into mental disorders makes the availability of postmortem brain tissue increasingly important. While there are two federally sponsored brain bank centers in the United States, as well as an informal supply, the amount of tissue available for research is simply inadequate. Improving the banking of brains requires consideration of several factors: funding, standardization of tissue retrieval and handling methods, attracting tissue donors, the need for complete medical histories, and safeguarding confidentiality. In an effort to improve the acquisition process and to better disseminate information about the availability of sources of brain tissue from various centers, NIMH has created a task force to make recommendations on how to coordinate these efforts. A number of suggestions are under consideration, including the use of a private institution under contract to NIMH

as a clearinghouse for the collection and distribution of brain tissue. The NIMH task force is also identifying other needs related to the collection of brains for research. These include designing systems to address the problem of the limited samples of tissue available from persons with specific disorders, and the pressing need for tissue from normal individuals that can be used as experimental controls.

Studies of subjects who have mental disorders and who are not taking medications are critical in investigating the underlying biology of a disorder and in establishing the effectiveness of new treatments. While several issues influence this research, the cost of care for medication-free research subjects—who generally require hospitalization—is a major obstacle to clinical research. The cost of each hospital day can range from \$300 to over \$1,000; thus, the cost of supporting a single research bed for a year can range from \$109,500 to \$365,000. NIMH funding can be used to support bed costs, but generally this is not a realistic option, since it would divert an enormous proportion of funds from other research activities.

Many experts and organizations have drawn attention to the apparent shortage of clinician-researchers—namely, psychiatrists and psychologists—in the United States. Recently, NIMH convened a task force to make specific recommendations about the recruitment of investigators into clinical research careers. While the need for clinician-researchers is not peculiar to mental health research, some factors make the situation particularly acute in this field. Few students in mental health professional training programs receive formal exposure to research. And financial issues, including expected salary levels and the need to pay off medical and/or graduate school debts, tend to forestall the choice of a research career.

IMPLICATIONS OF BIOLOGY

Support for neuroscience research, in general and as it is applied to the study of mental disorders, stems from a palpable enthusiasm for advances in understanding the human brain. Support for research into the biology of severe mental disorders is also intimately linked to the hope for improved treatments for these disorders. While treatments exist, they are not effective in all cases, and side effects, some of which are serious, are common. Although a

detailed analysis of the development of new treatments lies outside the purview of this report, OTA finds that the development of new drugs to treat mental disorders is one of the greatest promises that biological research holds. History bears out this potential, as does the number of drugs being developed and tested (table 1-4). The increasing and more precise understanding of the action of chemicals in the brain has facilitated and will continue to facilitate the development of new medications for mental disorders. At the same time, important issues that cannot be overlooked—cost, side effects, forced treatment—accompany the development and use of psychoactive medication.

The zeal associated with the current focus on the biology of mental disorders may benefit from some tempering. Scientific advances can lead to better treatment, diagnostic tests, cures, and preventive measures. However, most new treatments will reflect incremental advances: Significant improvements in the understanding and treatment of mental disorders are likely to require years, even decades, to unfold. Some observers have noted that fostering expectations of rapid progress in discerning the biological underpinnings of mental disorders or developing new treatments may provoke impatience, disappointment, or even a backlash against this research. Perhaps most important, exclusive emphasis on biological factors could divert resources from other important areas of research and the provision of care for people currently suffering from these conditions.

Biological research into mental disorders has influenced the mental health care finance debate, as exemplified by recent court cases and State laws. Coverage for mental health care in both the public and private sectors is generally lower than coverage for “physical” illnesses. In order to gain parity in insurance coverage and to help defray the costs of these chronic and often severe disorders, some advocates have emphasized the biological basis of certain mental disorders, thus invoking the traditional medical model of illness as the most appropriate one for treatment. Also, emphasizing the biological basis of a disorder underlines the fact that the disorder is outside the control of the individual and invokes society’s perceived responsibility for providing care. Biological research may also help insurers in objectively determining an insurable event, by identifying biological markers for certain mental disorders, along with effective treatments.

Table 1-4—Drugs in Development for Mental Disorders

Disorder	United States	Other countries
Schizophrenia	76	42
Mood disorders	83	61
Anxiety disorders	91	46

SOURCE: PJB Publications, *Pharmaprojects* Surrey, England; PJP Publications, 1992).

