Catalyst

TREATMENT ADVOCACY CENTER

Volume 2, No. 5 September/October 2000

Refusing to Settle for Pigeon Research

Despite a promise "to continue phasing out questionable or irrelevant research," the National Institute of Mental Health (NIMH) continues to fund as many research grants for the study of pigeons as it funds to study the clinical or treatment aspects of manic-depressive illness. We must refuse to settle for pigeon research when so much rides on NIMH accomplishing its mission to "reduce the burden of mental illness through research."

To that end, on September 6, 2000, the Treatment Advocacy Center released ***Missions Impossible: The Ongoing Failure of NIMH To Support Sufficient Research on Severe Mental Disorders.***[1]

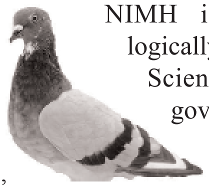
This report documents that only 22.1 percent of NIMH's 1999 research grants were related to the most severe disorders. Even more glaringly, only 8.3 percent of the institute's funding went to the clinical or treatment aspects of these illnesses.

Missions Impossible compares the number of NIMH research grants for schizophrenia, manic-depressive illness, severe depression, and other severe mental disorders with the number of NIMH grants for the study of pigeons, songbirds, fish, and crickets. In addition, the report exposes how NIMH has also lost track of its primary mission through its allocation of substantial research resources to human and social problems that are the responsibility of other government agencies.

A review of 1,349 new research grants funded by NIMH revealed that:

- For schizophrenia, which affects 2.2 million adult Americans, NIMH approved 110 new research grants, including 35 related to clinical and treatment aspects. At the same time, NIMH funded more than 110 other grants on subjects that should have been assigned to other divisions of the National Institute of Health (NIH), such as the National Cancer Institute.
- For major depression, which affects 9.9 million adult Americans, NIMH approved 120 new research grants, including 57 related to clinical or treatment aspects. At the same time, NIMH funded more than 120 other grants that should have been assigned to other government agencies outside of NIH, such as the Department of Education.
- For manic-depressive illness, which affects 1.6 million adult Americans, NIMH approved 32 new research grants, including 7 related to clinical or treatment aspects. At the same time, NIMH also funded 7 new research grants to study pigeons.
- For obsessive-compulsive disorder, which affects 4.4 million adult Americans, NIMH approved 11 new research grants, including 4 related to clinical or treatment aspects. NIMH also funded 4 new research grants to study fish.
- For panic disorder, which affects 2.6 million adult Americans, NIMH approved 14 new research grants, including 8 related to clinical or treatment aspects. NIMH also funded 8 new research grants to study songbirds.
- For autism, which affects 550,000 Americans, NIMH approved 9 new research grants, including 1 related to clinical or treatment aspects. At the same time, NIMH funded 1 research grant to study crickets.

Despite promises by its leaders to rededicate the Institute to its fundamental mission, ***Missions Impossible*** finds no increased distribution of NIMH resources to severe mental disorders last year as compared to 1997. It notes that, "Breast cancer, cognitive process of birds, alertness of railway engineers, reading problems, students' transition to middle school, adolescent romantic relationships, daytime sleepiness, how emotion is perceived in music—there are virtually no boundaries to what NIMH is currently funding." The report emphasizes that much of the behavioral and basic neuroscience research being funded by NIMH is worthwhile but should logically be done by the National Science Foundation and other government agencies. NIMH is only able to allocate significant resources to such research by neglecting severe mental disorders.



NIMH's failure to do research on severe mental illnesses is criticized in the report on economic grounds as well. A recent survey reported that severe mental illnesses account for 70 percent of the treatment costs for all mental illnesses and are responsible for 72 percent of all suicides. Federal expenditures for the cost of treatment and support of severe mental illnesses are among the fastest growing items in the federal budget.

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Catalyst

Catalyst is published six times a year by the Treatment Advocacy Center (the Center).

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The Center is a nonprofit organization dedicated to eliminating legal and clinical barriers to timely and humane treatment for the millions of Americans with severe brain diseases who are not receiving appropriate medical care.

Current federal and state policies hinder treatment for psychiatrically ill individuals who are most at risk for homelessness, arrest, or suicide. As a result an estimated 1.5 million individuals with schizophrenia and manic-depressive illness (bipolar disorder) are not being treated for their illness at any given time.

The Center serves as a catalyst to achieve proper balance in judicial, legislative and policy decisions that affect the lives of persons with serious brain diseases.

What To Do If a Loved One Threatens Suicide

by Sam Bloom

The suicide of a loved one is something we'd like to ignore or forget. Some of us deny it. Others can't say the word. It is frightening to contemplate. We think it can't happen to us. It can. Our 23-year-old son, Sammy, killed himself in 1982. He was diagnosed with a serious brain disease 10 months earlier. It has been a very painful experience for our family.

Thirty-one thousand Americans kill themselves every year. Compare this to 17,000 homicides. Suicide is a national problem. It is the ninth leading cause of death in the United States (third among ages 15-24). The U.S. Senate declared it a national problem with the unanimous passage of Senate Resolution 84 in 1997, and the U.S. House of Representatives followed with the almost identical House Resolution 212 in 1998.

Both resolutions called for the development and implementation of a national suicide prevention strategy, and for the availability of accessible and affordable mental health services for all Americans. The Suicide Prevention Advocacy Network (SPAN) is coordinating the efforts to meet these national objectives. SPAN is a country-wide grassroots organization made up largely of persons who survive the suicide of a loved one.

