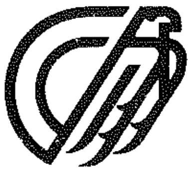

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July 18, 1984

Dear NAMI Member:

I was greatly impressed by your passion and commitment at the recent conference of the National Alliance for the Mentally Ill, so I devoted a special section to the conference in my national newsletter, MENTAL HEALTH REPORTS.

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Mental Health Reports

Vol. 8, No. 15 July 18, 1984

Major Stories In This Issue:

First-Time Funding of Program Could Help Chronically Mentally Ill Page 2

Membership of Fiery Family Advocacy Group Mushrooms . . . Page 3

NAMI Members Debate Treatment For Young Adult Chronic Patients . Page 4

PET Scans May Help To Discover Causes Of Mental Illness . . Page 6

Families Say Best Services Are The Least Available . . . Page 7

Legislative Update, State News, Resources . . . . Pages 7-10

DEMOCRATIC PLATFORM FAILS TO INCLUDE THE MENTALLY ILL

Despite planks advocating federal support for a large number of special interest groups, the 1984 Democratic platform contains not a single reference to the mentally ill.

As might be expected, the 55-page document repeatedly scores President Reagan's record on nearly every issue under the sun. But aside from one potshot taken at Reagan for the administration's handling of the Social Security Disability Insurance program, the platform only touches peripherally on mental health-related issues.

A member of the Democratic Platform Committee (DPC) was quick to point out, however, that the committee did not intentionally bypass programs or philosophies that deal with the problems of the mentally ill.

"If it [a plank championing the needs of the mentally ill] had been proposed during the regional hearings it would have been included," explained DPC advisory council liaison Stephen Kent.

When asked why the mentally ill were not mentioned in the Democratic platform, one Washington-based mental health advocate cited the difficulty advocates have in reaching a consensus. "You can't formulate a general mental health policy because everybody wants to go their own route and it's just a shame," Clarence Martin of the Association for the Advancement of Psychology said.

Martin said advocates had planned to get together to draw up a plank. But scant interest was shown and the effort never got off the ground, he said. "The bottom line is we just didn't do anything about it."

But one Washington-based mental health advocate offered another view. "I know that there was testimony presented by several of our groups at regional [DPC] meetings," said Bernie Smith, executive director of the National Alliance for

(more)

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DEMOCRATIC PLATFORM FAILS TO INCLUDE THE MENTALLY ILL (Cont.)

the Mentally Ill (NAMI). Smith said Washington and New York were two of the states where the groups spoke during DPC hearings.

Optimistic Despite the lack of a mental health plank in the platform, delegates from the state of Washington are optimistic about getting their state's mental health plank adopted during floor debate this week at the Democratic National Convention in San Francisco. The one-sentence plank reads: "We support [federal] increases in the budgeted amounts for state mental health programs."

"In every one of the caucuses at the local, county and state level it passed unanimously," said Eleanor Owen, a NAMI member from Seattle who lobbied for the plank. "I will predict that it will be included in the national platform."

But even if the Washington plank is included in the Democrats' platform, the modest statement will not approach the extensive platform planks that advocate for the elderly, the disabled and the poor.

Despite its failure to directly address the problems of the mentally ill, the platform does touch on a few related issues. For example, the platform calls for community-based child abuse prevention programs, an overhaul of vocational education, and job skills development for the unemployed and underemployed, who include the mentally ill.

The platform is especially critical of the Reagan administration's handling of the Social Security Disability Insurance program. It charges the administration with unfairly removing thousands from the disability rolls. --PR

FIRST-TIME FUNDING OF REHAB PROGRAM COULD HELP CHRONICALLY MENTALLY ILL

For the first time, a Senate panel has provided money for a rehabilitation program that could provide significant aid for the chronically mentally ill.

The Senate Appropriations Committee included $5 million for "Independent Living Services" (ILS) grants to states in its fiscal 1985 Labor, Health and Human Services, and Education money bill. The panel marked up the bill June 26.