Data from research point increasingly to the importance of biological factors in certain mental disorders. This has given rise to other concerns, however, including coverage of ‘nonbiological’ disorders or interventions. Furthermore, there is heightened concern about the cost of health care. Given the public health problem that severe mental disorders present and the complex issues involved in health care finance, the way in which care for persons with these disorders is financed warrants full evaluation.

OTA has identified ways in which information from research into the biology of mental disorders is used to counter the ignorance and negative attitudes that have long been attached to these conditions. Mental disorders have often been and continue to be perceived as a sign of moral or personal weakness. Biological explanations for mental disorders are used to counter the view that these conditions are based in moral turpitude, thus exculpating individuals whose disorders may lead to unusual, erratic, or frightening behavior. Also, the assertion that biological factors contribute to the development of mental disorders refutes the once-reigning and stigmatizing notion that bad parenting is the essential, causative factor. Despite the fact that little or no scientific evidence supports theories of bad parenting as a sufficient or necessary cause of severe mental disorders considered in this report, these theories continue to shape the attitudes of the public and even some experts.

The increased emphasis on biological aspects of mental disorders, while helpful in dismantling some negative attitudes, is not without limitations. Perceptions of what causes mental disorders are not the sole source of stigma; other factors, such as personal experiences and media portrayals (box 1-D), influence public attitudes as well. Also, with the increased publicity given biological research data, questions and worries may arise among individuals with mental disorders and their families. For example, many family members who have heard about genetic studies of mental disorders may overesti-

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.

mate their risk for these conditions. Furthermore, the perception that mental disorders are inherited could instill guilt among parents, who fear they might transmit ‘flaws’ to their progeny. While our current understanding of the genetics of mental disorders makes unlikely the development of a single, highly

Box 1-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.

predictive genetic test that would be useful across the general population, the future possibility of genetic testing—even the perception that mental disorders are inherited—raises additional concerns about possible discrimination.

Biological data also may be simplified or misinterpreted. Attributing behavior to biological, especially genetic, factors may lead to the perception that human actions are predetermined. Thus, biological explanations of behavior encroach uncomfortably on our sense of free will and moral agency. Furthermore, some observers fear that biological theories of mental functions reduce human behavior to the output of the gray mass in our craniums, thus robbing human thought and emotion of meaning and import. Individuals with mental disorders may be especially vulnerable in a society seduced by notions of biological determinism and reductionism; in this case, not only are mental functions just the reflection of brain function, but the brain function is diseased. The meaning attached to a person's thoughts and actions, and the extent to which he or she is responsible for them, are complex issues requiring the consideration of biological as well as social, philosophical, legal, and moral issues, which are beyond the scope of this report. Nevertheless, it is important to debunk some of the myths that surround these issues. Biological theories of causation are not necessarily more damaging to the person afflicted with a mental disorder than other theories; one need only be reminded of the cruel and stigmatizing concepts of family causation. Nor is it true that a biological underpinning is immutable and an environmental one malleable. Recent advances in neuroscience do not suggest that our brains are biologically fried; rather, results increasingly show the dynamic nature of nervous tissue and its responsiveness to environmental cues throughout life.

POLICY ISSUES AND OPTIONS FOR CONGRESSIONAL ACTION

The findings of this study attest to the recent growth of the neuroscience and to a corresponding surge of interest in the biology of mental disorders. Researchers have partially uncovered the biological substrates of some mental disorders and have propounded testable hypotheses about causes. The upshot of the scientific advances is expanded research opportunities, potential treatments, and new questions regarding how this knowledge is

used. The potential consequences of biological research into mental disorders raise several policy issues of congressional interest:

- . Federal support for research,
- . implications of scientific advances, and
- . dissemination of new information.

The following section covers each of these policy issues and sets forth several options for congressional action. Some options require direct congressional action, while others involve indirect efforts, such as oversight or direction of the executive branch. OTA has fashioned a list of reasonable responses to the policy issues that emerged during the course of this study. No priority is set nor course recommended; rather, an analysis of each option and its likely result is presented.

ISSUE 1: Federal Support for Research

Congress is faced with the question, *How should we support research on mental disorders?* The most important congressional response to this question is given annually, in the allocation to NIMH; several observations and results from this study may assist Congress with its funding decision.

Option 1: Support research at NIMH.