Research shows that 72 percent of suicide victims suffer from severe mental disorders. Long-term, follow-up studies report 10 percent of those with schizophrenia and 15 percent of those with major mood disorders eventually become victims of suicide. Suicide does happen and the loved ones with severe mental illness, as a population class, are at high risk.

Is suicide preventable? Yes. U.S. Surgeon General, David Satcher, MD, has stated so in several speeches and press conferences. What can we do about it? The most important task is to become informed in order to get beyond our fears so that we can act effectively if a crisis arises. We must be knowledgeable about the warning signs that 75 percent of suicidal persons present. We must know where to get help for the person in crisis, and, we need to know what we can do to help.

Warning Signs

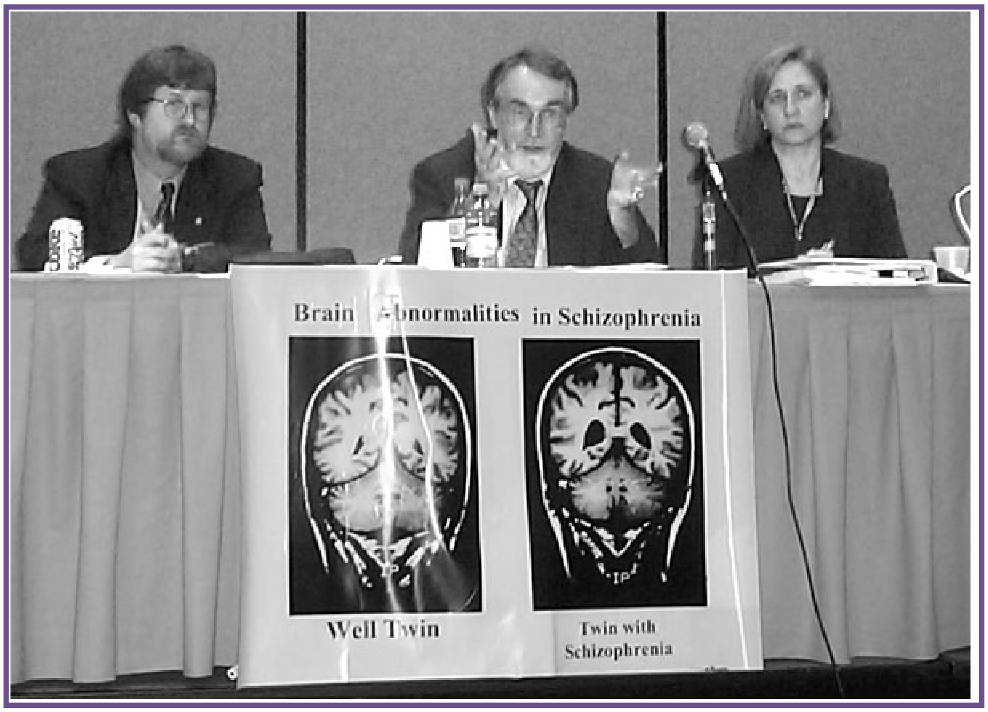
1. Previous suicide threats, gestures, or attempts.
2. Symptoms of depression.
3. Changes in eating habits.
4. Changes in sleeping habits.
5. Loss of interest or pleasure in formerly enjoyed activities.
6. Loss of energy.
7. Feelings of worthlessness or hopelessness.
8. Lack of concentration, indecision.
9. Thoughts or speaking about death or suicide.
10. Use of alcohol or drugs to blunt psychological pain.

Where to Seek Help in a Crisis

1. Your loved one's therapist or doctor.
2. Your loved one's mental health clinic.
3. Local psychiatric hospital.
4. Local general hospital emergency room.
5. County mental health services.
6. Encourage your loved one to call the nearest suicide prevention or crisis center for support or call yourself for advice on how to handle the immediate situation.
7. Seek assistance from other family members, friends, school counselors, teachers, clergy and law enforcement.

What You Can Do

1. Take all threats, gestures and previous attempts seriously! Make sure your loved one's professional caregiver also does this!
2. Be a nonjudgmental listener. Ask what is the matter. Get the person in crisis to talk about his or her problem(s).
3. If they were in crisis before, ask how they resolved it. Can they apply the same solution now? Discuss what other alternatives there might be.



Left to right: Risdon Slate, Ph.D., Associate Professor of Criminology, Florida Southern College; Dr. E. Fuller Torrey, President, and Mary T. Zdanowicz, J.D., Executive Director, Treatment Advocacy Center, presenting a workshop at the National Sheriffs' Association Annual Conference in Kansas City, Missouri.

4. If professional help is required, help them to find it. You may have to go with them.
5. Don't try to "talk" them out of suicide. This only indicates you are not listening. However, let them know you care and have a sense of what they are feeling. Let them know they are not alone. Help them to understand that their problem(s) is temporary and can be solved.
6. If the crisis is acute, do not leave them alone until help is available. Remove from the area firearms, knives, razors, medications and other potentially dangerous items.
7. After assistance is obtained, continue to follow up with your loved one's treatment and progress. Take an active role in ensuring that treatment compliance occurs.