Authorized under the 1978 amendments to the Rehabilitation Act, ILS is a program designed to teach basic life skills to persons who are too severely disabled to work. ILS, however, has never been funded by Congress, although money has been appropriated in the past for model independent living centers (ILC). These centers now serve 20,000 severely disabled individuals throughout the nation.

There are an estimated one million chronically mentally ill persons nationwide who need training in basic life skills such as how to budget money, how to use public transportation, how to keep a home and how to manage their medication. All told, there may be four to five million severely disabled persons in need of such services.

The ILS program would provide grants to state rehabilitation agencies for services to the severely disabled. Mental health proponents hope that if the program is funded by Congress, it can grow into a significant resource for the chronically mentally ill. --PR

Conference Report

MEMBERSHIP OF FIERY FAMILY ADVOCACY GROUP MUSHROOMS

In dramatically increasing numbers, relatives of the chronically mentally ill are coming out of the closet and marching headlong into the world of mental health advocacy.

That was the theme at a recent gathering of more than 1,000 relatives of the chronically mentally ill and a contingent of mental health services "consumers" at the sixth annual National Alliance for the Mentally Ill (NAMI) conference in Irvine, Calif., July 5-8.

If the passion and drive NAMI members brought to their Irvine meeting are any indication, this group could evolve into a dominant force in coming years, significantly influencing the ways providers and politicians approach mental health issues.

Grassroots A self-described grassroots organization, NAMI has mushroomed in size since its inaugural 1979 meeting in Madison, Wis. Since then, NAMI membership has grown from 300 to almost 16,000, with 3,000 new members in the last year alone. The organization now has 315 chapters nationwide.

At that first meeting, 300 disparate family advocacy groups from around the nation got together simply to share ideas and experiences. Out of that meeting NAMI was born.

NAMI focuses its efforts on family support, education and advocacy. The group also is in the process of setting up a research foundation similar to the fledgling American Mental Health Fund (AMHF) headed by Jack Hinckley.

Headquartered in Washington, D.C., NAMI elects four persons to its 12-member board of directors each year. Board members serve for three years. Anyone who wants to help the chronically mentally ill may join the group for a $15 yearly membership fee. Groups of individuals may also join for a one-time $25 fee plus $1 per member per year.

NAMI goals include promoting or providing:

- establishment of self-help advocacy groups;
- knowledge about the causes, symptoms and treatments of mental illnesses;
- practical information families of the chronically mentally ill need;
- education of families, friends, and the public about mental illnesses in order to eliminate the myths and stigma surrounding mental illnesses;
- research into the physiological, neurological, biochemical and genetic aspects of chronic mental illnesses; and
- legislation to ensure quality services for the chronically mentally ill.

Fervor But the fervor of its members is what sets NAMI apart from other advocacy groups. NAMI members all have a personal tragic tale to tell--of a son or daughter or other loved one who has been in and out of psychiatric hospitals and perhaps jail. And those experiences spur them on.

Throughout the conference NAMI members debated the issues long into the California night. The discussions were often highly charged and a tight-knit camaraderie among participants was apparent. As NAMI member Barbara Pilvin

(more)

MEMBERSHIP OF FIERY FAMILY ADVOCACY GROUP MUSHROOMS (Cont.)

explains it: "We are one enormous, often unhappy, but very loyal family."

Adds NAMI Vice President Helen Teisher: "We are now too many to be ignored and too committed to be dismissed."

For more information, contact National Alliance for the Mentally Ill, 1200 15th St. NW, Washington, D.C. 20005 (202)833-3530. --PR

NAMI MEMBERS DEBATE TREATMENT FOR YOUNG ADULT CHRONIC PATIENTS

Perhaps not surprisingly, the hardest-to-treat mentally ill patient--the young adult chronic--also inspires the most contentious debate among professionals and parents.

The tragic puzzle of this patient population was the subject of workshops and countless private discussions at the National Alliance for the Mentally Ill (NAMI) conference. NAMI members are by-and-large parents and siblings of chronically mentally ill young adults.

