A Federal Failure in Psychiatric Research:

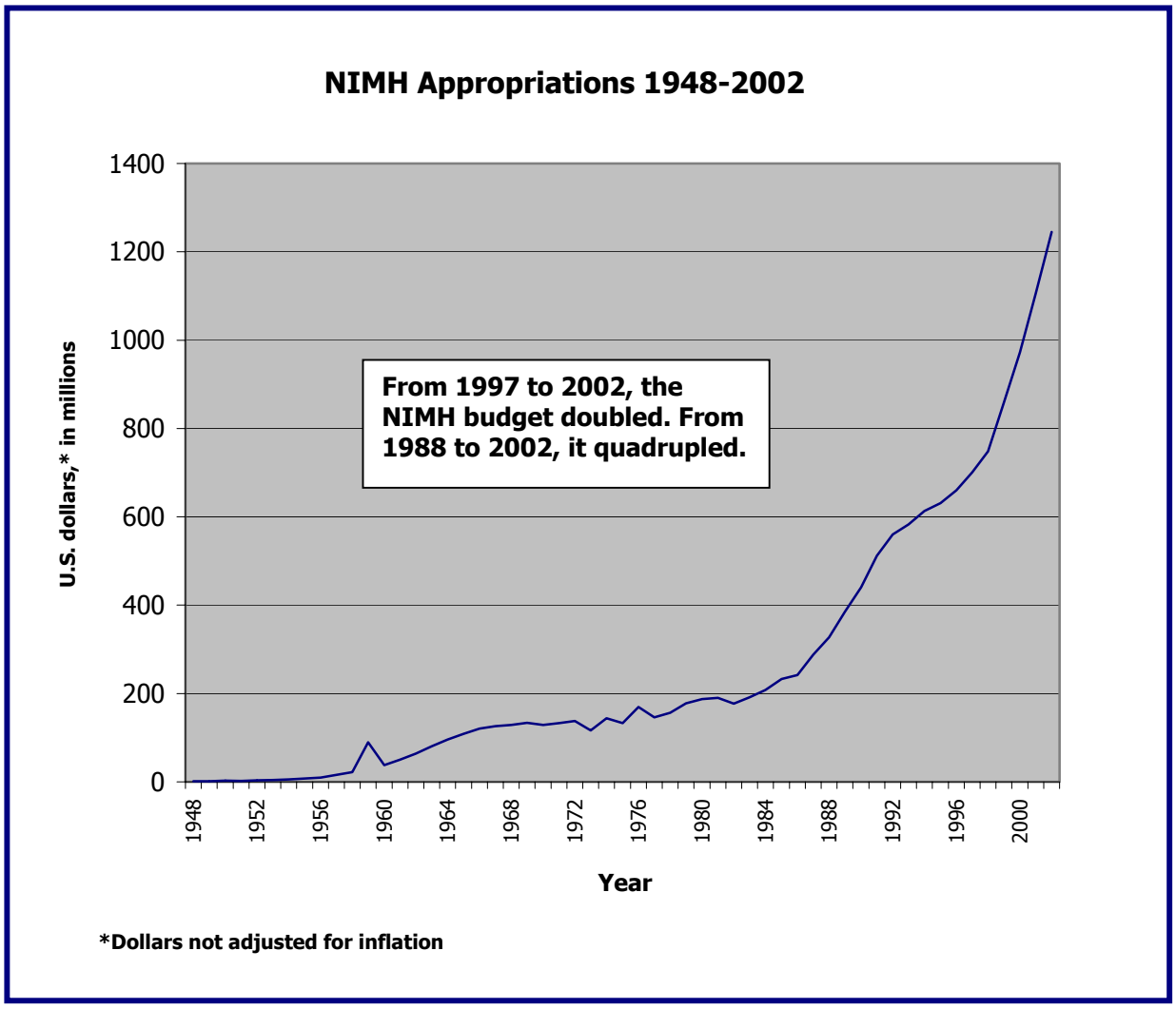
Continuing NIMH Negligence in Funding

Sufficient Research on Serious Mental Illnesses

E. Fuller Torrey, M.D., Treatment Advocacy Center, Arlington, Va.
Mary T. Zdanowicz, J.D., Treatment Advocacy Center, Arlington, Va.
Sidney M. Wolfe, M.D., Public Citizen Health Research Group, Washington, D.C.
Peter G. Lurie, M.D., M.P.H., Public Citizen Health Research Group, Washington, D.C.
Irving I. Gottesman, Ph.D., Departments of Psychiatry
and Psychology, University of Minnesota
John M. Davis, M.D., Department of Psychiatry, University of Illinois

November 19, 2003

Copies of this report may be downloaded from the websites of the Treatment Advocacy Center, www.psychlaws.org, and Public Citizen Health Research Group, www.citizen.org/hrg.



Acknowledgments

We are grateful to Dr. Barbara Zain for her analysis of the basic neuroscience awards. Jonathan Stanley, Alicia Aebersold, and D.J. Jaffe, among others, contributed useful suggestions. We also thank the anonymous researchers who contributed their unfunded NIMH research grant applications for inclusion in our study.

Contents

Executive Summary 4

Introduction 6

I. The Magnitude of the Problem of Serious Mental Illnesses 6

II. NIMH's Research Portfolio: Results of the 2002 Survey

A. Allocation of NIMH Research Awards to Serious Mental Illnesses, 1997 and 2002 11

B. Number of Clinically Relevant Research Awards to Serious Mental Illnesses, 1997 and 2002 12

C. Intramural Research Program, 1997 and 2002 13

D. Research Expenditures by Disease: Serious Mental Illnesses Compared to Other Diseases 13

E. Identification of Rejected Research Proposals, 1997 to 2002 15

F. Identification of NIMH-Funded Research Proposals That Could Have Been Assigned to the National Science Foundation (NSF) 16

III. NIMH's Awareness of Its Problem and Attempts To Correct It 19

IV. Why Does NIMH Do So Little Research on Serious Mental Illnesses? 21

V. A Five-Year Report Card: What Were the Effects of Doubling NIMH's Budget? 27

VI. Recommendations 29

Table 1. Number of NIMH Research Awards Related to Serious Mental Illnesses, 1997 and 2002 12

Table 2. Number of NIMH Research Awards That Were Clinically Relevant to Serious Mental Illnesses, 1997 and 2002 12

Table 3. NIH Research Expenditure By Disease, 1999 14

Appendix A: A Comparison of Selected NIMH Research Proposals, Unfunded and Funded, 1997 to 2002 30

Appendix B: Methods 39

Appendix C: How To Access Information on NIMH-Funded Research Awards 41

NIMH Research Vignettes

- NIMH and Sleep 18
- NIMH Is Doing the Work of the National Cancer Institute 26
- NIMH and Romance 37
- NIMH and Human Behavior 38
- Long-Term Funding 42
- Happiness Is Getting an NIMH Research Grant To Study Happiness 43
- NIMH and Birds 44

Executive Summary

The National Institute of Mental Health (NIMH) has primary responsibility for funding research on serious mental illnesses, defined as schizophrenia, bipolar disorder, autism, and severe forms of depression, panic disorder, and obsessive-compulsive disorder. This report is the third evaluation of NIMH's performance in this task. It covers the period 1997 to 2002, during which time NIMH's budget doubled from $661 million to $1.3 billion.

I. The Problem

- There are approximately 11.6 million adults in the United States who have a serious mental illness in a one-year period. Of these, 5.6 million have a severe and persistent form of mental illness.
- Individuals with a serious mental illness make up one-third of the homeless population and 5 to 7 percent of the jail and prison population. At any given time, there are approximately one-quarter of a million seriously mentally ill people who are homeless or incarcerated.
- Individuals with a serious mental illness account for 58 percent of total direct costs for all mental illnesses. This amount includes over 40 billion federal dollars spent under Medicaid, Medicare, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI) and is a major reason for the rapid increase in costs of these programs.

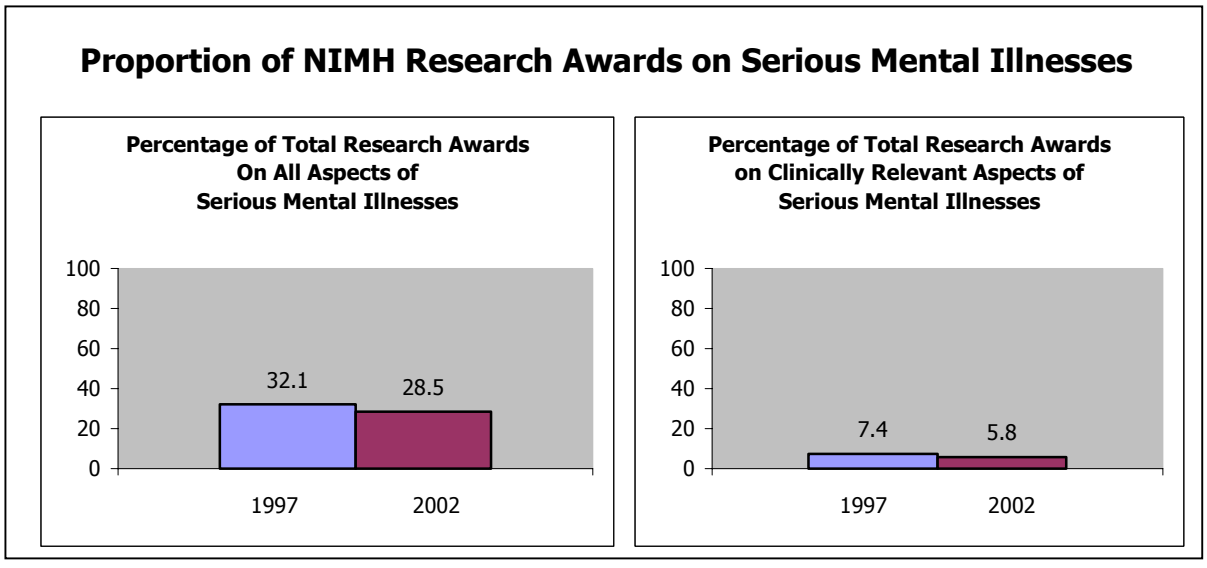
II. NIMH's Response to the Problem

- In 2002, 28.5 percent of NIMH awards went to research on serious mental illnesses. These illnesses account for 58 percent of the total costs of all mental illnesses.
- Only 5.8 percent of all NIMH awards went to clinically relevant research on serious mental illnesses. "Clinically relevant" means reasonably likely to improve the treatment and quality of life for individuals presently affected.
- Between 1997 and 2002, the proportion of NIMH research awards for all aspects of serious mental illnesses decreased by 11 percent (from 32.1 to 28.5 percent). For clinically relevant aspects of serious mental illnesses, it decreased by 22 percent (from 7.4 to 5.8 percent).
- During those same years, NIMH rejected for funding many reasonable research proposals on serious mental illnesses and funded much research that had no relationship to any mental illness. For example, NIMH rejected funding for a treatment trial for schizophrenia but funded research on how people think in Papua New Guinea; rejected funding for research on bipolar disorder in children but funded research on self-esteem in college students; and rejected funding for research on the causes of postpartum depression but funded research on the hearing mechanism of crickets, as detailed in Appendix A.

- NIMH's failure to fund sufficient research on serious mental illnesses is the main reason why research on these illnesses is so grossly underfunded compared to other diseases. For example, per person affected, for every $1 NIMH spent in 1999 for research on bipolar disorder, NIH spent over $12 for research on cervical cancer. For every $1 NIMH spent for research on depression, NIH spent almost $15 for research on multiple sclerosis. For every $1 NIMH spent for research on schizophrenia, NIH spent $30 on research for HIV/AIDS.
- Research on serious mental disorders is not an important part of the NIMH research portfolio.
- During the five-year period of doubling of the NIMH budget, a period that could have been used by NIMH to correct its traditional neglect of research on serious mental illnesses, the proportion of NIMH research awards allocated to serious mental illnesses actually decreased, rather than staying the same or increasing.

III. The Solution

- Congress should hold hearings to establish a minimum percentage of the NIMH budget that must be spent for research on serious mental illnesses.
- NIMH should be required to report to Congress annually how much it is spending on each serious mental illness.
- The Government Accounting Office should evaluate the NIMH research portfolio vis-à-vis the discrepancy between the allocation of NIMH resources and the public's needs.
- Behavioral research on diseases is important, and all NIH institutes are supposed to fund behavioral research on diseases for which they have primary responsibility. NIMH should therefore support behavioral research for psychiatric disorders but not for other diseases.
- Basic neuroscience research is also important. However, allocation of responsibility for such research needs to be better coordinated between the National Science Foundation (NSF) and various NIH institutes, including NIMH.



Introduction

In 1999, the National Alliance for the Mentally Ill (NAMI) and the NAMI Research Institute published *A Mission Forgotten: The Failure of the National Institute of Mental Health To Do Sufficient Research on Severe Mental Illness.*[1] It reported that only 33.2 percent of NIMH's 1997 research awards had any relevance for serious mental disorders and only 7.8 percent were directed to clinical and treatment aspects of these disorders. The report recommended that serious mental illnesses "should receive at least two-thirds of NIMH's research resources in any given year" and that "all new funds received from Congress should be invested in these diseases until a more equitable balance is achieved."