Some suicides occur without warning, but since 75 percent present one or more warning signs, the probabilities are good that with proper and timely intervention one can successfully prevent a suicide. It is important to be knowledgeable about the subject of suicide so we can help our loved ones. Suicide is a national problem and in many cases is preventable. Being informed increases one's chance of effecting the successful outcome of a crisis. On the other hand, the loss of a loved one is a devastating experience.

For additional information, contact the American Association of Suicidology (AAS), 4201 Connecticul Avenue NW, Washington, DC 20008, 202-237-2280; The American Foundation for Suicide Prevention (AFSP), 120 Wall Street, 2nd Floor, New York, NY 10005, 212-363-3500; your local suicide prevention/crisis center; or Sam Bloom, phone and Fax 310-377-8857.

[Note: Sam Bloom has been a volunteer survivor support group facilitator, crisis line trainer, and member of the speaker's bureau at the Suicide Prevention Center of the Didi Hirsch Community Mental Health Center, Culver City, California, for the past 15 years. He is also a Southern California Community Organizer for the Suicide Prevention Advocacy Network (SPAN), and is an active member of CAMI, NAMI, AAS, and AFSP.]

A Temporary Setback

By Jonathan Stanley, Assistant Director

The 2000 Session of the California State Legislature ended on August 31 and so did the hope of reforming California's antiquated treatment laws this year. On its last day the reform bill that the California Treatment Advocacy Coalition (CTAC) endeavored to make law, Assembly Bill 1800, remained where it had for the long, preceding weeks, deeply buried by Senator Majority Leader John Burton.

We fear for all those overcome by mental illness who will be abandoned to suffer in the upcoming months because AB 1800 was denied the chance of a vote before the Senate. Yet, at the same time, we are also proud, proud of what CTAC's members have accomplished.

Thousands of letters have made impressions on legislators and newspapers. At some point this year, almost every one of the state's lawmakers has had to look a CTAC member in the eye and explain his or her stance on treatment law reform. Organization after organization got behind the bill. For a piece of mental health legislation, the accumulated political weight behind AB 1800 was incredible. Almost every one of California's major newspapers came out for the measure. The two largest publications—the San Francisco Chronicle and the Los Angeles Times—got behind it time and time again. And, letters to the editor and op-eds by CTAC's faithful consistently popped up in papers across the state during the legislative session.

Under the extraordinary guidance of Carla Jacobs and Randall Hagar, CTAC's members strove to change a set of statutes that over the last 30 years have left tens of thousands crippled by mental illness. And CTAC made an impact. The momentum it generated was shown when AB 1800 swept through the Assembly 53-16. Unfortunately, nothing could convince Senator John Burton to permit the vital measure to be considered by the Senators elected to represent the people of California.

Assemblywoman Helen Thomson, AB 1800's author and champion, has already said that she will introduce another reform bill next session. John Burton has promised that something will be done to improve California's treatment laws. We will see how closely his idea of improving the law matches ours. What we do know is that next session CTAC's members will again be heard in the Capitol and throughout California.

State Updates

Finally, the pendulum is swinging away from suffering and towards treatment. Throughout the nation, numerous bills related to assisted treatment were introduced in state legislatures during the 2000 legislative sessions. The Center tracked over 60 such bills from more than 25 different states. The following chart provides examples of the types of bills that states pursued. They include proposals for assisted outpatient treatment, revisions to state treatment standards and improvements to assisted treatment hearing procedures.

As the chart illustrates, several bills were introduced that did not become law. We should be encouraged that legislators were educated and interested enough in assisted treatment to even propose legislation. The truth is, the majority of bills do not become laws. In the 1999 general sessions, for example, only 20% of all the bills introduced in the state legislatures were enacted.[1] Given how difficult it is for a bill to become law we still have some challenges ahead, even if the momentum has shifted towards reform.

Most states have completed their 2000 legislative sessions. Now is the time to prepare for next year. The break between sessions is a good time to network with other reform-minded advocates, contact and visit your elected officials, share your personal frustrations and stories, educate people about anosognosia (lack of insight) and inform decision-makers about the benefits of assisted treatment.

Thanks to your efforts, legislators are recognizing that laws should allow treatment for those who are in need of medical attention and lack the capacity to make rational treatment decisions for themselves. With some dedication, we can help move that pendulum back to a rational center.

Bill	Sponsor
CA AB 1800	Thomson and Perata
CT HB 5699	Committee on Judiciary
CT HB 5911	Committee on Appropriations
DE HB 520	Maier
IA HB 2366	Committee on Judiciary
IL SB 1371	Walsh
IL SB 1508	Parker
KY HB 31	Yonts
KY SB 344	Rose
MN HB 3107	Greiling et al
NY AB 8000	Committee on Rules
OK SB 1553	Weedn
PA HB 2203	Birmelin et al
PA SB 1506	Greenleaf et al
SD HB 1036	Committee On Health and Human Services
TN HB 3004	Eckles and Walley
UT SB 200	Montgomery
WA SB 6554	Long and Hargrove
WI AB 746	Rhoades + 28 other senators and representatives

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[1] Based on figures presented in THE COUNCIL OF STATE GOVERNMENTS, THE BOOK OF THE STATES 2000-2001, 108-109 (2000). (Note: the percentage of bills introduced that are enacted markedly varies from state to state.)