More Research While differing on details, NAMI members agreed on the need for a two-part effort to serve this difficult group. Members lobby hard for more research into the biological causes of mental illness, hoping that soon researchers can break through into significant new knowledge about the brain's role in mental illness.

NAMI members often point to the progress researchers have made against cancer in recent years, in large part because of an abundance of research dollars poured into the battle by the National Cancer Institute (NCI).

During fiscal 1984, NCI's research budget totaled $890 million while its counterpart, the National Institute of Mental Health (NIMH), received $174 million for research during the same year. Over five million Americans have a history of cancer and approximately three million of those are considered cured. In contrast, an estimated 33 million to 38 million Americans have a history of mental illness, according to NIMH.

Services However, expanded research won't quench "the hunger and the thirst of these very lonely people" or help them with their problems today, noted Dr. Bert Pepper in a workshop on the chronically mentally ill. "Let's not put all our eggs in one research basket; we need services and we need them yesterday," Pepper told the audience. The psychiatrist runs an inpatient unit for Rockland County, N.Y., and has worked with young adult chronic patients for over 15 years.

Using his 64-bed acute care facility, Pepper recently conpleted a study of 600 young adult chronic patients. Drawing from the study's findings and his personal experience, Pepper offered a wide range of observations and opinions regarding this patient group, including:

- Pepper says 70 percent of his patients admit to some form of drug or alcohol

(more)

NAMI MEMBERS DEBATE TREATMENT FOR YOUNG ADULT CHRONIC PATIENTS (Cont.)

abuse, which is "either a cause or a complicator of their diagnoses. For a seriously mentally ill person any substance use is substance abuse."

- "There is very little meaningful case management" for the young adult chronic patient. "One administrator told me he had a case-management ratio of 200 [patients] to one [case manager]. I told him: 'Shut down your program and stop perpetuating a fraud.'" Pepper's clinic has a ratio of about 35:1.

- Pepper says the young adult chronic is a person who lacks work experience and self-confidence, is "exquisitely rejection-sensitive," and is plagued by substance abuse, a personality disorder and often an underlying biological disorder.

- "The point at which we can start putting things together is at the point of crisis. If we just treat the crisis we've lost the ballgame." Pepper tries to bring the patient's family into the situation. Multi-family educational support groups like NAMI are essential if these people are to have a chance, Pepper says. "People burn out because there are too few people involved."

- Pepper also fights to get the patient active in a social rehabilitation program as a prelude to vocational rehabilitation. "Until we know he won't screw up a job, we don't send him." --PR

PET SCANS MAY HELP TO DISCOVER CAUSES OF MENTAL ILLNESSES

In this age of technological wizardry, researchers are beginning to look to high technology to help discover the baffling brain processes that contribute to and perhaps cause mental illnesses.

The latest weapon in this battle is called a positron emission tomography (PET) scan, which is a vastly superior successor to the now-famous computerized axial tomography (CAT) scan.

PET scans use radioactive isotopes to mark glucose activity in the brain. The brain uses glucose for energy and the sugar's chemistry is very well known, explained Dr. Monte Buschbaum, professor of psychiatry at the University of California at Irvine (UCI). Buschbaum was speaking to attendees at the recent National Alliance for the Mentally Ill (NAMI) conference.

PET scans produce color images that enable researchers--by watching the marked glucose--to see which areas of the brain are active at certain times.

In Its Infancy "The process is in its infancy," Buschbaum said. Although present PET scan images are limited in resolution to approximately one-half inch, the images will get as sharp as photographs in three to five years, he added.

Since glucose activity in the brain may be used to reveal actions of other brain compounds known to play a role in mental illnesses, the research possibilities using PET scans are vast and promising, Buschbaum said.

(more)

PET SCANS MAY HELP TO DISCOVER CAUSES OF MENTAL ILLNESSES (Cont.)