In 2000, the Treatment Advocacy Center issued a follow-up report, *Missions Impossible: The Ongoing Failure of NIMH To Support Sufficient Research on Severe Mental Disorders.*[2] It examined newly funded NIMH research awards in 1999 and concluded that, compared to 1997, "no improvement is seen in the percentage of those related to severe mental disorders."

The present report, the third in an ongoing effort to monitor NIMH research, analyzes NIMH research awards for FY2002. During the five-year interval between our initial report, for FY1997, and the present report, the budget of NIMH doubled, from $661 million in 1997 to $1.3 billion in 2002. This was a very positive step, supported by Senator Pete Domenici, the late Senator Paul Wellstone, and many other members of Congress, that theoretically made it possible for NIMH to improve its research portfolio. What effect has the doubling of NIMH's budget had on its research support for serious mental disorders? This report is essentially a report card on NIMH's research efforts over the last five years.

I. The Magnitude of the Problem of Serious Mental Illnesses

In 1992, in response to a congressional mandate, the National Advisory Mental Health Council defined "severe mental disorders" as including schizophrenia, bipolar disorder (manic-depressive illness), autism, and severe forms of depression, obsessive-compulsive disorder, and panic disorder.[3] This section will briefly summarize what is known about these mental disorders in terms of numbers of persons affected, costs, and humanitarian aspects.

---

[1] Torrey EF, Knable MB, Davis JM, Gottesman II, Flynn LM. *A Mission Forgotten: The Failure of the National Institute of Mental Health To Do Sufficient Research on Severe Mental Illnesses* (Arlington, Va.: National Alliance for the Mentally Ill, December 1999).

[2] Torrey EF, Gottesman II, Davis JM, Knable MB, Zdanowicz MT. *Missions Impossible: The Ongoing Failure of NIMH To Support Sufficient Research on Severe Mental Disorders* (Arlington, Va.: Treatment Advocacy Center, September 2000).

[3] Health Care Reform for Americans with Severe Mental Illnesses: Report of the National Advisory Mental Health Council, *American Journal of Psychiatry* 1993;150:1447–1465.

A. Numbers of Affected Persons

In 1999, the Surgeon General's Report on Mental Health reported that "a subpopulation of 5.4 percent of adults is considered to have a 'serious' mental illness (SMI)" and "about half of those with SMI (or 2.6 percent of all adults) were identified as being even more seriously affected, that is, by having 'severe and persistent' mental illness (SPMI)." The report further specified that SPMI "includes schizophrenia, bipolar disorder, other severe forms of depression, panic disorder, and obsessive-compulsive disorder." The report also said that "approximately 5 to 9 percent of children ages 9 to 17" have a "serious emotional disturbance (SED)."[4]

The 2003 adult population (18 and over) of the United States is approximately 214 million people. Thus, in this country, there are approximately 11.6 million adults with serious mental illnesses, of which 5.6 million have the most severe and disabling forms.

B. Costs

The President's Commission on Mental Health, in its July 2003 report, estimated that in 1997, the latest year for which comparable data were available, the United States spent "almost $71 billion on treating [all] mental illnesses."[5] These cost estimates include only direct costs for psychiatric services, such as hospitals, psychiatrists, and medications. Mental illnesses also have indirect costs, such as lost productivity of patients and their caretakers and premature deaths. NIMH studies have estimated that the indirect costs of mental illnesses are even greater than the direct costs and were estimated to be $79 billion in 1990.[6]

It was estimated in 1961 that the total direct costs of mental illnesses in the United States were "nearly $1 billion a year."[7] In constant dollars, and corrected for the intervening increase in population, the $1 billion in 1961 would today be worth $8 billion. However, we are spending $71 billion for treatment, which means that, in constant dollars, the costs of mental illnesses have increased almost ninefold in less than 40 years.

What percentage of the total cost of all mental illnesses is attributable to the most severe forms of these disorders? An NIMH study, based on 1992 and 1995 data, reported that "severe and persistent mental illness accounts for … 58 percent of total costs," including "70 percent of medical expenditures, 99 percent of premature mortality, and all of the costs of institutionalization, homelessness, and [for mentally ill

---

[4] U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General* (Rockville, Md.: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, December 1999), p. 46.

[5] The President's New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832 (Rockville, Md., 2003), p. 3.

[6] *Mental Health: A Report of the Surgeon General*, p. 411.

[7] Joint Commission on Mental Illness and Health. *Action for Mental Health* (New York: John Wiley, 1961), p. 4.

individuals] social welfare benefits."[8] The cost of severe and persistent mental illnesses in 1997 was thus $41.2 billion (58 percent of $71 billion). The NIMH study also calculated that the cost of treating severe and persistent mental illness was $19,990 per year per person, compared to $1,700 per year per person with a diagnosis of a less serious mental illness.[9]

The increasing costs of mental illnesses have been borne predominantly at the federal level, specifically by federal Medicaid, Medicare, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI).

> Medicaid: From 1987 to 1997, Medicaid expenditures for mental illnesses almost tripled from $5.7 to $14.4 billion.[10] As noted in the President's Commission report, "Medicaid is now the largest payer of mental health services in the country."
>
> Medicare: From 1987 to 1997, Medicare expenditures for mental illnesses tripled, from $3.0 to $9.1 billion.[11]
>
> SSI: From 1986 to 1998, the percentage of SSI payments that went to the diagnostic group "mental disorders not including mental retardation" increased from 22.6 percent to 31.4 percent. This is the single largest diagnostic group for SSI payments. In dollars, the increase was from $1.5 billion to $7.4 billion.[12]
>
> SSDI: From 1986 to 1998, the percentage of SSDI payments that went to the diagnostic group "mental disorders not including mental retardation" increased from 20.1 percent to 26.6 percent. This is the single largest diagnostic group for SSDI payments. In dollars, the increase was from $3.1 billion to $11.0 billion.[13]

Therefore, total federal dollars allocated to treating and supporting individuals with mental illnesses was $23.5 billion for federal Medicaid and Medicare in 1997 and $18.4 billion for SSI and SSDI in 1998, for a total of $41.9 billion. The President's Commission report, using more recent unpublished data, estimated the total federal spending to be $45 billion.[14] It should also be noted the increase in federal dollars for these programs between 1986–87 and 1997–98 was $2.6 billion per year, making these programs almost certainly one of the most rapidly growing programs in the federal budget.

---

[8] Harwood H et al. *The Economic Cost of Mental Illness* (Rockville, Md.: National Institute of Mental Health, July 2000), pp. 1–2.

[9] Ibid.

[10] Mark TL, Coffey RM, King E, Harwood H, McKusick D, Genuardi J, Dilonardo J, Buck JA. Spending on mental health and substance abuse treatment, 1987–1997, *Health Affairs* 2000;19:108–120.

[11] Ibid.

[12] SSI and SSDI data are taken from the Social Security Administration's *Annual Statistical Supplements to the Social Security Bulletin* (Washington, D.C.: Government Printing Office, 1987, 1998, 2002).

[13] Ibid.

[14] The President's New Freedom Commission on Mental Illness, op cit., p. 28.

C. Humanitarian Considerations

Many individuals with serious mental disorders lead extremely difficult lives, and this often profoundly affects their families as well. Homelessness, incarceration, victimization, and acts of violence are common experiences for individuals with these illnesses.

Studies have reported that approximately one-third of all homeless individuals have a severe and persistent mental illness.[15] The total number of homeless individuals in the United States has been estimated to be approximately 400,000.[16] This suggests that at any given time, there are approximately 130,000 seriously mentally ill individuals who are homeless. A study of patients discharged from a Massachusetts state psychiatric hospital reported that 27 percent of them became homeless within six months.[17] Life for such individuals is very hard; one study, for example, reported that 28 percent of all homeless mentally ill individuals use garbage cans as "their primary food source."[18]

A study of jail inmates in the United States reported that 7.2 percent suffer from a serious mental illness.[19] Studies of prison inmates in three states reported that 5.4 percent (range 4.3% to 6.3%) had ever received a diagnosis of schizophrenia or bipolar disorder.[20] Other studies have reported a higher proportion of jail and prison inmates as being mentally ill, but such studies have defined mental illness more broadly. In 2002, local jails held 665,475 inmates, while state and federal prisons held 1,367,856 inmates.[21] This suggests that there are approximately 120,000 seriously mentally ill individuals in the nation's jails and prisons. The Los Angeles County Jail is, *de facto,* the largest mental institution in the nation. Life for seriously mentally ill prisoners is especially hard and includes victimization and suicide.

Since there are approximately 130,000 seriously mentally ill individuals who are homeless, and an additional 120,000 who are incarcerated in the nation's jails and prisons at any give time, their total is approximately 250,000 individuals—a quarter of a million people.

Victimization is also a common experience for many individuals with serious mental illnesses who live in the community. A Los Angeles study of such individuals living in board-and-care homes found that one-third of them "reported being robbed and/or assaulted during the preceding year."[22] Multiple studies suggest that at least one-third

---

[15] *Psychiatry and Homeless Mentally Ill Persons. Report on the Task Force of the Homeless Mentally Ill.* (Washington, D.C.: American Psychiatric Association, 1990).

[16] Jencks C. *The Homeless* (Cambridge: Harvard University Press, 1994), p. 16.

[17] Drake RE, Wallach MA, Hoffman JS. Housing instability and homelessness among aftercare patients in an urban state hospital, *Hospital and Community Psychiatry* 1989;40:46–51.

[18] Gelberg L, Linn LS. Social and physical health of homeless adults previously treated for mental health problems, *Hospital and Community Psychiatry* 1988;39:510–516.

[19] Torrey EF, Stieber J, Ezekiel J et al. *Criminalizing the Seriously Mentally Ill.* A report of the National Alliance for the Mentally Ill and Public Citizen's Health Research Group, 1992, p. 13.

[20] Diamond PM, Wang EW, Holzer CE et al. The prevalence of mental illness in prison. *Administration and Policy in Mental Health* 2001;29:21–40.

[21] Bureau of Justice Statistics, U.S. Department of Justice, *www.ojp.usdog.gov/bjs/correct.htm.*

[22] Lehman AF, Linn LS. Crimes against discharged mental patients in board-and-care homes, *American Journal of Psychiatry* 1984;141:271–274.

of seriously mentally ill women, especially those who are sometimes homeless, have been raped.[23]

Studies suggest that individuals with severe mental illnesses who are being treated are not more dangerous than the general population.[24] However, when they are not being treated, individuals with serious mental illnesses commit a disproportionate number of acts of violence, including homicides. For example, a 1990 study of NAMI members reported that 11 percent of seriously mentally ill individuals had physically harmed another person in the previous year.[25] A 2002 study of 802 adults with serious mental illnesses reported that 14 percent had been violent in the previous year (physical fighting, assaults, use of lethal weapons, or sexual assault).[26]

When serious mental illness is accompanied by substance abuse, acts of violence increase sharply. An NIMH study reported that individuals with serious mental illnesses without substance abuse are "responsible for no more than about 3 percent of violent crime," including homicides. However, individuals with serious mental illnesses and substance abuse were said to be responsible for "three to five times as much violence" as those with serious mental illness alone.[27]

As measured by numbers, costs, or humanitarian considerations, the problem of serious mental illnesses is immense. It is reasonable to expect a correspondingly immense NIMH response to the problem.

---

[23] Goodman LA, Dutton MA, Harris M. Episodically homeless women with serious mental illness: prevalence of physical and sexual assault, *American Journal of Orthopsychiatry* 1995;65:468–478.

[24] Torrey EF. *Out of the Shadows: Confronting America's Mental Illness Crisis* (New York: John Wiley and Sons, 1997), pp. 43–60.

[25] Steinwachs DM, Kasper JD, Skinner EA. *Family Perspectives on Meeting the Needs for Care of Severely Mentally Ill Relatives: A National Survey.* (Arlington, Va.: National Alliance for the Mentally Ill, 1992).

[26] Swanson JW, Swartz MS, Essock SM et al. The social-environmental context of violent behavior in persons treated for severe mental illness. *American Journal of Public Health* 2002;92:1523–1531.

[27] Harwood H et al., *The Economic Cost of Mental Illness,* pp. 1–5.

II. NIMH Research Portfolio: Results of the 2002 Survey

From June to September 2003, we carried out a detailed study of the NIMH research portfolio for 2002. We then compared the results with a previous study we had carried out on the NIMH research portfolio for 1997. During the intervening five-year period, the NIMH budget doubled in size.