Description	Status as of 9/9/00
Reforms Lanterman-Petris-Short Act by expanding “gravely disabled” standard for treatment placement to include those incapable of informed medical decisions and at risk of physical or psychiatric harm absent treatment; allows qualifying patients to select community assisted outpatient treatment instead of inpatient court-ordered care; combines treatment placement and medication authorization hearings.	Passed Assembly. Died in Senate subcommittee. Did not become law.
Establishes a limited form of assisted outpatient treatment.	Did not become law.
Includes a rider that was offered as an alternative to CT HB 5699. Instead of the AOT provided by the first bill, the rider creates a voluntary intensive service pilot program with peer engagement specialists.	Signed into law by Governor.
Provides the criteria for involuntary outpatient commitment; establishes a greater range of justifiable reasons why commitment for a mentally ill person would be an appropriate treatment alternative.	Pending.
Establishes a procedure for assisted outpatient treatment.	Did not become law.
Provides that a law enforcement officer may execute a petition asserting that another person is subject to involuntary admission; provides that if the court finds that the petition is in order, the court shall order that the respondent be admitted to a State-operated mental health facility for a minimum of 45 days; provides that the facility shall cause the respondent to be examined separately by two psychiatrists during that 45 day period.	Did not become law.
Includes a provision that a petition for the administration of authorized involuntary treatment may be heard immediately following the hearing on a petition for the involuntary admission to a mental health facility.	Signed into law by Governor.
Requires that if an individual is presented at an admitting facility who has been involuntarily admitted three times in the past 12 months for treatment for mental illness, then a petition shall be filed for involuntary hospitalization. The previous hospitalizations serve as the factual basis for the petition.	Did not become law.
Provides that prior to the release of a person who has been involuntarily committed the releasing authority must determine if the patient needs continuing medication or treatment, or a combination thereof and, if so, present a plan to monitor the patient upon release to assure compliance with medication and treatment plans; provides for court review of release and treatment plans.	Did not become law.
Includes a modification to provisions related to early intervention mental health treatment; further relaxes criteria in existing law; adds "the proposed patient is in need of treatment to prevent progression of the illness" as alternative criterion of early intervention standard.	Did not become law.
Includes a provision that extends the involuntary mental health outpatient mental health treatment pilot project until June 30, 2002.	Did not become law.
Expands the category of petitioners who the district attorneys shall represent in court proceedings (for emergency and involuntary admissions) to include certain mental health professionals, facility administrators, correctional institution administrators, peace officers and district attorneys.	Passed Senate and House. Bill did not become law.
Amends the Mental Health Procedures Act. Establishes a Kendra's Law type of program (assisted outpatient treatment).	Pending.
Amends the Mental Health Procedures Act. Establishes a Kendra's Law type of program (assisted outpatient treatment).	Pending.
Revises definitions of danger to self and danger to others; removes imminence requirement by deleting "very" from "very near future;" provides that treatment history and recent acts/omissions can be used as evidence; expands "gravely disabled" provision to include a reasonable expectation of serious physical harm due to a person's inability to take care of essential medical care.	Signed into law by Governor.
Includes a provision that amends code relating to mandatory outpatient treatment; specifies who shall be involved in developing the mandatory outpatient treatment plan.	Signed into law by Governor.
Includes a provision which removes the requirement for a court to find that a person is an "immediate" danger to self or others for a civil commitment and specified criminal commitments; amends criteria for civil commitment.	Passed Senate. Did not become law.
Provides that courts are to consider prior history or pattern of decompensation of a committed person when deciding whether or not to continue a less restrictive alternative mental health (outpatient) commitment.	Did not become law.
Includes a provision to ensure that the State's relaxed need for treatment standard, the so-called "fifth standard," would be effective beyond 2002 for court-ordered treatment.	Passed Assembly. Did not become law.

Treatment Advocacy Center Honorary Advisory Committee

The Committee is composed of distinguished individuals who are devoted to improving the lives of individuals who suffer from severe mental illnesses. Each individual has made his or her own contributions to furthering that goal. We thank them for their work and for supporting our mission.

The report makes five recommendations for improving the NIMH research portfolio:

- ♦ Rapidly and markedly increase NIMH research spending on severe mental disorders.
- ♦ Hold Congressional hearings to clarify the primary mission and priorities of NIMH.
- ♦ Merge NIMH with the National Institute of Neurological Disorders and Stroke to create a National Brain Research Institute.
- ♦ Change the name of NIMH to the National Institute of Mental Illnesses, as an interim measure.
- ♦ Shift large amounts of basic behavioral research from NIMH to the National Science Foundation.

Missions Impossible is a call to action for those with a vested interest in research into the nature, treatment and prevention of severe mental illness. The AIDS movement would never acquiesce to a similar failure to do AIDS research. Nor would the breast cancer community concede research funds that are so desperately needed. We also must refuse to relent in our demands for vital research. We must keep hope alive. Contact your representatives in Congress. Tell them not to let NIMH go to the birds!

The authors of the report encourage everyone to log onto the NIH web site (**www.nih.gov**), click on FUNDING and CRISP DATABASE and examine for yourself the summaries of NIMH-funded research grants. (For more details on accessing the CRISP database, see the box below.)

To view the full report online, visit the Center's web site at **www.psychlaws.org** or more specifically, **www.psychlaws.org/nimhreport/index.htm**. For copies of the report, contact the Treatment Advocacy Center at 703-294-6001 or by Email to info@psychlaws.org.