It is no exaggeration to state that advances in neuroscience have revolutionized the study of mental disorders. While the causes of mental disorders remain unknown, data from various and diverse studies illuminate the role of biological factors in schizophrenia, bipolar disorder, major depression, OCD, and panic disorder. Furthermore, the intense efforts and rapid progress in neuroscience portend increased knowledge about these disorders in the years to come. New technologies enable scientists to probe more thoroughly everything from the tiniest molecules to the interaction of large collections of nerve cells, giving us insights into the more than 100 billion nerve cells that together make up the brain. This confluence of technological advances, rapidly accruing knowledge in the neuroscience, and considerable excitement among researchers calls for, at the very least, a sustained level of funding for biological research into mental disorders; undoubtedly, this research enterprise could effectively use even higher levels of funding. To reduce funding would be to ignore the opportunities that exist at this time, thus failing to capitalize on the investment and gains to date.

While this report does not detail the research and development of specific treatments for mental disorders, OTA finds that one of the greatest promises of research into the biology of mental disorders is the development of more effective medications. The need for and promise of better medications also argue for continued or enhanced funding. New drugs resulting from the investment in research could more than pay for their development costs by offsetting some of the tremendous burden now borne by society. For example, it is estimated that the 1969 introduction of lithium to treat bipolar disorder resulted in average yearly savings in treatment costs of \$290 million in the United States. It was also estimated that \$92 million in lost wages was regained in the first year following the introduction of lithium. It is important to note, however, that the translation of new scientific findings into new treatments will probably take place over a period of years, if not decades. Therefore, this must be viewed as a long-term investment.

Although the social burden of mental disorders is difficult to compare with that of other types of illness, it is generally of the same magnitude as cancer and heart disease. Mental disorders lead to considerable suffering, disability, and death. These conditions take a large toll on society, afflicting millions of Americans and costing the nation more than \$100 billion each year. Yet based on the costs of the disorders, research spending for mental disorders is lower than that for cancer or heart disease. Increased allocation of funds for mental disorders research would redress this inequity in funding and demonstrate the priority given to mental disorders by the Federal Government. The relative cost of a health problem cannot be the sole determinant of research funding; however, together with the fact that significant research opportunities exist in this field, it serves as a strong argument for increased funds.

It is apparent that several factors argue for continued, if not increased, funding of mental disorders research, but Congress must weigh the relative importance and need for this investment of Federal dollars against a host of competing programs. It is also important to note that additional funding would certainly enable researchers to pursue more scientific opportunities and would yield fruitful gains, but it would also enlarge the system and increase the number of deserving competitors for Federal support. Scientific research budgets, includ-

ing that of the NIMH, have fared well during the past years of fiscal constraints; however, the growing Federal debt and mechanisms enacted to address it have sharpened the competition among federally financed programs. While a main conclusion of this report is that continued support for research into the biology of mental disorders is necessary in order to reap the potential benefits, this study did not assess the state of knowledge, relative promise, or warranted priority of other programs or fields of inquiry.

Whatever the level of support for mental disorders research, it is critical that funding go to the highest quality research. Given the state of knowledge and existing research opportunities, how are Federal monies best invested, with the highest likelihood of return? OTA finds that maintaining abroad portfolio of research is the key. Continued investment in basic research is central to this effort, given the rudimentary, if rapidly growing, state of our knowledge concerning the brain and its functioning. Basic neuroscience research will produce more sophisticated hypotheses and methods of analysis, which are essential to understanding the complex manifestations of mental disorders.

Disorder-targeted funding is also necessary. This report notes many areas that are prime for research and that are likely to improve public health. Various viable hypotheses have been put forth concerning the causes of mental disorders, but further information is needed concerning the specific manifestations of these conditions and their pattern of inheritance. Advances in molecular biology and imaging technologies make possible more detailed examination of brain function and structure in these disorders.

Support for disorder-targeted research encompasses clinical studies. Congressional support for clinical research can be shown in various ways, among them additional funding for NIMH. The options that follow are also means of supporting clinical research.

Option 2: Support clinical research by the VA.

Since the **costs** of medical care in clinical investigations at VA hospitals are charged to health care delivery funds rather than research dollars, a modest increase in research appropriations could significantly **increase clinical** research. Thus, Congress could enhance clinical research by increasing the VA's research budget. Furthermore, to foster

mental disorders research, Congress could direct the VA to move forward on a recommendation from the VA Advisory Committee for Health Research Policy, which recommended the creation of a Health Research Advisory Council to identify and prioritize those areas with the greatest promise of enhancing VA health care. The council could be a useful mechanism for redressing the disparity between VA medical research expenditures for mental disorders and their clinical costs.