For example, receptors of a brain compound known as dopamine could be located by attaching the radioactive isotope to drugs normally used to treat psychotic patients. Since the drugs, known as neuroleptics, attach to dopamine receptors in the brain, the drugs' activities could be pinpointed, Buschbaum said. This would tell researchers whether dopamine-active areas of the brain are important in psychosis as many psychiatrists believe.

By using computer techniques, PET scans also are able to produce images of the brain from different angles.

Although there are 25 PET scans now in operation throughout the world, UCI has the only one located in a department of psychiatry, Buschbaum noted. The researcher is gearing up for the university's first major experiment using the PET scan.

The research will compare the scans of two different groups diagnosed as schizophrenic, one group in which the disease started prior to age 10 and a second group labeled schizophrenic during adulthood. "Studying the onset of the disease before and after puberty might sort out some the biological factors involved," Buschbaum said.

Expensive One major drawback to the PET scan process is its expense. The radioactive isotope used in the process must be produced in a cyclotron, a large electromagnet that can be used to change the structure of atoms. Since UCI does not have a cyclotron, the isotope will have to be airlifted from the University of California at Davis upon its creation. Each PET scan experiment requires precise timing since the isotope has a half-life of only 108 minutes.

In addition, each PET scan machine costs $750,000 and testing a single patient osts $2,500.

For more information contact Dr. Monte Buschbaum at (714)856-4244. --PR

FAMILIES SAY BEST SERVICES ARE THE LEAST AVAILABLE

Results of a California survey of families of chronically mentally ill patients show that some of the most effective types of mental health services for these patients are among the least available.

Although the survey was not a rigorous academic study, its results shed light on how families who see first-hand the results of treatments perceive mental health services.

Survey results were based on a questionnaire filled out by 199 members of the California Alliance for the Mentally Ill (CAMI). CAMI is affiliated with the National Alliance for the Mentally Ill (NAMI), a grassroots organization of relatives of chronically mentally ill individuals.

Crisis Centers Most Helpful Of 12 types of services listed as tried by relatives of the 199 families, crisis centers and skilled nursing facilities

(more)

FAMILIES SAY BEST SERVICES ARE THE LEAST AVAILABLE (Cont.)

were deemed the most helpful. Socialization centers and private hospitals were next in line. Vocational rehabilitation and counseling from clergy members were ranked as least helpful.

Crisis centers and socialization centers fall under the "community residential treatment centers" rubric. Families most often mentioned these types of centers when asked what mental health services could best fit their needs. Many also noted "that they wanted work and training that was appropriate for their family member, with support and low pressure," the report added.

Private psychiatrists were sought out by 88 percent of the families responding to the questionnaire, but were ranked midway on the helpfulness scale. On the other hand, neuroleptic drugs prescribed by psychiatrists "were very or somewhat helpful" 85 percent of the time, families said. Eleven percent said neuroleptics did not help or had negative effects.

Perhaps it is not surprising that families surveyed don't rate psychiatrists as high as the drugs they prescribe.

NAMI literature, as well as discussions at the group's recent conference in Irvine, Calif., reflect a certain wariness toward traditional psychiatric practices. A NAMI flyer describes NAMI as an "active constituency... to promote and provide information about professionals willing to work with, not against, families." The group also advocates "changes in training for mental health professionals to foster a more enlightened awareness of the nature of chronic mental illnesses and how we as families can be involved in their treatment."

Turning to types of mental illnesses, families mentioned schizophrenia as the most frequent diagnosis. Sixty-six percent of the mentally ill family members have been diagnosed as schozophrenic, with an additional 17 percent labeled schizophrenic in combination with another mental illness, usually an emotional disorder.

Peak Period Almost two-thirds of the families surveyed noticed a member's mental illness when the person was between the age of 15 and 24, the report said. "The peak period of mental breakdown is clearly in the late teens," with 42 percent of families reporting onset of illness during those years, the report said. Also, 73 percent of the mentally ill were male.