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[1] The report is authored by E. Fuller Torrey, M.D., President, Treatment Advocacy Center, Irving I. Gottesman, Ph.D., Department of Psychology, University of Virginia, John M. Davis, M.D., Department of Psychiatry, University of Illinois, Michael B. Knable, D.O., Stanley Foundation Research Programs, and Mary T. Zdanowicz, J.D., Executive Director, Treatment Advocacy Center.

Access Information on NIMH-Funded Research Grants

To access abstracts, in the address box on the Internet:

1. enter the address: **www.nih.gov**
2. click on GRANTS & FUNDING OPPORTUNITIES
3. under the heading GRANTS PAGE click on CRISP DATABASE
4. For currently funded grants, click on CURRENT AWARD INFORMATION. Current research grants can then be searched by search term (e.g., schizophrenia), name of PI (Principal Investigator), or grant number.
5. Under AWARD TYPE indicate whether you want new, competing, non-competing, or all types of awards. Then indicate which NIH institute you wish to review (e.g., NIMH).
6. Clicking on SUBMIT QUERY yields a Hit List that includes grant number, PI, and title. Clicking on the title yields the abstract, which provides details on the project and includes the state in which the principal investigator's research institution is located. You will need to know the state to obtain information on the amount of money a specific grant has been funded.

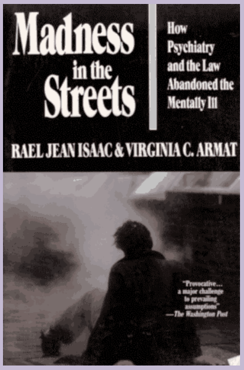
To obtain information on funding: Follow steps 1 and 2 above; then

3. click on GRANTS PAGE; click on AWARDS DATA. For current grants, go to the heading GEOGRAPHIC AREA and click on AWARDS BY STATE AND FOREIGN SITE. For earlier recent fiscal years, go to the heading REFERENCE SHELF and click on HISTORICAL DATA. For both current and earlier grants, click on the appropriate fiscal year and then on the state.

After the page is completely downloaded, use your browser's FIND function to search for grant number, PI name, or grant title. The FIND function is usually found under EDIT on the main toolbar and can also often be accessed by pressing the control key and the 'F' key at the same time.

MADNESS IN THE STREETS — HOW PSYCHIATRY AND THE LAW ABANDONED THE MENTALLY ILL

BY RAEL JEAN ISAAC AND VIRGINIA C. ARMAT



FINALLY BACK IN PRINT: *MADNESS IN THE STREETS*, originally published in September 1990, is mandatory reading for anyone who asks why thousands of individuals who clearly suffer from brain disease go without care. The Treatment Advocacy Center is proud to republish Madness in the Streets so that this valuable tool for reform continues to remain available to them, and to all who ask, "How can we stop this neglect?"

TO ORDER *MADNESS IN THE STREETS*:

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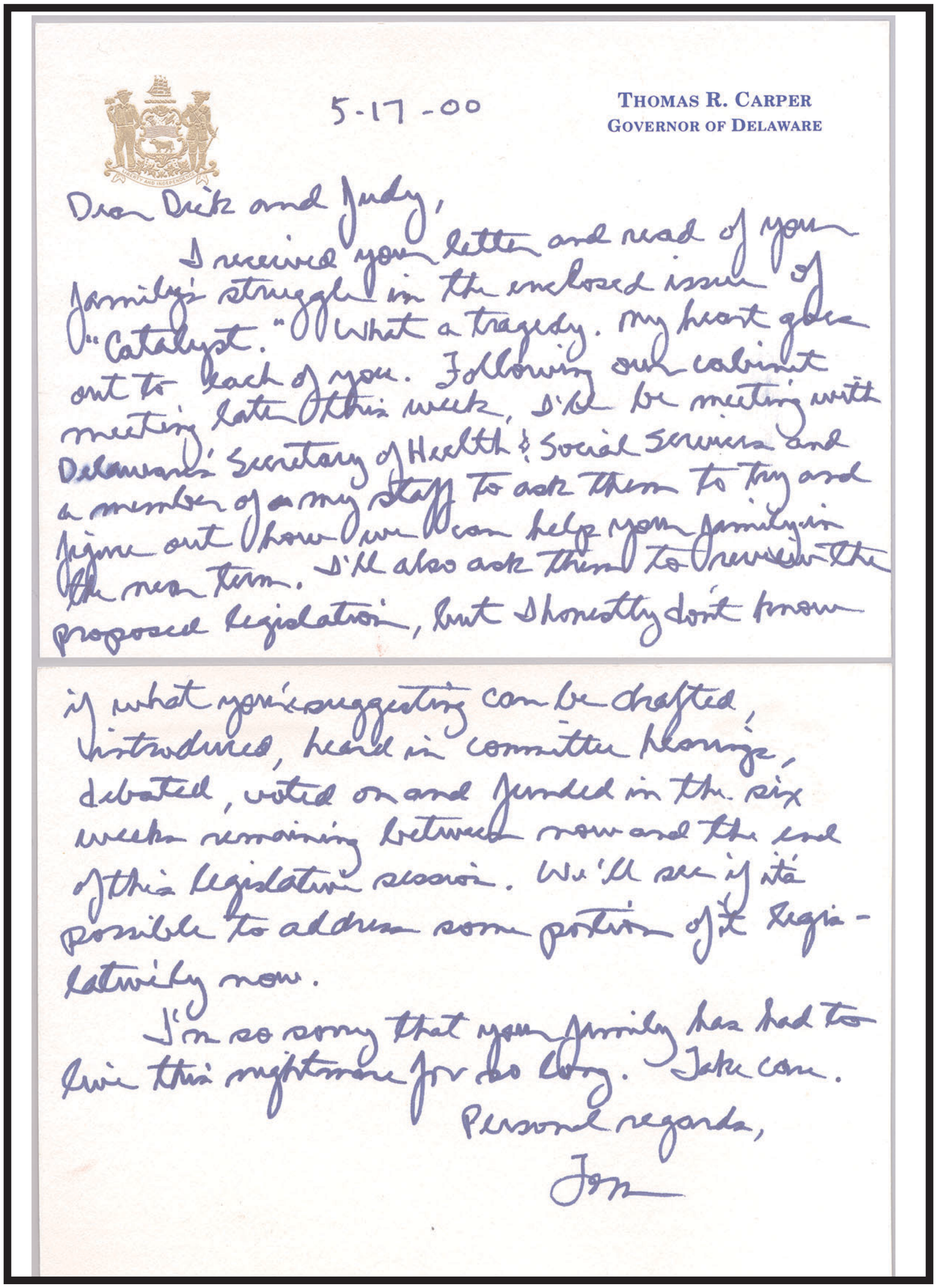
FROM A RECENT NIMH REPORT: "RESEARCH INDICATES THAT SPMI [SERIOUS AND PERSISTENT MENTAL ILLNESS] IS A FACTOR IN PERHAPS 10 TO 15 PERCENT OF VIOLENCE."