A. Allocation of NIMH Research Awards to Serious Mental Illnesses, 1997 and 2002

For 2002, all NIMH-funded research awards were assessed, including extramural and intramural grants, contracts, fellowships, and training awards. They were assessed by reviewing the publicly available abstracts on the NIH CRISP Internet website, as explained in the Methods section (Appendices B and C). All awards were graded by the senior author. Relevance to a serious mental illness was interpreted liberally; for example, all basic neuroscience research awards on neurotransmitters or on the cell signal transduction system were considered to be relevant. The majority of these awards were for basic neuroscience research that may lead to important advances in understanding causes or better treatments for these disorders sometime in the future but are unlikely to improve the treatment or quality of life of individuals presently affected.

The results are presented in Table 1. They show that 28.5 percent of NIMH's 2002 research awards (1,187/4,157) had some relationship to a serious mental illness. In order to compare the results of the 2002 research portfolio with the 1997 portfolio, additional 1997 awards were analyzed, as explained in Appendix B. This made the data in the two studies similar. In 1997, 32.1 percent of NIMH's 1997 research awards (832/2,593) had some relationship to serious mental illness. Thus, although there has been an absolute increase in the total number of research awards related to serious mental illnesses during the 1997–2002 period, the proportion of such awards decreased by 11 percent (32.1 percent to 28.5 percent).

NIMH itself, apparently concerned about its allocation of resources to serious mental illnesses, recently carried out a similar survey. In contrast to our survey, which assessed numbers of research awards for all extramural and intramural research programs, the NIMH survey assessed total dollar allocations for these same programs. The NIMH survey was completed in early 2003; we requested a copy of it on May 22, 2003, under the Freedom of Information Act, but to date NIMH has refused to release it.

However, NIMH presented some of the findings of its study at a scientific meeting in May 2003.[28] According to its own survey, the percentage of 2002 NIMH research funds allocated to research related to schizophrenia and "mood disorders and suicide" (which would include bipolar disorder and depression) was 27.3 percent.[29] This is

[28] Insel T. Overview of NIMH Research. Presented at the annual meeting of the Society for Biological Psychiatry, San Francisco, Calif., May 15, 2003.

[29] NIMH presented the results of its own assessment as percentages of all non-AIDS research awards. AIDS research is an integral part of NIMH, totaling $128.3 million in 2002. The effect of presenting their results in this manner would have been to artificially inflate the percentage of funds that appear to be going to other research efforts. Therefore, we corrected the NIMH percentages by adding back in the AIDS research funds. The NIMH non-AIDS schizophrenia percentage went from 12.4 to 11.0 percent when corrected for the

consistent with our finding of 26.3 percent of research awards allocated to schizophrenia, bipolar disorder, and depression.

Table 1. Number of NIMH Research Awards Related to Serious Mental Illnesses, 1997 and 2002

	1997 awards related to the disease (2,593 awards assessed)		2002 awards related to the disease (4,157 awards assessed)	
	number	percent	number	percent
schizophrenia	311	12.0	495	11.9
bipolar disorder	86	3.3	136	3.3
depression	341	13.2	462	11.1
panic disorder	60	2.3	57	0.9
obsessive-compulsive disorder	34	1.3	37	1.3
Total	832	32.1	1,187	28.5

B. Number of Clinically Relevant Research Awards to Serious Mental Illnesses, 1997 and 2002

In addition to assessing the number of NIMH research awards that were related to serious mental illnesses, we also assessed the number that were clinically relevant, i.e., reasonably likely to improve the treatment and quality of life for individuals presently affected with these disorders. As detailed under Methods (Appendix B), clinically relevant awards include those related to treatments, detection of cases, medical care, medication compliance, rehabilitation, quality of life, and family support.

The 1,187 research awards related to serious mental illnesses were assessed for clinical relevance. As shown in Table 2, 242 awards, 5.8 percent of the total, were judged to be clinically relevant. Thus, only 1 out of every 17 NIMH 2002 research awards is reasonably likely to improve the treatment and quality of life for individuals presently affected by a serious mental illness.

Table 2. Number of NIMH Research Awards That Were Clinically Relevant to Serious Mental Illnesses, 1997 and 2002

	1997 clinically relevant awards		2002 clinically relevant awards	
	number	percent	number	percent
schizophrenia	43	1.7	63	1.5
bipolar disorder	23	0.9	29	0.7
depression	100	3.8	121	2.9
panic disorder	13	0.5	14	0.3
obsessive-compulsive disorder	13	0.5	15	0.4
Total	192	7.4	242	5.8

AIDS budget. The mood disorders and suicide number went from 18.4 to 16.3 percent when similarly corrected.

The 2002 clinically relevant awards were compared to those from the 1997 study. As shown in Table 2, the percentage of clinically relevant awards for serious mental illnesses decreased by 22 percent, from 7.4 to 5.8 percent, between 1997 and 2002, with the decrease being most prominent for research on depression.

C. Intramural Research Program, 1997 and 2002

The NIMH Intramural Research Program (IRP) manages the research carried out on the NIH campus; its funding is approximately 10 percent of the total NIMH budget. In 1997, an IRP planning committee recommended major changes to the program, including phasing out some programs and starting new ones. Thus, during the 1997 to 2002 period, there was a substantial turnover of staff and implementation of new research programs.

In 1997, the IRP had 155 active research projects; in 2002, this number had decreased to 101, reflecting the changes taking place. We assessed the abstracts of the 1997 and 2002 existing research protocols to determine how many were related to serious mental illnesses. In 1997, 35 percent (54/155) of the protocols focused on some aspect of serious mental illnesses. In 2002, this had decreased to 30 percent (30/101). A major reason for this reduction was the closing in 1998 of the NIMH Neuropsychiatric Research Hospital on the grounds of St. Elizabeths Hospital in Washington, D.C. The reduction was also caused by the impact of the death or retirement of IRP researchers who had been active on research projects related to serious mental illnesses. The greatest impact of IRP reduction in research relevant to serious mental illnesses was on schizophrenia research, which decreased from 24 projects in 1997 to 12 projects in 2002. The percentage of intramural research projects that were clinically relevant in 1997 was 4.5 percent (7/155) and in 2002 4.0 percent (4/101).

In September 2003, NIMH announced a new IRP research initiative for genetic research on schizophrenia. The projected welcome increase in resources will restore IRP schizophrenia research to approximately the level that existed in 1997, prior to the reductions in IRP schizophrenia research.

D. Research Expenditures By Disease: Serious Mental Illnesses Compared To Other Diseases

As part of the 2002 survey, an effort was made to compare NIH research expenditures on serious mental illnesses to its expenditures on other major diseases. This was done by utilizing existing NIH data for neurological and other common diseases and calculating the NIH research dollars spent per person affected with each disease in a year (Table 3). For comparison purposes, 1999 research expenditures were the most recent available.

It is clear from the table that research on schizophrenia, bipolar disorder, depression, panic disorder, and obsessive-compulsive disorder is markedly underfunded, compared to other major diseases. For example, for each $1 NIMH spent on research for a person with schizophrenia, NIH spent $30 on research for a person who was HIV-positive. For each $1 NIMH spent on research for a person with bipolar disorder, NIH spent over $12 on research for a person with cervical cancer. For each $1 NIMH spent on research for a person with depression, NIH spent almost $15 on research for a person with multiple sclerosis. The NIH expenditures, of course, do not include research expenditures by private organizations that raise funds for these diseases.

Our findings are generally supported by NIH's own analysis of its spending. In an article published in the *New England Journal of Medicine* in 1999,[30] based on spending in 1996, NIH used a number of different approaches to assess the relationship between disease burden and NIH research expenditures. Most measures of disease burden, including prevalence (the measure used in our analysis), incidence, and the number of hospital days were unassociated with research spending. The strongest relationship was with disability-adjusted life-years (DALYs), a measure that takes into account the number of years someone has the disease and how disabling it is. Schizophrenia and, especially, depression were underfunded according to this measure, although less so than peptic ulcer disease and perinatal conditions, for example.

Table 3: NIH Research Expenditure By Disease, 1999

Disease	FY 1999 NIH research expenditures	Prevalence: Individuals with this disease	NIH research dollars per person affected
HIV (including AIDS)	$1,792,700,000	800,000	$2,240.88
lung cancer	$163,100,000	342,457	$476.26
cervical cancer	$75,200,000	231,064	$325.45
multiple sclerosis	$96,300,000	350,000	$275.14
breast cancer	$474,700,000	2,197,504	$216.02
colorectal cancer	$175,900,000	1,041,499	$168.89
Parkinson's disease	$132,300,000	1,000,000	$132.30
prostate cancer	$177,500,000	1,637,208	$108.42
Alzheimer's disease	$406,500,000	4,000,000	$101.62
schizophrenia	$196,515,000	2,632,396	$74.65
bipolar disorder	$57,805,000	2,227,412	$25.95
depression	$199,600,000	10,732,076	$18.60
panic disorder	$19,049,000	3,239,872	$5.88
obsessive-compulsive disorder	$12,693,000	4,859,808	$2.61

Sources of data:

- The 1999 NIMH expenditures by disease were provided by the NIMH budget office, July 24, 2000. There are suggestions that some of these expenditures are inflated. The $196.5 million estimate for schizophrenia research in 1999, for example, is more than 50 percent higher than the $124.3 million estimate for 2002, recently made public by NIMH. The number of persons affected with serious mental illness was derived by using the "best estimate" one-year prevalence figures from the 1999 *Report of the Surgeon General* (op. cit., p. 47) and multiplying by the 1999 U.S. population figures for all individuals 18 and over (202,492,000). The figure for schizophrenia and bipolar disorder is consistent with other prevalence figures for these disorders. However, the figures for depression (unipolar major depression), panic disorder, and obsessive-compulsive disorder clearly include individuals with non-severe forms of these disorders. The authors are not aware of reliable prevalence data that include only severe forms of these disorders.
- The 1999 NIH expenditures for other diseases were obtained from NIH's annual report "Research Initiatives/Programs of Interest " for 1999, *http://www4.od.nih.gov/ofm/diseases/index.stm.* The number of individuals with various cancers was obtained from the National Cancer Institute, *http://seer.cancer.gov/faststats/html/pre_all.html* (click on "Prevalence" on the left, under "Available Statistics") and represents complete prevalence, i.e., anyone who has ever had that cancer who is still alive. The number of individuals with other diseases was taken from the websites of the various advocacy organizations.

[30] Gross CP, Anderson GF, Powe NR. The relation between funding by the National Institutes of Health and the burden of disease. *New England Journal of Medicine* 1999;340:1181–1887.

E. Identification of Rejected Research Proposals, 1997 to 2002

Anecdotally, psychiatric researchers have claimed for many years that NIMH regularly rejects for funding many potentially valuable research proposals on serious mental illnesses while simultaneously funding other projects that have no relevance to serious or any other form of mental illness. As far as we are aware, NIMH has never made public any study of its rejected research proposals. Furthermore, rejected proposals are considered to be confidential and cannot be obtained under the federal Freedom of Information Act.

We therefore decided to solicit such proposals from our research colleagues and to compare them with selected proposals that NIMH did fund. With relatively little effort (see Appendix B for details), we identified 30 research proposals that had been rejected for funding by NIMH between 1997 and 2002, during which time the NIMH budget was doubling.

The rejected research proposals are listed in Appendix A. They all propose research that relates directly to the causes or treatment of schizophrenia, bipolar disorder, or severe depression. Some were rejected for methodological reasons, while others received good reviews but did not receive a sufficiently high priority score to be funded. For comparison purposes, the rejected proposals are juxtaposed with research proposals that were also funded by NIMH between 1997 and 2002 and that appear to have no relationship to serious mental illnesses. Whenever possible, we selected funded proposals within the same monetary range as the rejected proposals.

Examples of the rejected and funded proposals include the following: NIMH rejected funding for a trial to improve the treatment of schizophrenia but funded a study to ascertain how people in Papua New Guinea "think about their own relationships in the real world." NIMH rejected funding for a study of bipolar disorder in children but funded a study of self-esteem in college students. NIMH rejected funding for a study to improve the treatment of major depression but funded a study of "sources of friendship" in elementary school students. NIMH rejected funding for a study of the causes of postpartum depression but funded a study of the hearing mechanism of crickets. NIMH rejected funding for a study of medication noncompliance in individuals with serious mental illnesses but funded a study of social communication among electric fish. NIMH rejected funding for research on means of supporting patients being released from psychiatric hospitals but funded a study of preschool children's understanding of love. NIMH rejected funding for research on measuring lithium in the brain but funded a study of how people in Czechoslovakia cope with social change. These examples and others are detailed in Appendix A.

In viewing such comparisons, it is important to note that the review and funding decisions are made by many different review committees at NIMH. A review committee that is responsible for schizophrenia treatment trial proposals may legitimately claim that, given its total budget, it funded its best proposals. However, that is the precise purpose of such comparisons: to emphasize the point that NIMH's

priorities and allocation of research funds are far too disconnected from the needs of society. The comparisons are simply a way to illustrate NIMH's unbalanced research portfolio.