Option 3: Convene a task force to delineate mechanisms for underwriting bed costs.

Rapidly rising bed costs threaten clinical studies, which often require hospitalization of subjects during trials, as well as other persons who are free of medication. Bed costs can be included in the NIMH funding made available to the Clinical Research Centers. Yet few center directors choose to use funds in this fashion, since it would divert an enormous proportion of their total funding away from other priorities. The pharmaceutical industry has recently recognized the obstacle created by increasing bed costs; and while some companies have begun providing support, it is difficult to document the extent of such support. NIMH has not taken any direct action in regard to bed costs. In the absence of congressional action, it is unclear whether NIMH will address this issue. Thus, this acute need may go unmet.

Some virtually untapped resources exist to help defray the expense of bed costs in clinical research. In an effort to deal with the issue of bed costs, Congress could direct that a task force be established. The task force could include representatives of all parties who have a stake in this research and who can contribute to the solution: clinical investigators, NIMH, health insurance companies, private foundations, advocacy groups, pharmaceutical companies, State mental hospitals, the VA hospital system, and general and private hospitals. While it might be difficult for the many different parties involved to form a consensus, together they could devise a workable plan that would take advantage of existing and unutilized resources (e.g., VA hospitals, State hospitals). In addition to considering cost issues, the task force could explore research approaches that might be less expensive (e.g., day hospitals and partial-care centers). NIMH can be directed to follow the findings and recommendations of the task force.

Option 4: Fund the training of clinician-researchers.

The limited availability of researchers trained as clinicians has a continuing impact on the quality and quantity of clinical research. Professionals and policymakers acknowledge this problem, and NIMH is poised to address it by enhancing exposure to research for psychiatrists and psychologists during training. Support for research centers, which bring together clinicians and researchers with various skills to work together on research projects, also addresses the need for the clinician's expertise in studies.

Congress could, however, further respond to the need for clinician-researchers. Congress established the National Research Service Awards (NRSA) to provide for the training of clinician-researchers, but its appropriations for NRSA have not increased in the last 12 years. When adjusted for inflation, the 1991 training budget of \$26.9 million is \$2 million less than the 1980 budget. Increasing total funding and increases in the maximum salary for individual investigators could make this program more effective. Earmarked funds could also be directed to Research Career Awards and Scientist Development Award for Clinicians programs, which are generally considered successful, although underfunded. Simply providing additional training funds is not the whole solution, or even the most efficient mechanism for dealing with the problem. For example, forgiveness of medical school debt would be a powerful incentive. Congress may, therefore, want to link increased funds to such programmatic issues.

ISSUE 2: Implications of Scientific Advances

Advances in biomedical research during the latter part of the 20th century have raised new and difficult ethical, legal, and social questions; research into the biology of mental disorders is no different. In this study, OTA considered issues raised both by the conduct of research and by new findings.

Issues of informed consent and confidentiality inevitably emerge during the conduct of mental disorders research. While these issues are neither new nor entirely unique to the study of mental disorders, there are special concerns deriving from the nature of mental illness, its impact on the mind, and the associated stigma. Furthermore, scientific advances may add a new twist to these issues. For example, the process of gathering clinical informa-

tion for genetic studies poses questions about what to tell relatives of individuals with mental disorders who are contacted for this research. Existing guidelines specify that an Institutional Review Board (IRB) review the medical, legal, and ethical aspects of proposed research projects that will involve human subjects.

The results of research into the biology of mental disorders also have ethical, legal, and social implications. For example, findings concerning the biology of mental disorders have become an issue in the mental health care financing debate. The development of new medication interfaces with ongoing concerns about the right to refuse treatment. Increased understanding of the genetics of mental disorders raises the specter of a new age of discrimination against individuals with mental disorders (box I-E). Advances in brain research challenge our very conceptualization of the human mind, affecting such issues as personal responsibility and free will. Researchers, clinicians, advocates, policymakers, ethicists, and lawyers have addressed some of the implications of research findings. However, NIMH pays little formal attention to the ethical, legal, and social implications of the results of the research they sponsor.

Option 1: Direct NIMH to formalize consideration of ethical, legal, and social issues.