THOMAS R. CARPER
GOVERNOR OF DELAWARE

5-17-00

Dear Dick and Judy,

I received your letter and read of your family's struggle in the enclosed issue of "Catalyst." What a tragedy. My heart goes out to each of you. Following our cabinet meeting later this week, I'll be meeting with Delaware's Secretary of Health & Social Services and a member of a my staff to ask them to try and figure out how we can help your family in the near term. I'll also ask them to review the proposed legislation, but I honestly don't know if what you're suggesting can be drafted, introduced, heard in committee hearings, debated, voted on and funded in the six weeks remaining between now and the end of this legislative session. We'll see if it's possible to address some portion of it legislatively now.

I'm so sorry that your family has had to live this nightmare for so long. Take care.

Personal regards,

Tom

Pictured is a personal note that Delaware Governor Thomas Carper sent to Dick and Judy Taylor after learning of their family's struggle with untreated mental illness.

Mr. Taylor's extraordinarily moving account of their son's illness and the family's incredible journey trying to help their son was published in the March/April 2000 Catalyst (Volume 2 Number 2). The Taylor's demonstrate that persistence pays off, and they prove that sometimes the people in power do listen. Their devotion to their son is admirable. We also thank Governor Carper for his compassion.

Your Voice— Will Make a Difference

Please note me as an advocate for the Treatment Advocacy Center. When I speak on behalf of NAMI Austin and NARSAD, I'd like to educate our members on the Center's position. Do you have brief speech outlines? Do you have brochures or newsletters I could make available at NAMI meetings? If so, send them home.

Thanks and good luck,

Pam Brown
Austin, Texas

[Editor's note: The Treatment Advocacy Center is pleased to help local advocates in any way we can. We can provide talking points and materials that can be distributed at local meetings.]

We are members of NAMI and certainly would appreciate it if you could send us about 10 more copies of "Model Law for Assisted Treatment."

We know several families that would be interested in this important information.

Enclosed find our check to help in your important work. Hello to Dr. Torrey.

Nelson & Terry Goguen
Ashby, MA

Thank you for sending me the booklet, "Model Law for Assisted Treatment."

My 23 year old daughter has been diagnosed with schizoaffective disorder and lacks any insight into her illness. Over the last year and a half she has been hospitalized 12 times. If your model for assisted treatment existed, it would have made a tremendous difference in the type of care my daughter received over this period of time.

I am a member of the Board of Directors of NAMI Bucks County in Pennsylvania, the secretary of a NAMI Family Advocacy Group whose primary goal is to establish PACT programs in our county, and a family member on the advisory board of a new Community Treatment Team in Penndel, Pennsylvania. I would like to distribute your booklet [Model Law] to as many people as possible. Please send me one or two dozen copies.

I am also enclosing a check that is a donation to your organization. I joined TAC several months ago and had meant to send it sooner.

Thank you for all of the dedication and hard work of TAC. I look forward to receiving all of your emails and updates.

Jeanette M. Pulley
Newtown, PA

Dear Dr. Torrey, Mary, et al,

The following letter [from Sad Sister] was written by my daughter, Danette Dieffenbach, last year. This gift in her honor [enclosed] is her birthday present from me. She specifically requested that I make a donation to the Advocacy Center. Thank you all so much for your hard work.

Pattie Hunt, President
NAMI St. Johns, FL

Dear Ann Landers: I read the letter from "Grieving Mom," whose mentally ill daughter could not get the help she needed to recover from her alcoholism. It is time to re-examine the issue of personal freedom and mental illness.

My brother is schizophrenic and has had this problem for more than 20 years. He has been in and out of hospitals and recently was placed in an apartment with limited supervision of his daily activities. The problem is his medication.

When he takes it, he functions well. Unfortunately, when he is functioning well, he thinks he no longer needs his medication and stops taking it. This starts a downward spiral with which we are all too familiar. The results are disastrous.