F. Identification of NIMH-funded Research Proposals That Could Have Been Assigned to the National Science Foundation (NSF)

In our previous reviews of research awards funded by NIMH in 1997 and 1999, we noted a large number of basic neuroscience research awards that appeared to be similar to research that traditionally has been funded by the National Science Foundation (NSF). Many of these research projects are highly meritorious and may lead to a better understanding of human brain function. However, they have no direct relevance for serious mental illnesses and were classified as such.

NSF was founded by Congress in 1950 with a mandate to support "research and education in science and engineering." It funds approximately 9,000 new basic science research projects each year. NSF's mission is basic research, and it does not support research on human diseases, which is the primary mission of NIH. The NSF website, *www.nsf.gov,* specifically states: "Research with disease-related goals, including work on the etiology, diagnosis, or treatment of physical or mental disease, abnormality, or malfunction in human beings or animals, is normally not supported."

As described on its website, NSF has three general research areas that are especially relevant for basic neuroscience research:

1. Division of Integrative Biology and Neuroscience:

   The purpose of this division is to support "research on all aspects of nervous system structure, function and development." This includes research that ranges "from fundamental mechanisms of neuronal function at the molecular and cellular levels to adaptations of the brain for appropriate behavior in particular environments." Within the neuroscience cluster of this division are specific research grant programs for the following: behavioral neuroscience, computational neuroscience, developmental neuroscience, neuroendocrinology, neuronal and glial mechanisms, and sensory systems.

2. Behavioral and Cognitive Sciences

   The purpose of this program is to support research on "how the human brain supports thought, perception, affect, action, social processes, and other aspects of cognition and behavior." Within this program are specific research programs for human cognition and perception and for cognitive neuroscience.

3. Division of Molecular and Cellular Biosciences

   This division supports research "contributing to a fundamental understanding of life processes at the molecular, subcellular, and cellular levels." Within this division are specific research programs for cellular organization and for signal transduction and cellular regulation.

It should be noted, however, that NSF is relatively modestly funded ($5.3 billion in 2003) compared to NIH ($27.3 billion in 2003), and the amount of funding for the neuroscience program is less than $100 million. It is therefore necessary for some basic neuroscience research to be supported by NIH as well unless the NSF neuroscience budget is substantially increased.

In this study, we decided to try to quantify the number of NIMH extramural research grant awards that could potentially also have been funded by NSF if NSF had had funds to cover them. We were assisted in this task by Dr. Barbara Zain, a recently retired NSF program director who reviewed the NIMH extramural research grant awards, as explained methodologically in Appendix B.

Among the 2,188 NIMH 2002 extramural research awards reviewed by Dr. Zain, 269 (12.3 percent) were basic neuroscience research, having no obvious known relationship to the causes or treatment of serious mental disorders, and thus fitting the criteria for potential research funding by NSF. The average annual amount of these NSF-assignable NIMH awards was $254,700, and together they totaled $67.8 million. The $67.8 million in NIMH research grants that could instead be funded by NSF would represent approximately two-thirds of the NSF neuroscience program. We have not studied the appropriateness of the NSF neuroscience grants and do not, therefore, wish to imply that many of them should be defunded. Thus, in order to accommodate the research reassigned from NIMH, there would have to be a substantial increase in NSF's neuroscience funding.

To illustrate the overlapping funding by NIMH and NSF, we identified several researchers who have been or are currently being funded by both NIMH and NSF to do similar research. Examples of these include the following:

- A researcher at Brandeis University, was funded by NIMH from 1999 to 2004 ($178,385 for 2002) to study "Short Term Synaptic Plasticity in Cortical Circuits" (5R01MH058754-04). He was also funded by NSF from 2003 to 2007 (average of $129,500 per year) to study "Mathematical Modeling of Neural Populations" (0235463). The abstracts of these proposals suggest that they are similar or related.

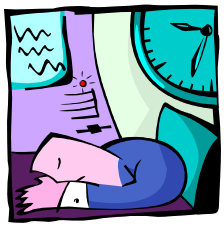
- A researcher at the University of Michigan, was funded by NSF from 1999 to 2004 (average of $88,340 per year) to study "Regulation of Sodium Channel Density and Localization in Polarized Cells" (9905991). She was also funded by NIMH from 2000 to 2004 ($255,128 for 2002) to study "Functional Modulation of Sodium Channels by Tenascin-R" (5R01MH059980-03). The abstracts suggest that the two research projects are similar or related.

- A researcher at Brandeis University, was funded by NSF from 1998 to 2003 (average of $90,273 per year) to study "Physiological Basis of Working Memory: Modeling of Prefrontal Cortical Circuitry and Neuromodulation" (9733006). This researcher was also funded by NIMH for 2001 to 2006 ($262,450 for 2002) to study "Cellular and Network Models in Prefrontal Working Memory" (5R01MH062349-02). The abstracts suggest that the two projects are similar or related.

- A researcher at the University of Pittsburgh, was funded by NSF from 2000 to 2004 (average of $78,750 per year) to study "Reelin and Migration of Sympathetic Preganglionic Neurons" (9982673). He was also funded by NIMH from 2000 to 2005 ($293,998 awarded for 2002) to study "Molecular Control of Cell Migration in the Spinal Cord" (5R01MH062180-03). The abstracts suggest that the two projects are similar or related.

In summary, some of the basic neuroscience research awards supported by NIMH substantially overlap those being supported by NSF. This can best be illustrated by researchers who receive funding from both NIMH and NSF to carry out similar research projects. Receiving funding from both NIMH and NSF is an accepted practice according to NIMH. In fact, the current director of NIMH, Dr. Thomas Insel, was funded by NIMH from 1997 to 2006, prior to taking the NIMH position ($245,241 awarded in 2002), to study "Oxytocin and Social Attachment" in prairie voles (2R01MH056538-06). He was also the original Principal Investigator for an NSF-funded Center for Behavioral Neuroscience Award (NSF9876754) of $11.9 million over five years, 1999–2004, which included research on social attachment in animal species. It is thus accepted by NIMH that some of the research it supports overlaps that of NSF.

NIMH and Sleep



NIMH likes sleep. One of its many current sleep studies is "Characteristics of Sleep in Insects" (1F31MH067318-01), a $35,267 research award. The goal of the study is "to identify an electro-physiological signature for sleep in locusts." Other research awards are used to study sleep in dogs ("Pharmacological Studies of Human and Canine Narcolepsy," 5K01MH001600-05, $115,523) and rats ("The Psychobiology of Rhythms in Diurnal Mammals," 2R01MH053433-07A2, $328,023). The rat research is in its ninth year.

There are also many sleep studies in people. These include studies of children ("The Validation of a New Measure of Sleep in Children," 1F31MH065831-01, $25,035); adolescents ("Epidemiology of Disturbed Sleep Among Adolescents," 1R01MH065606-01, $621,756), and older people ("Tai Chi Training and Sleep Enhancement in the Elderly," 5R03MH062327-02, $80,130).

The goals of one NIMH sleep study "are to estimate the prevalence of excessive daytime sleepiness (EDS) in the general population" ("Daytime Sleepiness: Prevalence, Consequences and Risks," 5R01MH059338-04, $398,920). The researchers correctly point out that daytime sleepiness is an important factor in automobile accidents and industrial accidents. What they do not point out, however, is that research on the causes of automobile accidents is the responsibility of the U.S. Department of Transportation and that research on industrial accidents is the responsibility of the National Institute of Occupational Safety and Health. Like many research awards, NIMH insists on doing everybody else's job but its own.

III. NIMH Awareness of Its Problem and Attempts To Correct It

NIMH officials have indicated awareness of the shortcomings of the Institute in regard to research on serious mental illnesses. Dr. Steven Hyman, NIMH's director from 1996 to 2001, wrote that "major depression, schizophrenia, alcohol use, manic depressive illness [bipolar disorder], obsessive-compulsive disorder, and drug use account for six of the leading 10 causes of disability, measured in years lived with a disability, in the United States."[31] In response to our previous report criticizing NIMH's 1999 research awards, Dr. Hyman publicly acknowledged that there were some grants that he was "not pleased to be funding," and he promised "to continue phasing out questionable or irrelevant research."[32] Dr. Thomas Insel, Hyman's successor as director, has acknowledged that "bipolar disorder has been conspicuously under-represented in the institute's portfolio."[33]

NIMH officials have also indicated an awareness that Congress expects them to be doing more research on serious mental illnesses. This is reflected each year when NIMH officials testify before congressional budget committees. In the testimony given by NIMH in March 2002, for example, three-fourths of the testimony described NIMH research initiatives to develop better treatments for adult schizophrenia; new research on childhood schizophrenia; new initiatives for depression, bipolar disorder and anxiety disorders in the intramural research program; and NIMH-supported genetic research on autism.[34] There was no mention by NIMH officials of the importance of ascertaining how pigeons think or of studying adolescent romantic relationships.

In recent years the discrepancy between what NIMH publicly claims to be doing and what it is really doing has increased. Publicly, NIMH recently told Congress that "the Institute's *public health mission* [is] reducing the burden of mental disorders through improved treatments and, ultimately, preventive interventions."[35] Privately it must be aware that an unacceptably small percentage of its resources is being allocated to this "public health mission."

Because of increasing concern about this discrepancy, NIMH has undertaken recent initiatives to strengthen its research on serious mental illnesses. These initiatives should be applauded and encouraged, even if they are relatively minor in comparison to the improvements that should be made. Some of NIMH's attempts to improve its research portfolio have been as follows:

---

[31] The NIMH perspective: next steps in schizophrenia research, *Biological Psychiatry* 2000;47:1–7.

[32] Holden C. Mental health agency shrugs off critics. *Science* 2000;286:2248.

[33] Insel TR. NIMH update, *5th International Conference on Bipolar Disorder,* Pittsburgh, Pa., June 23–24, 2003.

[34] Statement of the [NIMH] Acting Director to the House Subcommittee on Labor-HHS-Education and Related Agencies, March 13, 2002, and to the Senate Subcommittee on Labor-HHS-Education and Related Agencies, March 21, 2002, <*http://www.nimh.nih.gov/about/2003budget.cfm*>.

[35] National Institute of Mental Health, *FY 2003 Budget,* p. 5.

- Over the past five years there has been a major effort to reorganize the Intramural Research Program, as noted previously. NIMH has recruited several new senior researchers to work in this program.
- In 2001 NIMH funded large-scale, multi-site treatment trials to compare the effectiveness of various medications for treating schizophrenia (CATIE), bipolar disorder (STEP-BD), adult depression (STAR-D), and adolescent depression (TADS).
- Attention has been directed to the problem of appropriate medication strategies for children with serious mental illnesses by setting up a series of Research Units on Pediatric Psychopharmacology (RUPPs).
- NIMH began funding a series of Centers for the Neuroscience of Mental Disorders, called Conte Centers.
- For the first time, a few research awards have been made for problems such as adherence to medication, issues of informed consent, and stigma against individuals with serious mental illnesses.
- In 2002, in an effort to encourage members of the NIMH Review Committees to focus more on public needs, NIMH began adding members of the public to many committees.
- In 2002 and 2003, NIMH funded eight centers for Studies To Advance Autism Research and Treatment (STAART).
- In 2003, NIMH funded seven academic research centers to do coordinated research on the genetic antecedents of schizophrenia.
- In 2003 NIMH announced a new initiative, called MATRICS, to develop better medications to treat specific symptoms of schizophrenia, such as cognitive impairment.
- In 2003, NIMH announced a new intramural research program to study genes that are thought to be predisposing for the development of schizophrenia.

These initiatives are good as far as they go, but should not be mistaken for what is needed. Despite these initiatives, research on serious mental illnesses is grossly underfunded and has been proportionately losing ground at NIMH, as is reflected in this report.

IV. Why Does NIMH Do So Little Research on Serious Mental Illnesses?

In 1995, a Panel on Clinical Research was set up by the director of the National Institutes of Health (NIH) to encourage all institutes to allocate more resources to "studies of living human subjects, including … studies of the mechanisms of human disease and evaluation of therapeutic interventions."[36] In 1998, the Institute of Medicine urged NIH to consider public needs when allocating research funding.[37]

In 1999, a study was published ranking 29 disease conditions by severity of disability-adjusted life-years (DALYS), a measure of loss of healthy life to disease. Depression and schizophrenia were included among the 29 diseases, ranking third and tenth, respectively, and scoring higher on DALYS than multiple sclerosis, Parkinson's disease, AIDS, or cancer of the breast, cervix, ovaries, colon, or prostate.[38] In 2003, Dr. Elias Zerhouni, the new NIH director, published an NIH "roadmap," which emphasizes the need to more rapidly translate NIH research efforts into clinical improvements that may actually help patients.[39]

Despite overwhelming data, including the documented fiscal and humanitarian costs, NIMH has continually failed to give a high priority to research on serious mental illnesses. The Institute is thus continuing its traditional pattern of research neglect of these disorders. It is useful to ask why this is so. There are at least seven reasons, many of which are interrelated.

A. <u>The institutional culture of NIMH has never emphasized serious mental illnesses as its core mission, except when NIMH is testifying before Congress</u>.