Congress could stipulate that NIMH devise a systematic plan to deal with the ethical, legal, and social implications of both the conduct and the results of mental disorders research. By mandating such a program and providing funds for it, Congress would draw attention to these issues and create a process of anticipating the social impact of research results. The structure of a program devoted to such issues could take various forms. It could be modeled after the National Institutes of Health-Department of Energy program that considers such implications of the Human Genome Project: the Ethical, Legal, and Social Implications, or ELSI, program. Like the ELSI program, it might fund research into the likely implications and conduct of biological research into mental disorders. The NIMH program would foster the development of knowledge upon which consideration of these issues can be based and would increase the number of professionals with expertise in this area.

Such a program is not without potential problems. Forecasting the impact of scientific advances is

difficult. Also, without a specific focus and a specific charge, the program might be ineffectual. The ethical, legal, and social issues raised by research are complex and sometimes emotionally charged; they lie at the interface of scientific knowledge and social values and beliefs. Forming a consensus about these complex and sensitive issues is often hard, if not impossible. The resolution of these issues may be more properly dealt with, in a democratic society, by a political process such as in the U.S. Congress rather than an academic or bureaucratic one.

Option 2: Request topic-specific studies as issues arise.

Rather than erecting a bureaucratic structure to handle the ethical, legal, and social implications of research, Congress could request individual studies from various governmental or nongovernmental organizations. This strategy would permit timely identification of topics for consideration, and the issues and charges of the study could be clearly elucidated and circumscribed. While this mechanism would give Congress more direct control over individual studies and would serve to focus the studies, it could lead to a piecemeal approach that does not provide the continuity and comprehensiveness of a permanent program.

Option 3: Establish an advisory commission on the ethical, legal, and social implications of mental disorders research.

Individuals with various backgrounds and expertise who are not normally a formal part of the policymaking process have important insights into the ethical, legal, and social issues raised by mental disorders research. Furthermore, such persons have a stake in how the issues are addressed. In order to tap into the expertise and interests of these groups, Congress could establish an advisory commission to study and make recommendations on aspects of policy related to the implications of mental disorders research sponsored by the Federal Government. Such bodies, including the ongoing Advisory Panel on Alzheimer's Disease, have proven useful.

A successful panel would be composed of distinguished and expert representatives from biomedical research, the social sciences, the legal profession, care-providing professions, law enforcement, consumers, families, and relevant organizations and businesses. It is important that membership on the

Box 1-E—Eugenics and Mental Disorders

In Nazi Germany and the United States during the earlier part of this century, people with mental disorders were among the initial targets of eugenic policies. People with mental disorders were subjected to immigration restrictions, involuntary sterilization, and extermination. While moderns deny that such practices could be repeated, the record of eugenics and its historical link to mental disorders raise uncomfortable questions: Is the new age of genetics a harbinger of a new age of eugenics? Are people with mental disorders especially vulnerable?

Eugenics enjoys a long, well-bred intellectual pedigree, with the cousin of Charles Darwin, Sir Francis Galton, as its modern forefather. Galton coined the term “eugenics” in 1883, christening the scientific pursuit of improved inborn human qualities through judicious matings: positive eugenics. Prior to Galton, eugenic notions can be traced back as far as Plato’s *Republic*, wherein the philosopher also proposes positive eugenic practices. Of course, the human genetic pool can be distilled by other means. Negative eugenics refers to the systematic attempt to minimize the passing of deleterious genes by reducing or preventing the reproduction of individuals carrying such genes.

A number of scientific discoveries planted the seeds of eugenic policies in the 19th and 20th centuries. Galton himself observed that many accomplished men of his day were linked by blood lines, which led to his belief that proper matings could produce a race with enhanced intellectual, behavioral, and physical characteristics. In addition, Galton, as well as others, developed statistical techniques that permitted the quantitative analysis of inherited traits.

While these and other scientific advances were the seeds of eugenics, they were not solely responsible for such policies in the United States. Social, political, and economic factors of the late 19th and early 20th centuries fertilized the growth of the eugenics movement. National attention was increasingly focused on social issues of unemployment, criminality, prostitution, and chronic alcoholism. Also, concerns arose that increased immigration from southern and eastern Europe was drawing the United States away from its “Anglo-Saxon **superiority.**”

At the Federal level, eugenic policies took the form of increasingly restrictive immigration laws. Eugenicists, asserting the simple inheritance of such traits as lunacy, epilepsy, alcoholism, pauperism, criminality, and feeble-mindedness, proffered scientific rationales for excluding individuals from entry to the United States. It is important to note that while authentic advances in genetics seeded the eugenics movement, they provided no evidence for the simple inheritance of the traits mentioned above.