My brother will probably fold out of this program and wind up in a hospital again. How could it possibly be considered cruel to force him to stay on his medication? He can be a wonderful, kind, intelligent person when he is taking his medicine. The only time he loses his freedom is when he declares himself "cured" and stops taking it. Is there a solution to this dilemma?

—Sad Sister in N.C.

Dear Sister: I do not know the answer. Schizophrenics should accept the fact that there is no "cure," but in most cases, they can live a normal life if they stay on their medication and get checked by a doctor periodically. Those who are dependable enough to do this should be left alone. The problem is, as you said, the person who feels perfectly normal stops taking the medication and runs into trouble—paranoia, hallucinations and anxiety attacks.

Perhaps it is time the government intervened for the good of those who cannot care for themselves. Allowing loved ones to commit mentally ill family members to residences where medication is monitored under the supervision of trained personnel may be the solution.

Hi Folks,

I just came across your site in my ongoing self-education about mental health issues, and I wanted to make the following comments:

I've been involved in civic/governmental activism for over 20 years, working primarily to help people understand the importance of getting involved and influencing the decision-making process of the governmental process. One of the many social phenomena I've observed is the extent to which people are resistant to be "public" about their opinions and activities. I have been successful in overcoming that in many of the issues I've promoted, getting the public to attend meetings in numbers sufficient to influence the outcomes.

Recently, I've become involved in mental health issues, particularly those surrounding [people with manic-depression]. The problems associated with sufferers acknowledging they have a problem, them seeking treatment, and their continued "compliance" are topics I hear and discuss frequently.

It isn't clear to me whether your organization has members with actual personal experience with these issues, or whether your organization is simply a legislation advocacy group. Assuming it is the latter, I would like to suggest that the legislation you propose will do more harm than good.

Most people, because of the social stigmas surrounding mental illness, are fearful of seeking treatment, fearful of acknowledging that they have a problem, and fearful of the repercussions a diagnosis of mental illness will have on their jobs and family. Now you propose to add the fear of involuntary treatment. Of involuntary "guardianship". And you openly state that this "involuntary treatment" should be imposed "...BEFORE individuals become a danger to themselves or others."

continued on page 10

continued from page 9

With what you propose, WHY would ANYONE who even suspects they have a mental health problem even SEEK treatment, thus making themselves vulnerable to “involuntary treatment”?

Clear-thinking people with minor problems will be scared away from seeking appropriate treatment, but imagine how your approach would be viewed by the fearful, the deluded, the paranoid? Would the fear of your proposal actually INCREASE violence, as untreated, extremely ill people are approached by either innocent passers-by or civil servants, who are viewed as enforcers of your policies?

Fearful and confused people need reassurance that they will be listened to, that their particular problems will be heard and acted on in a compassionate manner. Any successful hostage negotiator will confirm this. Forcing people into positions that are fixed and undesirable to them creates a “no-win” situation, and they often react with a “nothing-to-lose” approach.

I believe your intentions are well meaning, but appear to be a bit reactive to recent media stories. I have worked with the media on stories for approximately 15 years (some of which aired globally), have written press releases, and organized a number of “media events.” I am fully aware the extent to which the public and decision-makers can be swayed by dramatic reconstructions of current events. From my research into this issue, it appears your proposal relies heavily on the emotional and reactionary elements of the publics' fear and misunderstanding of those suffering with mental illness.

It will be a relatively simple effort to interview a number of people whose lives were ruined by their MISDIAGNOSIS, people who lost everything, even the families of people who have died as a result of such "treatment." Dramatic presentations of "Reality" work both ways!

The mentally ill need to be ENCOURAGED to seek treatment, not driven from it by the fear your proposal generates.

Few would argue against forcing those that have demonstrated their violent behaviors [into treatment], but existing laws are ALREADY in place to address that problem.

Given my history of activism, and interest in this issue, I stand ready to prepare a public presentation to be distributed to both the media and appropriate law makers. I would be very interested in your thoughts.

Thanking you in advance,

Tyler

[Note: The following response is from Jon Stanley, Assistant Director]

Dear Tyler:

I appreciate you taking your time to develop your thoughts. It was kind of you to share them.

I will, however, respectfully disagree with you. It is not that your concern about some people becoming reluctant to utilize voluntary services if treatment laws are reformed isn't legitimate. It is. Although, I think the extent and quality of that effect is, as of yet, undetermined.

I think our views differ as to the extent

The following memorials and tributes were received by Treatment Advocacy Center in July/August 2000. Please accept our deep appreciation for choosing our mission to support in memory or in honor of someone very special to you. . . .Governing Board and Staff.