During the congressional hearings in 1945 and 1946 that led to the creation of NIMH, it was very clear that research on serious mental illnesses was intended to be NIMH's core mission. Surgeon General Thomas Parran pointed out that "half of all hospital beds in the country, some 600,000, are occupied by mental patients." Major General Lewis B. Hershey, the Director of the Selective Service System, testified that 18 percent of men rejected for induction during World War II had been rejected because of "mental illnesses."[40] NIMH was created to find the causes and develop better treatments for serious mental illnesses.

From its earliest days, NIMH subverted the original intent of Congress. Dr. Robert Felix, NIMH's first director, was a psychoanalyst who viewed all social problems as NIMH's legitimate province. Felix viewed NIMH's mission as providing "a climate in which each citizen has optimum opportunities for sustained creative and responsible participation in the life of the community and for the development of his own particular

---

[36] Nathan DG, Wilson JD. Clinical research and the NIH—a report card. *New England Journal of Medicine* 2003;349:1860–1865.

[37] Institute of Medicine, *Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health* (Washington, D.C.: National Academy Press, 1998).

[38] Gross et al. The relation between funding by the National Institutes of Health and the burden of disease.

[39] Zerhouni E. The NIH roadmap. *Science* 2003;302:63–72.

[40] Hearings on the National Neuropsychiatric Act, Subcommittee of the Committee on Interstate and Foreign Commerce, House of Representatives, September 18–21, 1945.

potentialities."[41] Research on serious mental illnesses was not the core of NIMH but rather an incidental part of its mission. This institutional culture continues to exist and is reflected in the current allocation of NIMH's resources.

B. Leadership and staff have rarely viewed serious mental illnesses as a priority.

NIMH has had nine permanent directors, four of whom have viewed research on serious mental illnesses as important. During the 1980s and early 1990s, NIMH started giving greater emphasis to such research. In 1980, for example, a National Plan for the Chronically Mentally Ill was put forth, and in 1989 the NIMH Neuroscience Center and NIMH Neuropsychiatric Research Hospital at St. Elizabeths Hospital was dedicated to focus on schizophrenia research. In the late 1980s there was more NIMH interest in serious mental illnesses than at any time before or since.

Most of the permanent staff of NIMH, even more than the directors, have viewed serious mental illnesses as an incidental activity. Directors come and go, but the permanent staff, many of whom have stayed for 20 years or longer, set the tone for the agency. An analysis of the NIMH staff for 2002 shows that among the 28 senior officials who are listed in organizational charts as having direct responsibility for the development of research priorities and proposals and the appointment of review committee members, 7 have MDs, 17 have PhDs, and 4 do not have doctoral degrees. In reviewing data on these individuals available on the Internet, only 4 of the 28 appear to have had direct experience working with, or doing research on, individuals with serious mental illnesses.

C. NIMH review committees include few individuals with major interests or expertise in serious mental illnesses.

Members of the committees that review research proposals submitted to NIMH are selected by the NIMH permanent staff. Not surprisingly, the review committees, with few exceptions, reflect the general lack of NIMH interest in serious mental illnesses.

This lack of interest is well known and a frequent topic of discussion among individuals doing research on serious mental illnesses. It was also reflected in comments we received from researchers whose proposals had been rejected by the review committees. Some examples follow:

- A researcher studying individuals with bipolar disorder had a proposal rejected, as explained by review sheets, because the researcher could not include a test required by an NIMH reviewer that entailed the collection of all urine for 8 hours continuously in patients who were acutely manic or psychotic. Anybody who has ever worked clinically with such patients knows that collecting even a single urine specimen is a challenge, and that to collect urine for 8 hours continuously would be impossible.

[41] Felix RH, *Mental Health and Social Welfare* (New York: Columbia University Press, 1961), p. 8.

- A researcher who has for many years been developing better treatments for depression commented: "The administrative persons responsible for shepherding my research at NIMH have been negative. I see three factors involved: the inexperience of the [review] officials at NIMH; the structure of the review committees with an overemphasis on psychology and social work; and … the flashy allegiance of the leaders of NIMH and NIH for the basic sciences."

- A widely respected expert on bipolar disorder commented: "Quite frankly, we have pretty much given up submitting clinical research proposals regarding bipolar disorder to the NIMH," because they had almost all been rejected.

D. The organization of NIMH de-emphasizes serious mental illnesses.

The organizational chart of NIMH suggests its real priorities. For the extramural program, which administers the research awards, there are specific designated programs to coordinate extramural research for Cognitive Science; Personality and Social Cognition; Traumatic Stress; Social and Interpersonal Factors; Emotional Processes; Child and Adolescent Psychosocial Intervention; Adult Psychotherapy; and Geriatric Psychotherapy. There are no designated programs to coordinate extramural research for schizophrenia, bipolar disorder, depression, obsessive-compulsive disorder, or panic disorder.

For two decades at NIMH, there was an Center for Studies of Schizophrenia in the extramural research program to coordinate research for that disease, but that was abolished in 1997 during a reorganization. There is now, however, a Center for Mental Health Research on AIDS within NIMH, funded in 2002 for over $128 million. The National Institute of Allergy and Infectious Disease (NIAID) is the lead NIH Institute for AIDS research. Yet NIMH has a well-funded center to coordinate AIDS research but no similar center to coordinate any one of the serious mental illnesses.

NIMH argues that research on serious mental illnesses is divided among many programs. This is theoretically reflected by extramural program names such as "Developmental Neuroscience of Schizophrenia, Mood and Other Brain Disorders Program," which supports basic neuroscience. The majority of the clinically relevant extramural research awards for serious mental illnesses are under the Psychotic Disorders Program and the Mood, Anxiety and Regulatory Disorders Program. Together these two programs had a 2002 budget of $25.7 million, one-fifth the budget of the NIMH AIDS program.

As all administrators know, saying that everyone is responsible for something is a sure way to ensure that nobody is responsible.

E. It is easier to study rats, pigeons, and adolescent romantic relationships than to study individuals with serious mental illnesses.

Research on serious mental illnesses is difficult. Some researchers may regard individuals with these illnesses as uncooperative, irrational, and ungrateful for any attempts to work with them. High school and university students who do not have serious mental illnesses are much more attractive to work with. And rats and pigeons can simply be put in their cages for the night or the weekend.

It is also a status issue. Researchers working directly with individuals with serious mental illnesses are regarded by many in the research community as having a lower status than basic neuroscientists who may be characterizing the function of a novel gene, protein, or cognitive effect. Since most NIMH extramural research officials have themselves come from this latter group, there is a subtle but perceptible institutional disdain for researchers who are actually working with patients.

F. The American Psychological Society and American Psychological Association exert strong influence on the allocation of NIMH research resources.

The American Psychological Society (APS) is an organization of academic and research psychologists that separated from the American Psychological Association in 1988. Its mission is "to promote, protect and advance the interests of scientifically oriented psychology in research, application, teaching, and the improvement of human welfare." According to its website *(http://www.psychologicalscience.org/),* it has approximately 13,500 members, including "the leading psychological scientists and academics."

The Executive Director of APS is a psychologist. His wife, also a psychologist, is the NIMH Director of Extramural Activities and thus the NIMH official who oversees NIMH research grant priorities and awards. The research areas that have been most heavily funded by NIMH are areas in which many APS members work.

In addition to the influence of the American Psychological Society, NIMH is also heavily influenced by the older American Psychological Association, whose membership is composed primarily of clinical psychologists. Psychologist Patrick DeLeon, who was a member of the board of directors of the American Psychological Association for nine years and president in 2000, is a senior staffer for Senator Daniel Inouye, who is on the Senate Committee on Appropriations, which oversees the NIMH budget.

G. There is virtually no oversight or public advocacy to encourage NIMH to focus research attention on serious mental illnesses.

Many diseases, such as AIDS, breast cancer, cystic fibrosis, and Parkinson's disease, have active strong public advocates for increasing research on their diseases. There are no comparable strong advocacy organizations for serious mental disorders. Those that exist have essentially functioned as cheerleaders for NIMH, always ready to testify before Congress that the Institute needs more funds but usually unwilling to ask well-researched questions about how the funds are being spent.

NAMI is the best-known mental illness advocacy group, and for several years it encouraged NIMH to do more research on serious mental disorders by using quiet diplomacy. In 1999 it also co-sponsored *A Mission Forgotten: The Failure of the National Institute of Mental Health To Do Sufficient Research on Severe Mental Illnesses.* Since that time, however, NAMI has publicly supported NIMH. In a 2002 statement, for example, in response to public criticism of NIMH, NAMI said: "We recognize that building a quality portfolio and a cadre of skilled researchers is a slow process. NAMI believes that NIMH has begun that process and is moving in the right direction."[42] It should be noted that NIMH has been making research awards for 55 years.

Another group that should be advocating for more research on its diseases is the Depression and Bipolar Support Alliance, previously known as the National Depressive and Manic-Depressive Alliance. In 2002 this organization, in response to the same public criticism of NIMH, proclaimed its support for NIMH research and said that "NIMH is on the right track."[43] Similarly, the Obsessive-Compulsive Foundation issued a statement saying that NIMH is "providing the resources and support that is needed to get research done on all mental illnesses."[44] The public support of these last two organizations for NIMH is extraordinary, since bipolar disorder and obsessive-compulsive disorder are among the most research-neglected major diseases in the United States.

Finally, there is theoretical oversight of NIMH by the National Advisory Mental Health Council, a 17-person group that meets three times a year at NIMH and gives final approval for the research applications selected for funding by NIMH review committees. Council members are appointed for four-year terms and include a majority of individuals who are receiving, or have received, NIMH awards as well as some political appointees. The NIMH official who coordinates appointments to the Council and its agenda is the director of the Extramural Division and thus the NIMH official ultimately responsible for the research grants program. Although the Council has made useful suggestions regarding areas for future NIMH research, it has been ineffectual in providing oversight or criticism of NIMH's research directions or priorities.

---

[42] "NAMI condemns CBS's 60 Minutes for 'sound bite journalism," *NAMI Statement* (Release No. 02-14), April 24, 2002.

[43] PR Newswire Association, Inc., "Responding to charges made on CBS' 60 Minutes, leading mental health groups support National Institute of Mental Health," PR Newswire April 23, 2002.

[44] Ibid.

NIMH Is Doing the Work of the National Cancer Institute

The National Cancer Institute (NCI) is the NIH institute responsible for research on cancer, including behavioral aspects of cancer. Specifically, NCI covers all aspects of cancer research, including "the cause, diagnosis, prevention, and treatment of cancer, rehabilitation, and the continuing care of cancer patients." Its budget is more than three times larger than NIMH's budget. As part of its extramural research awards program, NCI has an Office of Cancer Survivorship, which "supports research that explores the long and short term physical and psychological effects of cancer and its treatment" [emphasis added].

NIMH is funding many research projects that should be funded by NCI. In 2002, these included:

- "Psychosocial Treatment Effects on Cancer Survival" (5R01MH047226-13), $373,016 paid in 2002. This is a 15-year grant, from 1990 to 2005, that to date has cost NIMH over $5.4 million. It is an attempt to see whether cancer patients live longer if they participate in "weekly supportive/expressive therapy groups."
- "Risk of Major Depression among Breast Cancer Patients" (1R01MH063172-01A2), $562,114 paid in 2002.
- "Spirituality in the Psychological Adjustment to Cancer" (5F31MH012932-02), $32,137 paid in 2002. "This study examines the role of spirituality in the lives of cancer patients."
- "Group Exercise in Women with Breast Cancer" (5P50MH061083-040005), funds paid not available. The goals "are to determine the efficacy of a group exercise training intervention in older women with breast cancer."
- "Behavioral Effects of Cancer and Its Treatment" (5K05MH001900-03), $123,152 paid in 2002.
- "Presurgical Stress Reduction, Mental Health and Cancer" (5R01MH059432-05), $451,842 paid in 2002.
- "Computer Aided Stress Reduction, Mental Health and Cancer" (5R21MH062031-03), $150,000 paid in 2002.

While NIMH does NCI's work, nobody is doing NIMH's work.

V. A Five-Year Report Card: What Were the Effects of Doubling NIMH's Budget?

Since there is never enough money to fund everything that could be funded, all government agencies must make choices regarding what they fund. This is true even in the best of times, and a doubling of one's budget over five years certainly qualifies as the best of times.

Between 1997 and 2002, NIMH's budget doubled from $661 million to $1.3 billion. During that time, the total number of research awards in all award categories increased from 3,219 to 4,157, an increase of 29 percent. Although the absolute number of NIMH research awards related to serious mental illnesses increased during this period, the proportion of awards for research related to serious mental illnesses decreased by 11 percent (from 32.1 to 28.5 percent). In addition, the proportion of awards for research related to clinical aspects of serious mental illness—the research that might improve the lives of individuals currently affected by these disorders—decreased by 22 percent (from 7.4 to 5.8 percent).