Eugenic considerations also prompted States to enact laws regarding compulsory sterilization. In 1907, Indiana passed the first law legalizing the compulsory sterilization of inmates at the State reformatory; by 1931, 30 States had passed compulsory sterilization laws applying to individuals categorized as feeble-minded, alcoholic, epileptic, sexually deviant, or mentally ill. Individuals with mental disorders made up half of the 64,000 persons in this country sterilized for eugenic reasons between 1907 and 1964. When eugenic sterilization laws were challenged in 1927, the Supreme Court ruled the practice was constitutional.

What is the current status of eugenic policies in the United States? While immigration laws still restrict the entry of people with mental disorders, denial of entry is not based on eugenic principles, but rather on concerns about whether behavior associated with a disorder poses a threat. State sterilization laws still stand, as does the 1927 Supreme Court ruling upholding them. As of 1987, compulsory sterilization laws remained on the books in 22 States; however, these laws are rarely invoked.

The current application of immigration and compulsory sterilization laws suggests that eugenics is not a major concern at this time. Furthermore, the understanding that mental disorders do not have a simple genetic basis and that nongenetic factors play an important role would seem to limit the potential of eugenic policies. Perhaps most important, Americans’ repulsion by the Nazi legacy and the emphasis in this country on individual reproductive rights also make State-determined eugenic policies unlikely. But indirect pressure not to have children may well come to bear on individuals seen to have a greater genetic risk of mental disorders; society may brand them irresponsible or immoral for transmitting disorders to their children. Given the financial strain posed by mental disorders today and the stigma attached to them, in conjunction with scientific advances, it is possible that these factors could unlock what some call a backdoor to eugenics.

SOURCES: T. Duster, *Backdoor to Eugenics* (New York, NY: **Routledge**, 1990); ILL. Carver and B. Garvex, “Eugenics: Past, Present, and Future,” *American Journal of Human Genetics* 49:1109-1118, 1991; I.I. Gottesman, *Schizophrenia Genesis: The Origins of Madness* (New York, NY: W.H. Freeman, 1991); D.J. Kevles, *In the Name of Eugenics* (New York, NY: Knopf, 1985); D. Suzuki and P. Knudtson, *Genethics: The Clash Between the New Genetics and Human Values* (Cambridge, MA: Harvard University Press, 1989); N.A. Holtzman, *Proceed with Caution: Predicting Genetic Risks in the Recombinant DNA Era* (Baltimore, MD: The Johns Hopkins University Press, 1989).

commission be balanced in terms of the points of view represented, something rarely achieved in mental health policy. This advisory commission could be established by the Secretary of Health and Human Services, or Congress itself, and could be assigned specific issues to address every year or two. The commission could then study the issue, identify the problems of concern, develop a consensus on how such problems can best be met, and present recommendations for legislation to the Congress and the States; the commission could also recommend executive branch regulations, activities, and other programs.

ISSUE 3: Dissemination of New Information

The Federal Government does not support research into the biology of mental disorders merely to gain new knowledge. Rather, Federal funds for this research reflect in large measure a desire for improved medications as well as for improved public perceptions of mental disorders and of individuals with these disorders.

The enthusiasm for and considerable gains in information about the brain and mental disorders that have accrued during the last several years speak to the potential gains in treatment and social handling of persons with mental disorders. However, to effect better treatment, care, and consideration of such individuals, the knowledge gained from biological research must be transferred to the public at large, including individuals with mental disorders and their families, as well as mental health professionals and policymakers.

There are many indications that the transfer of new knowledge to those who need and can act upon it is inadequate. Studies show that providers of mental health care are sometimes inadequately informed about the diagnosis and treatment of mental disorders or that they harbor some negative feelings about their patients. As noted earlier, the public at large commonly holds negative attitudes toward people with mental disorders or are ignorant about the prevalence, manifestation, or cause of these disorders. Such ignorance and attitudes have adverse consequences beyond stigmatizing people with mental disorders and their families. They also interfere with successful treatment: Individuals with



Photo 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.

a mental disorder may avoid seeking treatment in order to avoid the associated stigma. Perhaps of most importance to Congress is the fact that uninformed and negative attitudes contribute to discriminatory public policies. A recent report by the Interagency Task Force on Hopelessness and Severe Mental Illness highlights the malignant consequences of negative attitudes on public policy:

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.