Half of the families said their mentally ill family members had been in jail, although some said the jail stays were just overnight detentions until the individuals could get into hospitals. --PR

Legislative Update

■ Fiscal 1985 Budget--H. Con. Res. 280 House-Senate conferees failed to reach a compromise on the first budget resolution for fiscal 1985 before leaving town. the Senate version of the budget resolution, passed May 18, would freeze most domestic discretionary programs, including the Alcohol, Drug Abuse and Mental Health Services (ADAMHS) block grant, at 1984 levels. The House

(more)

LEGISLATIVE UPDATE (Cont.)

budget resolution was passed April 5 and would hold most domestic programs, including those serving the mentally ill, to 3.5 percent before-inflation increases (MHR, April 11).

The budget resolution only sets recommended spending ceilings and is not legally binding. This year, the Senate's budget figures were shifted around to give health-related programs more money despite the freeze, says Tony McCann of the Senate Budget Committee. The amount of the money the programs will actually get next year, however, depends primarily on the recommendations of the House and Senate appropriations committees, he said.

■ Fiscal 1985 Labor, HHS and ED Appropriations--S. 2836 The Senate Appropriations Committee June 26 approved a fiscal 1985 money bill for the departments of Labor, Health and Human Services and Education.

The panel would boost the ADAMHS Block grant by $28 million to $490 million and give NIMH $195.9 million for research, $12 million for demonstration projects and community support services, $21.2 million for research training and $25 million for clinical training. The research dollars would be up from $174 million in fiscal 1984.

The House Labor, HHS and Education Appropriations Subcommittee marked up its version of the money bill in secret June 26 and embargoed its recommendations until the measure is considered by the full committee. However, sources say the subcommittee deferred action on all programs, including the ADAMHS block grant, that have not yet been reauthorized by Congress (MHR, July 4).

■ ADAMHS Block Grant Reauthorization--S. 2303, HR. 5603 The House passed its version of the ADAMHS block grant reauthorization June 11. The bill would authorize $532 million for the block grant next year, $546 million for 1986 and $598 for 1987 (MHR, June 20, May 23).

The measure would require states to spend 10 percent of their block grant allotment for treatment programs for women substance abuser and severely mentally ill children and teenagers.

The Senate passed its $522 million block grant package April 26. The measure includes $490 million for the block grant, an additional $7 million to fight substance abuse among women, $20 million for demonstration projects and services for the chronically mentally ill and $5 million in grant money for research (MHR, May 9).

The two versions await a House/Senate conference that proponents hope will be scheduled during Congress' July 23-August 10 mini-session between the Democratic and Republican National Conventions.

■ Social Security Disability Insurance Reform Bill--S. 476, H.R. 3755
The Senate May 22 passed its version of the Social Security Disability Insurance reform bill, a compromise package backed by the Reagan administration. A similar bill had sailed through the House on March 27 by a vote of 410-1.

Staffers from the Senate Finance Committee and the House Ways and Means Committee have been conferring in an attempt to iron out the differences in the two bills prior to a House/Senate conference. Although a conference date has not yet been set, advocates expect the conferees to take up and complete work on the bill during the upcoming three-week session July 23-August 10.

State News

■ Dr. Joseph Bevilacqua was reinstated July 5 as Virginia's director of mental health by Gov. Charles Robb. Bevilaqua was suspended without pay May 24 when Robb ordered an investigation into alleged mismanagement and criminal wrongdoing at Virginia's Department of Mental Health and Mental Retardation (MHMR). Robb ordered the investigation after reviewing a sealed grand jury report in mid-May.

However, a report drawn up by Robb's office and released shortly after Bevilacqua's reinstatement charged the director had "seriously neglected the management of the central office." In addition, Bevilacqua was given two weeks to come up with a plan to deal with a list of problems outlined in the report.

Bevilacqua inherited in 1981 an agency fraught with dissension among staff and serious managerial deficiencies, the report said. But as director, the report continued, Bevilacqua failed to address those problems and other abuses throughout the system.