Perhaps the most disturbing finding from the present study is the number of research applications that were rejected by NIMH, yet had the potential to improve the lives of individuals afflicted with serious mental disorders. It is not, as NIMH has sometimes claimed, that NIMH does not receive a sufficient number of disease-relevant applications. It is, rather, that NIMH chooses not to fund them in favor of funding research on other problems. Thus, NIMH chose to fund research on how people in Papua New Guinea think but not to fund a trial to improve the treatment of schizophrenia; to fund research on self-esteem in college students but not to fund research on bipolar disorder in children; to fund research on the hearing mechanism of crickets but not to fund research on the causes of postpartum depression, etc., as detailed in Appendix A. NIMH made choices about what research it believed to be most important so that, for example, between 1997 and 2002, the number of NIMH-funded research awards on romantic relationships increased from 9 to 26; in 2002, this number almost equaled the 29 research awards on clinical aspects of bipolar disorder.

NIMH has frequently defended its decision to fund fewer research projects on serious mental illnesses by saying that it must also fund research on other mental disorders, such as anorexia, bulimia, and borderline personality disorder. In order to test this claim, we reviewed the 2002 CRISP database to identify all research awards related to these three disorders. We found only 92 awards for the three disorders combined; this would account for only an additional 2 percent of the NIMH research portfolio.

The truth of the matter is that NIMH is not very interested in serious mental disorders. Rather, its interests lie in studying normal human behavior and basic neuroscience. Serious mental illnesses are viewed as merely a necessary justification for the Institute's existence, especially useful at the time of congressional budget hearings, but not to be taken seriously.

A continuing problem for the research priorities of NIMH is the institute's propensity to do everyone else's research work except its own. This is illustrated by NIMH research awards for behavioral research in general and behavioral aspects of other diseases in particular; see boxes on NIMH and Sleep (page 18), NIMH Is Doing the Work of the National Cancer Institute (page 26), NIMH and Romance (page 37), and NIMH and Human Behavior (page 38). Behavioral research on diseases is important, and it is the responsibility of all NIH institutes to support behavioral research on diseases for which they have primary responsibility. Thus, NIMH does not have to fund research on social and behavioral aspects of diseases other than psychiatric diseases.

While NIMH is doing the work of other NIH institutes, the other NIH institutes are not doing the work of NIMH. The only exception to this is the National Institute on Drug Abuse (NIDA), which in 2002 supported 30 research projects on individuals with serious mental illness who also were abusing drugs. Other NIH institutes are not doing NIMH's work. For example, in 2002 the National Cancer Institute (NCI) supported only 1 research project, out of 11,128 total awards, that was relevant for schizophrenia or bipolar disorder. At the same time, NIMH was supporting 15 research projects, out of 4,157 total awards, that were relevant for behavioral aspects of cancer.

The discrepancy between NIMH's vision of what should be funded and the needs of society is immense. By NIMH's own count, serious mental illnesses affect 11.6 million Americans, with 5.6 million of them having the most severe and persistent forms of these disorders. Serious mental illnesses cost the federal government over $40 billion each year, and these costs have been growing at a rate of $2.6 billion per year. The human costs of serious mental illnesses are incalculable, with approximately one quarter of a million individuals with these illnesses either homeless or incarcerated in jails or prisons at any one time. NIMH's own data also show that research on serious mental disorders is grossly underfunded compared to nonpsychiatric diseases.

The 1998 Institute of Medicine's report on NIH strongly urged it to make its research priorities coincide with public needs:

> "In setting priorities, NIH should strengthen its analysis and use of health data, such as burdens and costs of diseases, and of data on the impact of research on the health of the public."[45]

It appears that NIMH did not hear that message. During the intervening years, NIMH has done almost nothing to correct its longstanding neglect of research on serious mental illnesses.

[45] Institute of Medicine*, Scientific Opportunities and Public Needs,* p. 5.

VI. Recommendations

A. A congressional committee should hold hearings to clarify NIMH priorities and specifically address two issues:

   1. What percentage of NIMH research resources should be allocated to research on serious mental illnesses in general?

   2. What percentage should be allocated to clinically relevant research on serious mental illnesses, i.e., research that is reasonably likely to improve the treatment and quality of life of individuals currently affected with these disorders?

B. NIMH should be required to report to Congress annually the percentage of its funding that is supporting research on each serious mental illness and the subset of that number that is supporting research on clinically relevant aspects of that illness.

C. Dr. Elias Zerhouni, Director of NIH, and Tommy Thompson, Secretary of the Department of Health and Human Resources, are ultimately responsible for NIMH. Both officials should review the discrepancy between NIMH resource allocation and the public's needs.

D. The General Accounting Office (GAO) should be asked by Congress to evaluate the current research portfolio of NIMH in relationship to public needs. This is consistent with GAO's mandate to "improve the economy, efficiency, and effectiveness of the federal government through financial audits, program reviews and evaluations, … and the government's accountability to the American people."

E. Basic neuroscience research is important, but its support should be coordinated. NIMH officials should meet regularly with officials from the National Institute of Neurological Disorders and Stroke (NINDS), other NIH institutes supporting basic neuroscience research, and the National Science Foundation (NSF) to coordinate such research and establish targeted amounts of funds that each organization will spend on such research.

F. Consideration should be given to ultimately merging NIMH with NINDS to form a National Brain Disease Research Institute to coordinate research on all brain diseases, including serious mental illnesses. If Congress deems that more non-disease-related behavioral research is needed other than what is already supported by NSF and the National Institute of Child Health and Human Development (NICHD), then a National Institute for Behavioral Research could be created.

Appendix A. A Comparison of Selected NIMH Research Proposals, Unfunded and Funded, 1997 to 2002*

Rejected Research Proposals	Funded Research Proposals
Treatment Trial for Schizophrenia **$150,000** requested Proposed to do a multicenter trial to compare two antipsychotics, olanzapine and risperidone, at higher doses for patients with severe, refractory schizophrenia, the most difficult patients to treat.	**How People Implement Their Models for Social Relations (5R01MH043857-10)** **$185,350** awarded This research is investigating how people generate social relationships and includes field research in Burkina Faso and Papua New Guinea. "Most of the research will focus on how people think about their own relationships in the real world and what they actually do in real social interactions."
Treatment of Bipolar Depression **$146,000** requested Proposed to carry out a treatment trial using methylphenidate to treat bipolar depression, a form of bipolar disorder that has proven very resistant to treatment.	**Cognitive Structure and Change in Marital Satisfaction (5R01MH059712-03)** **$140,750** awarded This research is examining "the structure of spouses' representations of the marriage for its role in the resiliency of marital satisfaction over time" through interviews and questionnaires administered to 150 newlywed couples every six months for four years.
Treatment of Major Depression **$400,000** requested Proposed to study repetitive transcranial magnetic stimulation (rTMS) as an alternative to electroconvulsive therapy (ECT) in individuals with severe major depression and to assess the relative cognitive side effects for both types of treatment.	**Friendship, Transition to Middle School, and Adjustment (5R01MH058116-05)** **$393,270** awarded The general objective of the research is "to study the nature, quality, functions, and sources of friendship during the transition from elementary school (fifth grade) to middle school (sixth grade), and to relate these aspects of friendship to child and family characteristics and to child socioemotional adjustment."
Genetic Predictors of Treatment Response in Schizophrenia **$100,000** requested Proposed to study genetic aspects of the medication response in schizophrenia to try to understand why some individuals are more refractory to treatment.	**Personality and Daily Relationship Processes (1K01MH064779-01A1)** **$109,816** awarded The goal of this research is "to understand better the role of personality in close relationship processes" and examine "the role of several personality variables on daily stress and intimacy processes within the context of both positive and negative events in marriage."

* All funds in this table are for the amount awarded by NIMH in FY2002. All direct quotations are taken from the NIMH abstracts provided on the CRISP website.

REJECTED	FUNDED
How Antipsychotic Medications Help Individuals with Schizophrenia **$342,000** requested Proposed to study 60 individuals with schizophrenia and controls over one year to try to understand how antipsychotic medications improve them. Would have specifically assessed changes in brain structure, in brain neurochemistry as reflected in the cerebrospinal fluid, and neuropsychological function associated with antipsychotic effects of medications.	**Environment, Behavior, and Reproduction in Rodents (2R01MH057535-12A2)** **$331,690** awarded This is the twelfth year of a research project to study the regulation of seasonal breeding in mice. "The general goal of the current proposal is to continue the discovery of the physiological mechanisms that underlie variation in reproductive responses to extrinsic factors both in the brain and in the testes of adult deer mice."
Bipolar Disorder and Conduct Disorder in Children **$441,000** requested Proposed to screen 200 children with bipolar disorder with and without conduct disorder and 100 normal controls to ascertain whether children who have both disorders, who are known to be difficult treatment cases, have special clinical or genetic features that can be used to predict treatment.	**Contingencies of Self Esteem (5R01MH058869-02)** **$276,508** awarded This research focuses on "the development of reliable and valid measures of contingencies of self-esteem among college students" and attempts to identify "predictors of the activities and psychological distress experienced by college freshmen." Using daily diaries, one study "will examine daily fluctuations in the self-esteem of women who feel overweight or normal weight."
Causes of Postpartum Depression **$97,000** requested Proposed to use an existing study of pregnant mothers to ascertain a possible relationship between maternal dietary intake of omega-3 essential fatty acids during pregnancy and postpartum depression. Preliminary analysis showed a doubling of the risk for mothers who consumed too little omega-3 fatty acids. This proposal would ascertain whether omega-3 tablets would decrease postpartum depression.	**Neuroethological Models for Acoustic Communication (5K05MH001148-05)** **$109,120** awarded This is the fifth year of research on the hearing mechanisms of crickets and flies. The research focuses on the investigation of neurobehavioral mechanisms that underlie auditory function and communication in crickets and flies, because these insects can serve as model systems for understanding communication in higher animals.
Treatment of Schizophrenia **$420,000** requested Proposed to carry out a multi-site treatment trial to test the combined effects of cognitive remediation and two different pharmacological agents, in separate treatment arms, to see whether the combination cognitive remediation plus drug would improve cognitive function in individuals with schizophrenia.	**Adolescent Close Relationships and Their Development (5R01MH050106-06)** **$411,705** awarded This research involves 200 tenth-grade students who are being observed interacting with "their romantic partner." "Questionnaires about relationships, sexual behavior, and adjustment will be gathered from multiple agents" and used to establish "predictors and outcomes of individual romantic and sexual development."

REJECTED	FUNDED
Choosing an Antipsychotic for African-Americans with Schizophrenia **$356,000** requested Proposed to compare two second-generation antipsychotics for the treatment of schizophrenia in African-Americans, specifically looking at the effects of a liver enzyme that may differ in such individuals. The antipsychotics would be compared on clinical outcomes (e.g., symptoms, side effects, patient satisfaction) as well as medication compliance and costs.	**Mental Processes During Conversation (5R01MH049685-07)** **$272,773** awarded This is a 12-year research award, the goal of which "is to discover the mental mechanisms that allow people to communicate with language." The experiments use an eye-tracking device "to investigate the way people take the other's perspective during conversation." The researcher is recording real conversations to test the theory "that perspective information is used in conversation as function of the diagnosticity of perspective, and that language users adapt to structures in the environment that affect this diagnosticity."
Identifying Patients Who May Respond to Clozapine **$50,000** requested Proposed to study gene polymorphisms on 120 patients with schizophrenia to try to be able to predict which individuals are more likely to respond to clozapine.	**The Secure Base Function of Caregiving in Relationships (1R03MH066119-01A1)** **$74,000** awarded This project is investigating 180 married couples for the "couple members' support of their partners' personal growth, goal strivings, and explorations, as well as the effects of this type of support (and lack thereof) on the recipient."
Improving Medication Compliance for Bipolar Disorder **$150,000** requested Proposed to study the effectiveness of psychoeducational group therapy to improve medication compliance for individuals with bipolar disorder.	**Models for the Study of Two Person Relationships (5R01MH051964-08)** **$130,179** awarded This was the eighth year of funding "to make several important extensions" of the Social Relations Model (SRM), "a model of two-person interaction." "Methods for the refinement and elaboration of theories to study interpersonal perception in close relationships are to be developed."
Measurements of Brain Lithium **$94,000** requested Proposed to measure brain lithium, using magnetic resonance spectroscopy, in individuals with bipolar disorder, especially focusing on those individuals with a rapid cycling course who are considered difficult to treat. The lithium measurements would be used to help predict treatment as well as to investigate the cause of the disorder by looking at the brain signal transduction system.	**Coping with Change in Czechoslovakia (5R01MH050369-06)** **$97,940** awarded This is the sixth year of a "study of the post-communist transformation's effect on the well-being of families and individuals in the Czech Republic." "The project's aims are to refine the connection between the transformation and stress, model the stress-distress process, and compare the results with those in the United States."