One conclusion that OTA draws from this analysis is that advances in knowledge about mental disorders do not in themselves ensure better diagnosis, care, or prevention; nor do they guarantee that public policy keeps abreast of research and development. Those improvements and informed policy also depend on the dissemination of accurate information about mental disorders.

The current excitement about brain research, already recognized by Congress' declaration of the 1990s as the Decade of the Brain, can provide both an impetus to and a focus for information dissemination efforts, which began in 1983. That year and every year since, Congress has passed legislation that designates one week as Mental Illness Awareness Week.* More recently, several members of the

* The first legislation, in 1983, authorized a National Mental Health Week. All subsequent resolutions fell under the designation of Mental Illness Awareness Week.

House of Representatives, who formed a working group on mental illness, see as one of their first tasks the education of the “Congress and the American people about the *causes* of mental illness and about *new breakthroughs* in research and treatment modalities, and to eliminate the *ignorance and stigma* surrounding mental illness” (emphasis added).

OTA identifies several options for congressional action to improve the publics’, providers’, and policymakers’ understanding of mental disorders. These options are not mutually exclusive; in fact, a combination of them may best serve the ultimate goal of facilitating the transfer of accurate information to the various parties who affect mental health care and policy.

These options focus on Federal programs, but they can also influence other dissemination activities. OTA knows full well that there are many other sources of information about mental disorders. The media, which often provide a skewed or inaccurate view of mental disorders, are far and away the public’s primary source of information about mental disorders (see box 1-D). Furthermore, virtually every major national mental health organization and organizations promoting research (e.g., the National Institute for Brain Research, the Society for Neuroscience) direct educational materials toward the public. All of these activities may benefit from improvements in Federal programs that pay attention to recent advances in research and the promise of more to come.

Option 1: Build upon existing and planned educational efforts on mental disorders supported by the Federal Government.

The primary Federal source of information on mental disorders is NIMH. While NIMH has supported an assortment of educational activities, the centerpiece of its educational effort is the DEPRESSION Awareness, Recognition and Treatment (D/ART) campaign, which was launched in 1986 (box 1-F). Only last year, NIMH announced a new and similar program on panic disorder.

Congress can build upon existing and planned Federal activities, namely the D/ART program, the panic disorder campaign, and the recommendations of the Interagency Task Force on Hopelessness and Severe Mental Illness, to capitalize upon the strengths of programs already in place. For example, the use of multimedia presentations, the collabora-

tion with various private organizations, and the targeting of specific audiences (e.g., care providers) are all strong points of the D/ART program that could form a solid foundation for future educational efforts.

Expanding congressional support for ongoing Federal educational activities could take several forms. At the most basic level, Congress could augment the modest funding for these programs (\$8.5 million for D/ART since 1986, or less than \$2 million annually). Additional funds could ensure the expansion of existing programs and the full implementation of planned ones. Of particular importance to a successful public education campaign are evaluations of “outcomes.” There has been less than adequate evaluation of the D/ART program’s effectiveness, due at least in part to the expense of such research.

Money is not the only issue. To date, the entire D/ART program has been managed by only one and one-half full-time professional staff persons. Thus, Congress could urge NIMH to give a higher priority to educational activities in order to maximize the effectiveness of such programs.

Without establishing any new functions, Congress could direct NIMH to centralize all educational campaigns within a single office, thus improving the efficiency of the programs. At present, the panic disorder campaign, for example, will be administered separately from the D/ART program, even though both have similar goals and objectives: increased recognition and treatment of a disorder.

Option 2: Target educational activities at secondary schools.

Currently, students in junior high school and high school learn little, if anything, about mental disorders, despite the fact that adolescents are especially interested in the topics of health and human behavior. The Department of Education recognizes the importance of such instructional opportunities and includes some mental health information as part of the health curriculum. That information targets mental health in the context of family violence, rape, other emotional crises, the prevention of drug abuse, stress management, and assertiveness training rather than specific mental illnesses. Congress could direct the Department of Education, alone or in conjunction with NIMH, to initiate a grants program to develop model supplemental curricula on advances

Box I-F—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 1-5). 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 1-5) 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 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 1-5-DEPRESSION Awareness, Recognition, and Treatment Program, Fiscal Years 1986-91

Area	(\$ thousands)						Total
	FY 86	FY 87	FY 88	FY 89	FY90	FY 91	FY 86-91
Training	142	520	646	824	1,146	1,250	4,528 (53%)
Public education	292	924	447	745	616	631	3,655 (43%)
Worksite	N/A	N/A	50	50	100	100	300 (4%)
Total	434	1,444	1,143	1,619	1,862	1,981	8,483

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 communication, 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, Bismarck 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).

in neuroscience and mental disorders. Outstanding materials, capturing the excitement and complexity of a scientific area, have been developed on other topics, including a recent supplement on the genome project and the ethical issues it poses.