In part, the controversy has focused on $575,000 in contracts awarded by MHMR during 1982-1983, as well as charges that top mental health officials did little to clean up longstanding mismanagement practices at the sprawling Central State Hospital complex at Petersburg. Auditing, capital outlay and maintenance practices also came under fire in the governor's report.

Despite a strict state law that limits sole-source contracts to products available from only one vendor, Robb's investigators found MHMR had awarded more than a quarter of its contract bids without competition.

■ A legislative review says Indiana's mental health program has made progress in recent years, but still needs major revamping in certain areas. The 348-page report to the state legislature's Sunset Evaluation Committee calls for a joint effort from community mental health centers (CMHCs) and state psychiatric hospitals to coordinate programs. The report also notes that some areas of the state's mental hospitals fall short of Medicaid certification standards. But despite the shortcomings, the report adds, the state allows the hospitals to continue to receive Medicaid payments through extensions on compliance deadlines, waivers and appeals.

In addition, the report says Indiana fails to provide adequate aftercare treatment for patients released from State Department of Mental Health facilities. However, it praised initiatives undertaken by Mental Health Commissioner David Jones to increase community living arrangements for the mentally impaired.

■ In Rhode Island, intense lobbying has paid off for private mental health agencies that get state funds to provide services to drug and alcohol abusers and the state's mentally impaired. After learning that Governor Joseph Garrahy's fiscal 1985 budget for the state Department of Mental Health, Retardation and Hospitals (MHRH) proposed to keep funding of private community programs at this year's $19.4 million level, private agency representatives started a media blitz and descended in force on Providence.

When the smoke cleared, agencies had come away with a 4.4 percent boost in funding, which translates into a $850,000 increase. Agencies had argued that their employees are already among the lowest paid in the state and better workers would leave if they did not get raises. The state legislature passed the $145 million MHRH budget May 15.

Resources

■ **Health Insurance and Psychiatric Care: Update and Appraisal,** a book billed as the first major publication on insurance and mental health care in over 10 years, has just been published. The work examines the current status of what have become known as third-party payments for psychiatric care. These include both private and government-subsidized insurance.

Authors Steven Sharfstein, Sam Muszynski and Evelyn Myers tackle a number of prevailing problems regarding insurance of psychiatric care. They examine the special problems such care presents for insurers. They also explore the cost stability, predictability and cost effectiveness of third-party payments and emerging trends and challenges of the future.

The book also contains an extensive section on research findings from a variety of sources. Researcher Jo Brady has used the research results to plot the advantages and disadvantages of various mental health care insurance plans. The book is available for $19.95 plus $2.00 shipping from American Psychiatric Press, 1400 K St. NW, Washington, D.C. 20005 (202)682-6000.

■ **The National Association of Private Psychiatric Hospitals (NAPPH) has drafted guidelines** for inpatient psychiatric programs for the treatment of children and adolescents, for alcoholism treatment and for partial hospitalization. The guidelines describe admission and discharge criteria for each of the programs.

The guidelines are designed "to help those who create hospital-based psychiatric programs and those who reimburse for psychiatric inpatient care understand the treatment needs of the mentally ill," explained NAPPH Executive Director Robert L. Thomas. They are available free of charge from NAPPH, 1319 F St. NW, Suite 1000, Washington, D.C. 20004 (202)393-6700.

■ **Marketing for Mental Health Services,** a collection of articles from Health Marketing Quarterly, is now available. The volume looks at how marketing can be helpful in promoting mental health services and in making decisions relating to the accessibility, pricing, types and quality of such services. Articles in the book also deal with community relations. The book is available from Haworth Press, 28 East 22nd St., New York, N.Y. 10010 (212)228-2800 for $24.95 plus $2.00 shipping.

■ **A Department of Health and Human Services report,** "The Hidden Mental Health Network: Provision of Mental Health Services by Non-Psychiatrist Physicians", is now available. Based on a study by HHS' Bureau of Health Professions, the report documents the role played by non-psychiatrist physicians in mental health care. For copies of the report contact the National Technical Information Service, 5285 Port Royal Rd., Springfield, Va. 22161 (703)487-4650.

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