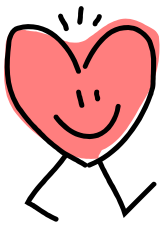
REJECTED	FUNDED
Improving Treatments for Bipolar Disorder **$412,000** requested Proposed to develop a center to specifically focus on finding improved treatments for bipolar disorder, including comparing the efficacy of various medications (e.g., lithium versus lamotrigine) and studying the reasons why some patients do not respond to medications.	**Effects and Meaning of Fathers for Adolescents (1R01MH064828-01)** **$356,828** awarded According to the investigators: "Research is notably lacking on how fathers impact the mental health and behavioral problems of their adolescent children, though studies have begun to show that fathers do influence adolescents in important ways." By interviewing 400 families and teachers, the investigator is developing "a Conceptual Model … that emphasizes the constructs of 'meanings' that children give to fathering behaviors."
Side Effects of Drugs Used in Adolescent Schizophrenia **$48,900** requested Proposed to study the side effects of second-generation antipsychotics and SSRI antidepressants in adolescents in the prodromal stages of schizophrenia. Would have specifically focused on weight gain and glucose and lipid abnormalities, all of which produce serious and troubling side effects.	**Molecular Variables Affecting Choice Behavior (2R01MH038357-15)** **$73,893** awarded This research is using pigeons and rats to understand how choices are made. "One line of research will examine the effects of delay in situations where pigeons must choose between a small but immediate work requirement and larger but more delayed work requirement."
Cost-Effectiveness of New Antipsychotics **$235,000** requested Proposed to compare two second-generation antipsychotics, olanzapine and risperidone, on their relative effects on clinical symptoms, rehospitalizaton rates, incidence of substance abuse, and level of psychosocial functioning in relationship to their costs.	**Goals, Identity, and Meaning in Life (2R01MH054142-06 A2)** **$214,355** awarded For this research, first-year college students are asked to keep a daily diary for one week, and then, one year later, "to tell the story of that week." "Multilevel modeling will be used to address the question, 'What makes a meaningful day?' … these stories promise to illuminate the process by which meaning is created and discovered in everyday life."
Antipsychotic-Induced Weight Gain in Adolescents **$52,500** requested Proposed to study a hormone suspected of being associated with weight gain in children and adolescents who are taking second-generation antipsychotics. This research could have helped identify individuals who are predisposed to such weight gain and/or provide targets for pharmacological neutralization of this side effect.	**Sources and Mediators of Jealousy (1R03MH068240-01)** **$78,792** awarded This research seeks to elucidate the "underlying causal mechanisms" of jealousy. A "new theory of jealousy is presented that is based on a single mediating mechanism: threat to self-esteem. … To investigate this question, jealousy will be induced through the development and subsequent threatening of valued working relationships involving participants [university students] and confederates acting as partners and rivals."

REJECTED	FUNDED
Support for Individuals Recently Released from the Hospital **$36,250** requested Proposed to study the efficacy of weekly telephone calls by a registered nurse to individuals with schizophrenia recently released from the hospital. A pilot study suggested that such calls may reduce the rehospitalization rate and that they may be especially useful in rural areas.	**Preschool Children's Understanding of Love (1R03MH064590-01 A1)** **$36,500** awarded This research "aims to explore preschoolers' understanding of love." Sixty mothers and their preschool children are participating in two videotaped laboratory interactions involving pretend play and picture book reading. "These findings will help provide a developmental framework for conceptualizing the development of young children's knowledge of the emotion of love."
Causes of Suicide in Women **$250,000** requested Proposed to collect blood samples in emergency rooms from women who had recently attempted suicide to ascertain the possible role of hormones, the menstrual cycle, and genetic predisposition to suicide attempts.	**Advice and Support: Self-Evaluation Considerations (5R01MH060729-02)** **$253,400** awarded The purpose of this research "is to better understand the effects of social support, particularly that offered by romantic partners and spouses."
Brain Studies in Severe Depression **$686,020** requested Proposed to study the possible causes of recurrent major depression using positron emission tomography (PET) scans on individuals with this disorder to assess the function of various brain areas with each other and with the endocrine system.	**Ethnicity, Economic Stress and Adaptation in Families (5R01MH054154-03)** **$671,940** awarded The purpose of this research is to study "the impact of economic hardships on families and children of Mexican-American and Euro-American background."
The Pathophysiology and Genetics of Schizophrenia **$1,500,000** requested Proposed to coordinate basic and clinical researchers at five research centers to study common genetic and developmental markers in individuals with schizophrenia. These would include neuropsychological and neurophysiological (e.g., visual processing) measures as well as neuroimaging.	**Raising Successful Children (5P30MH039246-189002)** **$1,303,016** awarded This research is "studying factors that moderate or mediate the risk of poor children of varying ethnicity for mental health problems associated with developmental impairment. … Special attention is paid to the processes by which children and families in poverty adapt to stressors arising from their economic conditions and social contexts."

REJECTED	FUNDED
Screening Procedures for Children with Severe Psychiatric Disorders **$250,000** requested Proposed to assess and compare the efficiency of different diagnostic instruments used to screen children with severe psychiatric disorders.	**Adult Attachment, Stress and Relationship Well-Being (2R01MH049599-04)** **$250,530** awarded This research is studying "long-term dating couples" and "first-time parents" to document the effect of stressors on romantic relationships and "how stressful events differentially affect personal and relational well-being."
Lack of Awareness of Illness in Individuals with Schizophrenia **$151,550** requested Proposed to study the neuroanatomical basis and neuropsychological correlates of lack of awareness of illness in individuals with schizophrenia, using functional magnetic resonance imaging (fMRI). Lack of awareness of illness is the main cause of noncompliance with medication, and understanding it could significantly improve treatment.	**Neuroethology of Electric Communication (5R37MH037972-18)** **$155,430** awarded This research is exploring social communication among electric fish found in South America and Africa. The research "will explore the neuronal basis for electric signal recognition among pulse-type electric fish," including ascertaining how the fish use electric signals to recognize their own species and fish of the opposite sex.
Prediction of Antipsychotic Drug Response **$463,000** requested Proposed to collect blood from hospitalized patients with severe psychiatric disorders, then use it to look for associations between specific genetic types and response to medication. If successful, it would help to predict a person's response to medication.	**Qualitative Study of Couples' Communication and Behavior (5R01MH062972-03)** **$478,290** awarded The purpose of this research project is "to conduct a longitudinal, descriptive study of the dynamic process of intimate communication, negotiation, and behavior between new partners." Young men and women are interviewed and asked to fill out questionnaires describing their first date and the "important events" in the first six months of their relationship.
Genetic Predisposition to Schizophrenia **$150,000** requested Proposed to study a specific neurophysiological measure (sensorimotor gating as measured by prepulse inhibition of the acoustic startle reflex) in individuals with schizophrenia and their relatives to see whether this measure might reflect a genetic predisposition to the disease.	**Neural Basis of Sexually Dimorphic Brain Function (5R01MH047538-08)** **$166,030** awarded This is the eighth year of research on the hormone vasopressin in two species of voles: prairie voles, "a monogamous species in which males and females provide parental care"; and meadow voles, "a promiscuous species in which only females provide parental care." The ultimate purpose of the research is to better understand "neural structures underlying paternal behavior in mammals."

REJECTED	FUNDED
Sleep Apnea and Schizophrenia **$50,000** requested Proposed to study sleep apnea in individuals with schizophrenia who are also obese because of medication-related weight gain. The research would have explored the benefits and risks of treating the sleep apnea in an effort to improve the person's function.	**Exploring the Interpersonal Component of Affectivity (5R01MH061804-03)** **$50,000** awarded This research project asks 100 dating couples and 100 married couples to "maintain interaction diaries for ten weeks [to] describe all encounters with their romantic partner that involve conflict."
Cognitive Functioning in Schizophrenia **$50,000** requested Proposed to study the reasons why individuals with schizophrenia have difficulties in planning and activities of daily living, by assessing patients and their immediate relatives using a neurophysiological measure, auditory evoked potentials.	**Selective Attention to the Parts of an Object (5R03MH060636-02)** **$73,500** awarded This research project asks: "Can attention select the individual parts of an object?" The research consists of showing university students pictures of faces in "a series of experiments aimed at understanding the relationship between part-based attentional processes and object recognition processes."
Association of Genes on the X Chromosome with Major Psychiatric Illness Funds requested not available Proposed to examine the expression of brain-related genes on the X chromosome and to specifically focus on men with schizophrenia who also have an extra X chromosome, as a model for abnormalities in X chromosome genes that lead to schizophrenia.	**Development of the "Virtual Rat" (3R24MH047188-08S10003)** Funds awarded not available This research is developing a computer model of the behavior of rats. "It is anticipated that a virtual rat graphics program with the associated computer models of schedule controlled responding could be used to substitute some of the time consuming, and expensive laboratory exercises involving rats or pigeons that are usually part of college courses on Conditioning and Learning, Experimental Psychology, etc."
Analyzing Brain Function in Schizophrenia Funds requested not available Proposed to develop advanced statistical techniques to compare functional magnetic resonance imaging findings from different brain regions in schizophrenia. The research would have focused specifically on cognitive functions to better understand the nature of the disorder and the brain region(s) primarily affected.	**Academic Achievement/Mental Health Outcomes in Children (1R24MH065485-010004)** Funds awarded not available This research is studying 200 elementary students to ascertain the relationship between academic competence ("academic achievement in reading and math") and their "psychological indicators of adjustment."

REJECTED	FUNDED
Cell Cultures for Research on Depression **$341,000** requested Proposed to utilize tissue samples from patients with severe depression to study the gene expression and cellular mechanisms that may be related to the causes of this disorder.	**Neuronal Basis of Courtship Specificity and Plasticity (1R01MH062684-01 A2)** **$350,000** awarded This research is studying courtship behavior among Drosophila fruit flies. "The anticipated results, together with the accumulated information of Drosophila behavioral genetics, will provide new insight into the neuronal mechanisms of higher-brain functions in flies."
An Animal Model for Mania **$146,000** requested Proposed to develop an animal model for mania that would facilitate research on bipolar disorder.	**Contingencies of Self-Esteem (5K02MH001747-03)** **$128,304** awarded Although the investigator acknowledges that "thousands of studies of self-esteem have been published," this research will "test hypotheses about the role of self-esteem in depression, self-esteem and aging, and self-esteem and culture."



NIMH and Romance

Using "romantic" as a key word in the CRISP database yielded 26 research projects involving romantic relationships funded by NIMH in 2002. This contrasts with only 9 similar projects funded in 1997.

An example is "Adolescent Social Relations and Well-Being" (7R03MH063792-02, funds awarded not available). This project is studying "psychological well-being [in high school students] as a function of the quality of their romantic relationships."

Another project is "Adolescent Close Relationships and Their Development" (5R01MH050106-06, $411,705 in 2002), now in its seventh year. High school seniors are interviewed "about their romantic relationships, friendships, and relationships with parents." In the current phase of this research, tenth graders are "observed interacting with their romantic partner."

If these romantic relationships do not work out, NIMH funded another researcher to study "Affective Processing Following Relationship Dissolution" (5F31MH012783-03, $19,865 in 2002). This research is based on the researcher's observation that "the unilateral or bilateral severing of a close romantic relationship is one of life's most distressing psychological experiences."

Like many research areas funded by NIMH, normal adolescent development is the primary responsibility of another federal agency—in this case the NIH Institute of Child Health and Human Development (NICHD). NICHD, in fact, is currently supporting research on topics such as "Development of Adolescent Romantic Relationships" and "Peer Cultures and Adolescent AIDS Risk." Such research legitimately belongs in NICHD. Hopefully, sometime in the near future NIMH will decide to do its own job and become romantically attached to serious mental illnesses.

NIMH and Human Behavior

There are an almost infinite number of human behaviors that can be studied. NIMH apparently believes that they all fall within its mandate. Take, for instance, the following examples:

- In "Expression of Identity in Virtual and Physical Spaces" (1R03MH064527-10A1, $72,973 in 2002), the investigator "will examine personal webpages on the Internet" and college students' dorm room walls to explore the idea "that environments individuals craft around themselves, such as bedrooms and offices, are rich with information about the occupants' personalities, abilities, values, and lifestyles."
- In "Influence of Hunger on Food Attitudes" (5R24MH047167-100012, $267,621 in 2002), the investigator notes: "An initial experiment revealed that people's attitudes toward food are more positive when they are hungry than when they are not hungry. The aim of the first experiment is to replicate and extend these initial findings by investigating how hunger influences attitudes toward food with different macronutrient compositions and calorie contents."
- In "Nosocomial Infection Control Through Handwashing Prompts" (3R44MH057562-03S1, $59,993 in 2001), the investigator is developing a computer-based device to encourage individuals in hospital restrooms to wash their hands:

  > "Stop Staph will detect anyone using a staff or patient's bathroom or entering a patient's room from the hall. If the person washes their hands properly, then Stop Staph will do nothing but record that fact. If the person does not wash their hands, then Stop Staph will emit a prompt to "Wash your hands, please," and record their compliance, if any."

  Decreasing the spread of infections is a laudable goal but should be supported by the National Institute of Allergy and Infectious Diseases or the Centers for Disease Control and Prevention (CDC). This is another egregious example of NIMH's inclination to support research on all human behaviors, regardless of whether they have any relationship to mental illnesses, and do everybody else's research except its own.