It is important to note that model supplemental curricula do have some limitations. While they can be distributed to school districts nationwide, the law prohibits mandating the use of such materials. Also, supplemental materials may not be the most fruitful approach, given the need for comprehensive curriculum development in science education and the large number of competing supplements now available in the sciences and in health education.

Option 3: Direct the Federal Government to play a role in coordinating the training and level of knowledge of persons caring for individuals with mental disorders.

Optimal care for individuals with mental disorders relies on providers having accurate, up-to-date information. Yet, providers face a widening pool of knowledge from basic, clinical, and rehabilitative research. Furthermore, the extent to which this information is included in academic and training programs remains a matter of institutional choice. This report did not evaluate in detail the extent of provider knowledge about mental disorders; however, it did note research evidence that some providers have less than adequate knowledge about diagnosing and treating these conditions. As a first step toward ensuring that providers receive current and accurate information about mental disorders, Congress could commission a study on the level of knowledge of providers and the way in which these professionals are trained and licensed. Furthermore, Congress could request that such a study devise mechanisms for improving the transfer of knowledge to providers.

Option 4: Formalize a mechanism for improving information transfer and communication among Federal agencies concerned with mental disorders.

One goal of giving the public information about mental disorders is to make it easier to develop public policies that will help people with these conditions. While such efforts can be important in shaping the political will needed to bring about successful policy initiatives, public education is unlikely to solve many of the problems people with

mental disorders face, at least in the near term. Indeed, the mechanisms by which Federal policies on mental disorders are formed and implemented erect barriers to a rational problem-solving process. No single agency is primarily responsible for the issues that affect people with mental disorders; rather, it is scattered among various agencies, including several offices and institutes within the Departments of Health and Human Services (NIMH, Health Care Financing Administration, and others), Veterans Affairs, Justice, Labor, Education, Housing and Urban Development, and others. While NIMH has sometimes offered Federal leadership on policy issues related to mental disorders, there is clearly a need for better dissemination of new research findings, better communication about areas needing research, and better coordination of policy planning. This need is likely to become more acute with the reorganization of the Alcohol, Drug Abuse, and Mental Health Administration and separation of NIMH and the newly formed services agency, SAMHSA, Substance Abuse and Mental Health Services Administration.

NIMH, recognizing the need for information transfer, has set out to develop methods and a system by which knowledge exchange can proceed. Congress could build upon these plans and ensure the involvement of high-level officials in other Federal agencies and institutions, so as to create a mechanism for the exchange of information and development of policies and programs, by creating an Interagency Task Force or Council on Mental Disorders that would include representatives from all relevant agencies in the Federal Government. It could be directed to coordinate research and policy issues concerning mental disorders and to establish a mechanism for sharing information among all officers and employees of the departments carrying out programs that concern people with mental disorders.

Some mechanism for facilitating talk among Federal agencies is needed, given that no single agency has the jurisdiction or expertise to address thoroughly the issues associated with mental disorders. The composition of the task force is the single most important key to its success. Representatives from every relevant agency should be included. In addition, task force members should have adequate experience, expertise, and authority to devise and help implement policies and programs. The chair of the task force is also important; ideally, this person

would bring personal dedication and sufficient authority to help drive the group's efforts. A clear charge is necessary to focus the work of the group. Congress could specify topics for study every year or two and request that a report be made at the end of that time. The report would elucidate the topic and provide for policy initiatives.

One topic could be consideration of the financing of mental health care. Research advances, whether the development of new treatments or changing conceptualizations of the causes of mental disorders,

clearly have influenced and will continue to influence the issue of mental health care financing. A study involving NIMH and other agencies in the Federal Government with expertise in and jurisdiction over the financing of health care and the provision of services could review the relevant factors and issues and develop a cohesive Federal policy. A final point should be made: Even in the event of a successful effort on the part of the task force, certain policy and program suggestions may be forestalled until adequate funds are provided.