Received From	City and State	In Memory Of	In Honor Of
NAMI Volusia/Flagler	Palm Coast, Florida		Neal and Mim Schaeffer
Stella Flynn	Nashville, Tennessee	Eddie Flynn	
Rose Mary Boheler	Wallingford, Pennsylvania		Victoria Ballard
Dorothy Groh	Raleigh, North Carolina	Scott Hardman	
Mary Zdanowicz	Arlington, Virginia		Alvin Englert
Mary Zdanowicz	Arlington, Virginia		The Webdale Family
JoAnn Zwack	St. Paul, Minnesota		Kyle Zwack
Loretta Houston	White City, Oregon		Ronda Houston
Ellen Rector	Denver, Colorodo		Joe Rector
Jim & Jane Carlson	Westlake, Ohio	Christopher John Carlson	
Walker & Sydney Pettyjohn	Chatham, Virginia	Stephen Kemp Pettyjohn, our beloved son	
Joan Zane	Sun City West, Arizona	Sam Johnston	
Pattie C. Hunt	St. Augustine, Florida		Mrs. Danette Dieffenbach
Susan Spadafora	Winter Springs, Florida		Ruthanne Stamper
Frances White	Haverford, Pennsylvania		Dr. E. Fuller Torrey
Betty Robertson	Florence, Alabama		David Robertson
Dave Gold	Woodhaven, New York	Ellen Westphal	
Michael & Joan Long	Mechanicsville, Maryland	Scott Hardman	
Willis & Jurine Schellberg	Hovland, Minnesota	Scott Hardman	

of the impact of that effect (if any) relative to the value of rational treatment laws.

Allow me to explain my assessment. I will address the two sides of the scale one at a time.

There is much about the need for treatment law reform and the benefits of doing so on our web site, so I will be brief on that subject. One of the two main reforms we promote is the adoption of a need for treatment standard in those states which allow for treatment only when a person is dangerous. Without such a standard, people who refuse treatment because they are psychotic cannot be helped unless they are dangerous at the time. While I am admittedly now jumping from one scale to the other, there is no fear of alienating such people from treatment because they are already refusing it. Many thousands who do not get help because of such laws end up homeless, in jail, or taking their own lives. I see great value in helping them

The second main objective of our reform effort is to get states to adopt and use assisted outpatient treatment. The substantial majority of the studies available (and there are quite a few) show that this treatment mechanism reduces hospital days, promotes treatment compliance, decreases subsequent admissions, and reduces violence. It also allows some patients to receive treatment in the community rather than an inpatient facility. I see value in doing all those things.

Now, as to the possible detrimental effect on treatment participation caused by legal reform in this area. What you say makes logical sense, but I am still unconvinced that it is true. One problem is that there is a dearth of studies on this. I would like to see more in the future. If you have any such research, I would be very interested in seeing it.

Some of the outpatient commitment studies show that people placed under treatment orders are more likely to maintain treatment once their order expires than people not placed under them. I also know that the Policy Research Associates study of the pilot outpatient commitment program at Bellevue found no significant difference in the level of coercion perceived by those who were in court-ordered treatment and those who were not.

Perhaps more significant is that the changes we seek are in some form in many states. Forty-one states have assisted outpatient treatment. About half have a type of need for treatment standard. We are in touch with hundreds of people all over the country. We have not heard about people in those states shunning treatment because of these progressive laws. Plus, as many of these have now been around for almost two decades, it is surprising that research demonstrating that treatment law reform leads to treatment avoidance has not emerged.

I also know that my own experience is not unique. I refused treatment for almost three years after I was diagnosed as having bipolar disorder, all the while sinking into an increasingly dramatic symptomatic spiral. Due to my behavior I was eventually placed in treatment against my "will." I was given treatment and got better. And because of that, I am now religiously faithful to my treatment. So for me, at least, it was an intervention that made me more likely to seek treatment.

All that information is not enough to come to a definite conclusion, but it is enough so that I am certain that I cannot come to one concerning the effect of treatment laws on voluntary access to treatment. Combine that with the vital benefits of treatment law reform, and you have why I am not in complete agreement with your take on this.

It may interest you that we have other staff and two board members who also have mental illness.

Again, thank you for your comments. I wish you luck in your advocacy efforts.

Jonathan Stanley
Assistant Director
Treatment Advocacy Center

The End Game

by Scott J. Mahoney

You turn my port in a storm
Into a profit business
How dare you make a profit
On my mental illness

The end game seems to be
Violence, prison and death
Sometimes baby, baby
I can barely catch my breath

Oh, whatever happened to
Corporal acts of mercy
When judgement time comes
I hope I'm on the jury

You say you want to make me
So strong and independent
When far away distant places
Are the places I can afford rent

Here I am living
In the richest of nations
I can barely afford sometimes
To buy my medication

They're building prison cells
To the left and the right
Cutting funding for the mentally ill
Say they're defending our rights

While some lucky few might make it
Most slip through the cracks
Mental illness is a horrible thing
To carry on your back

They say they want consumers
To live in society
Is eating out of garbage cans
Defending our liberty

You try to condemn me
When I self medicate
Like calling me to dinner
Giving me an empty plate

If life had dealt me cancer
I'd be treated with compassion
Since I have mental illness
I'm surrounded with inaction

Side effects do range
From dry mouth to impotence
Living with this day by day
Yeah, in the present tense

Living on the streets
And you say I've got rights
Stop and take a look for once
At the quality of life

While so called normal folks
Are living in denial
Life is just a vicious game
Of existence and survival

[Note: Scott Mahoney, who is diagnosed with schizophrenia, is an excellent writer who has contributed previously to Catalyst.]

TREATMENT ADVOCACY CENTER

CATALYST

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Please help the Treatment Advocacy Center achieve its mission to eliminate the legal and practical barriers to treatment for millions of Americans who suffer from, but are not being treated appropriately for, severe brain disorders, such as schizophrenia and manic-depressive illness, and to prevent the devastating consequences of non-treatment:

homelessness, suicide, victimization, worsening of symptoms, homicide, and incarceration.

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