Appendix B: Methods

In 1997, NIMH funded a total of 3,219 research awards of all kinds; in 2002, this number was 4,157. Our original study of the 1997 NIMH research portfolio was of 2,029 awards. It did not include 626 awards for which abstracts were not available or which provided insufficient information for evaluation. It also did not include intramural research protocols (n=155), contracts (n=61), and awards for some types of training (n=348). For the current report, we therefore assessed the 564 awards in this latter group, using the same methodology as that used for assessing the 2002 awards and added the results to those for the 2,029 awards in the original 1997 study, for a total of 2,493 awards. Our 2002 study assessed 4,157 awards in all research categories. Thus, the 1997 and 2002 award groups are basically comparable.

An assessment of NIMH research awards for autism was not done as part of the 1997 survey. For purposes of comparison with 1997, we therefore did not include autism awards in our present study; they numbered very few.

Allocation of Total NIMH Research Funds to Serious Mental Illnesses, 1997 and 2002

The research awards were assessed by examining the abstracts available on the NIH CRISP Internet website, *www.nih.gov,* as explained in Appendix C. These abstracts are publicly available and anyone can, therefore, carry out their own assessment of NIMH research. Since many research awards related to more than one serious mental illness, an effort was made to determine which illness it was most applicable to.

Clinically Relevant Research Awards

All 1,187 research awards funded by NIMH in 2002 and related to serious mental illnesses were reviewed by the senior author for clinical relevance. The criteria used for this determination were similar to those used in our 1997 study (related to "efficacy, outcomes, and factors influencing treatment"). Another way to phrase what we defined as "clinically relevant research" is to say that such research is likely to decrease the community burden of the disease by improving the treatment and clinical outcome for individuals who are currently affected.

To illustrate what was included under the category "clinically relevant," some examples of clinically relevant research awards for schizophrenia in the 2002 portfolio follow. They include treatment trials; improved use of antipsychotic drugs; use of non-drug therapies such as transcranial magnetic stimulation and cognitive behavior therapy; improved detection of early cases; methods to decrease risk of HIV infection in such patients; methods to improve medical care; guardianship and outpatient commitment; rehabilitation efforts, including skills training and work outcome; community integration; and family education and support. Excluded from clinical relevance were, for example, basic neuroscience research on neurotransmitters or the cell signal transduction system.

- Risperidone Treatment of Adolescents with Schizophrenia, 5R29MH057094-06
- Clozapine Treatment of Schizophrenic Patients, 2R01MH045074-11

- Genetics of Antipsychotic Metabolism, 5K08MH064158-02
- NeuroCognitive Assessment Meter for Psychiatric Drugs, 5R44MH060053-03
- Medications in Pregnancy: Defining Exposure, 1P50MH068036-01
- Psychiatrists' Adoption of Schizophrenia Guidelines, 1R01MH064029-01A1
- TMS Intervention Development for Auditory Hallucinations, 5R21MH063326-02
- Compensating for Cognitive Deficits in Schizophrenia, 5R01MH061775-02
- Environmental-Personal Treatment of Schizophrenia, 2R01MH030750-25A1
- Vulnerability Markers in Prodromal Schizophrenia, 5R01MH060720-03
- Treatment of Psychotic Disorders in Youth, 1K23MH001802-01A2
- Sexual Risk Reduction among Men with Mental Illness, 5R01MH058917-05
- HIV Risk Reduction for Women with Severe Mental Illness, 5K01MH001691-04
- Quality of Somatic Care for the Seriously Mentally Ill, 5K08MH001960-02
- Guardianship for Persons with Mental Illnesses, 1R03MH062303-01A1
- Effectiveness of Involuntary Outpatient Commitment, 5R01MH048103-08
- Work Outcome in Schizophrenia—Brain Function/Structure, 5R01MH057749-05
- Community Integration of Persons with Mental Illness, 5K23MH001903-03
- Skills Training for Schizophrenia: Enhancing Outcomes, 1R01MH066362-01
- Online Family Support and Education for Schizophrenia, 5R21MH062135-02
- Aging Parents with a Mentally Ill Adult Child at Home, 5R01MH055928-04

A total of 242 research awards were judged to be clinically relevant for one of the serious mental illnesses, and all were assigned to the disease for which they were most relevant. For example, ECT research was assigned to major depression, although it may also be useful in the depressed phase of bipolar disorder and in schizophrenia. When the research award was equally relevant for two disease entities, e.g., schizophrenia and bipolar disorder, it was split between them.

Identification of Rejected Research Proposals

NIMH research proposals rejected for funding between 1997 and 2002 for research on serious mental illnesses were solicited by mailing a request to members of the Society of Biological Psychiatry and by distributing a flyer at the International Congress of Schizophrenia Research in April 2003. In an attempt to identify rejected proposals on obsessive compulsive disorder, a letter was sent to the Executive Director of the Obsessive Compulsive Disorder Association, but she failed to respond.

Approximately 50 rejected research proposals were initially identified. Some of these were subsequently resubmitted to NIMH. In 6 other cases, the researcher decided that he/she did not wish to include the rejected research in this report. In all cases, we indicated that we would not identify the researchers by name.

For two proposals, the researchers declined to provide the amount of money requested, so we matched these with funded NIMH research awards for which the amount of the award was missing on the CRISP database and for which the magnitude of the two research projects seemed comparable.

Our category of "rejected" research proposals includes 90 percent that were initially rejected for funding following review by the review committee and 10 percent that were "approved but unfunded." This later category is a way of saying that the research proposal was sufficiently meritorious to deserve funding but that NIMH did not have sufficient money to fund it. The "approved but unfunded" category is somewhat disingenuous, since NIMH has, in fact, made decisions regarding its priorities for research, as the comparison of research proposals listed in Appendix A makes clear. From the point of view of the researcher and the patient who might benefit from it, rejected proposals and approved-but-unfunded proposals result in the same outcome: the research does not get done.

Identification of NIMH-funded Research Proposals That Could Have Been Assigned to the National Science Foundation (NSF)

Barbara Zain, Ph.D., a recently retired program officer at NSF, was the rater for this part of the study. For the 2002 NIMH awards portfolio, she assessed all extramural research grants by reading the abstracts in the CRISP database. She was asked to answer the question: Given existing NSF research programs, which NIMH extramural research awards could have been reviewed by NSF? The total number of NIMH extramural research grants assessed was 2,188; she did not assess intramural research grants, contracts, fellowships, or other NIMH award mechanisms.

In doing the ratings, Dr. Zain assigned NIMH proposals to NSF if they appeared to be basic neuroscience research , had no obvious known relationship to the causation or treatment of serious mental disorders, and fit criteria for research funded by NSF.

Appendix C: How To Access Information on NIMH-Funded Research Awards

To access abstracts: Go to *www.nih.gov* and click on "Grants," then "CRISP," then "Go to CRISP Query Form." Enter a search term, grant number, maximum number of records (up to 9999), etc., as desired. Click on "Submit Query" to yield a "Hit List" that includes grant number, principal investigator (PI), and title. Click on the title to access the abstract and other details on the project, including the fiscal year (FY) under which the grant was funded and the name of the state in which the PI's research institution is located. You will need to know the fiscal year and state to obtain information on funding.

To obtain information on funding: At *www.nih.gov,* click on "Grants," then "Grants Page," then "Award Data." Under "Award Trends," click on "State and Foreign Site." Next, click on the appropriate FY and then the state. After the page has downloaded, use your browser's 'find' function to search by grant number, PI name, or grant title. Many grants are funded for multiple years; to obtain information on funding for a different year for the same grant, return to the "State and Foreign Site" page and select another year and proceed as above.

Long-Term Funding

Long-term funding for some types of research, especially that involving the course and treatment of serious mental illnesses, is both necessary and useful. However, NIMH is also using long-term funding for many projects that have little or no relevance to any serious mental illness. The following are selected current NIMH research grants that have been continuously funded for 15 years or longer.

- "Transition into Early Adolescence" (5R01MH043899-13). This project is following a cohort of adopted children and has been continuously funded for 15 years. In 2002, NIMH awarded the researchers $230,834, but payments in other years have been as high as $361,197.
- "Young Adult Adjustment—Predictors and Consequences" (5R01MH043311-13). The purpose of this project is to "examine, comprehensively, the transition of adolescents into young adults." Specifically, it is attempting "to identify social interactional risk and protective factors that would moderate the deleterious influence of known stressors on social and psychological adjustment during adolescence." In 2002, NIMH awarded the researchers $695,509; they have been continuously funded for 16 years.
- "Marital Discord, Parenting and Child Outcomes" (5R01MH042484-12). This project is following 180 families to examine "meta-emotional processes in the family to discover the processes' influence on the development of emotion regulation in middle childhood and early adolescence." It has been funded continuously for 16 years, and in 2002 NIMH awarded the researchers $597,634.
- "Perceiving Groups as Entities" (5R01MH040058-16). This is the eighteenth year of funding for "research investigating the cognitive processes underlying the perception of individuals and groups. … The model gives central importance to the perception of entitativity—the perception that a number of individuals are, in some way, joined together in a social unit." In 2002, NIMH awarded the researchers $236,681.
- "Families in the Divorce Process" (5R01MH038318-13). This project is following mothers and children from couples who have divorced. Specifically, the research "implements a theory-driven intervention designed to prevent adjustment problems in families in the divorce process … by teaching skills hypothesized to control the problems." It has been continuously funded for 19 years, and in 2002, the researchers received $640,256.

Research projects such as the above are not without merit. However, these projects are being funded in place of research on serious psychiatric disorders.

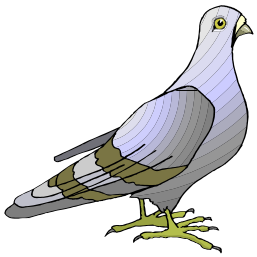
Happiness Is Getting an NIMH Research Grant To Study Happiness

NIMH makes some researchers happy. In 2001, it awarded $146,415 for the first of three years to study "Cultural Differences in Self-Reports of Well-Being" (1R01MH060849-01A1). The investigator is studying cultural differences in "subjective well being" among Asians and Americans, i.e., what makes people happy. In 2003, NIMH awarded $214,261, the tenth year of funding, to study "Goals, Identity, Meaning in Life and Well Being" (2R01MH054142-06A2). According to NIMH, this research utilizes first-year college students, who are asked to keep a daily diary for one week, and then, one year later, "to tell the story of that week." "Multilevel modeling will be used to address the question, 'What makes a meaningful day?' … these stories promise to illuminate the process by which meaning is created and discovered in everyday life."

These funded researchers are two leaders of the Positive Emotions Center under the Positive Psychology Network. According to its website (*http://www.positivepsychology.org/ progressreport2000.htm)*, the Positive Emotions Center promotes research on "subjective well-being" (SWB), which is defined as "the scientific study of life satisfaction, fulfillment, and positive emotions." This group recently held a meeting in Akumal, Mexico, at which, presumably, everyone experienced subjective well-being. The website states that the group "has continued to investigate the question, 'Is happiness a good thing?'" Their analysis has so far "revealed that the benefits of happiness include higher income and superior work outcomes," among other things.

These are only two of many happiness research grants awarded by NIMH in the past five years. In 1998, NIMH awarded $228,912 for the final year of a five-year study entitled "Ethnicity and Emotion" (5R01MH050841-05) to explore "ethnic differences in the processes of emotional reactivity, emotional control, and emotional perception." In 2000, another researcher received $22,990 for a study entitled "Learning from Experience about Affective Forecasting" (1F31MH012702-01). According to the NIMH summary, "the long term objectives of this project are to understand further how people know and come to know what factors influence their happiness."

If all of the NIMH funds being spent on research on happiness had instead been spent developing better treatment for depression, there would be a lot more happy people than just the NIMH grantees.



NIMH and Birds

NIMH supports a wide variety of research projects on birds. Pigeons are a favorite, with 18 different pigeon awards given in 2002. These included a $208,931 study of "the processes by which pigeons learn matching to sample" ("Learning Processes in Matching-to-Sample by Pigeons," 5R01MH061798-02). Another bird project studies the thought process of great bowerbirds, which build their nests with colored objects. The objective is to ascertain "whether perception of colored objects used by male great bowerbirds is categorical or continuous" ("Perceptual and Neural Aspects of Visual Displays," 1F32MH012326-01, $32,250 in 2002). Still another project studies quails to ascertain whether they can learn to imitate behavior. Male quails are allowed to view female quails as a learning incentive ("Imitative Learning," 1F31MH012046-01, $19,540 in 2002).

Some bird research, such as that done on the hippocampus of songbirds, has yielded interesting results. For most NIMH-funded research, however, it is exceedingly difficult to imagine what useful information could be derived that would have any value for understanding mental illnesses. There are an almost infinite number of behavioral questions that can be studied in hundreds of different animal species; NIMH appears determined to study them all.