

Family Advocacy: A Nuclear Movement



Remember the basic formula to effect change: Be well organized, strong, knowledgeable, credible, highly visible, very vocal and very determined. – Tony Hoffman, 1979

The grassroots organization and advocacy of family members of people with mental illness began in the 1960s. Initially focused on mutual support, family groups quickly became involved in advocacy at the local, state, and national levels, in fund-raising, and in working to influence policy and care for people with mental illness. In the 21st century, family members continue to serve as prominent advocates at all levels of government, and they provide support and education for patients and their families.

From Family Caregiving to the Asylum

The family care of people with mental illness in the United States dates back to colonial times. In the early years of the republic, families were responsible for meeting the basic needs of their relatives with serious mental illness. Though such care was most often a private matter, the care of “distracted persons” or “lunatics” became the community’s responsibility when a mother or father became ill and could no longer work, a loss that could spell financial ruin for the family.



Stockton State Hospital founded 1851

In the early 19th century, the responsibility for caretaking began to shift away from families toward public institutions. The rapid urbanization of the country created denser communities in which people with severe behavioral symptoms became more noticeable. Families often became widely separated when children moved to the cities or the Western states to seek employment. Unease about security rose, and the informal and communal approach to treating mental illness no longer passed social muster. The rise of asylums – later called mental or psychiatric hospitals – grew from the need to more systematically address mental illness in an urban, industrial society that relied less on its families and local communities to provide education, health care, and other social services. The institutionalization of people with mental illness increased over the next 150 years, peaking in 1955 with a nationwide inpatient psychiatric population of almost 559,000. In California, by the 1950s, fourteen state hospitals housed a population of over 36,000.

The Ideal of Moral Treatment and the Reality

Many 19th century asylums employed the “moral treatment” methods promoted by **Philippe Pinel** of France, methods that sought to normalize patient behavior through pleasant surroundings, humane treatment, productive activity, and a regular schedule.



Philippe Pinel 1745-1826

By the 20th century, the hospital beds were filled with the elderly and persistently ill and many psychiatrists had become convinced that people with serious mental illness had little hope for recovery. **Legally, patients enjoyed few rights.** Governed by vague, broadly-defined state rules defining the rationale and duration for involuntary hospitalization, people with an (undefined) “overall mental condition” who were believed to require treatment and supervision could be institutionalized indefinitely. In practice, these hospitalizations lasted from days to decades.

Although physicians and administrators saw themselves as providing compassionate care, overcrowding and inadequate staff often meant that patients were neglected, forced to live in substandard conditions and even abused.

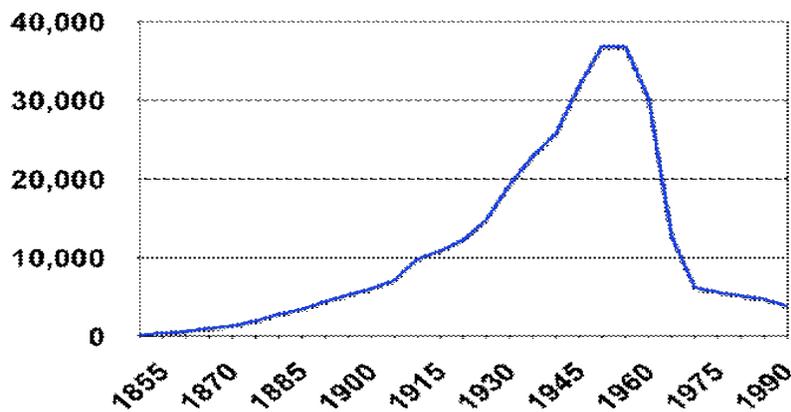


Deinstitutionalization

In response to the burgeoning costs of long-term hospitalization and the development of promising new medications such as chlorpromazine, policy-makers in the 1950s and 1960s began to reduce state hospital populations, while reformers hoped for a new community-based mental health care system, as envisioned in the Federal **Community Mental Health Centers Act of 1963.**

California was a leader in this movement. In 1957, the State legislature passed **the Short-Doyle Act**, which laid the initial philosophical and financial groundwork for community-based mental health care, providing 50% matching funds to augment county mental health services budgets. The state's 1968 **Lanterman-Petris-Short (LPS) Act** raised the state match to 90%, but also dramatically redefined new and restrictive conditions under which a person could be involuntarily committed to a psychiatric hospital. These key pieces of legislation mandated and funded treatment, and they shifted the clinical burden of mental health care from the state to local communities. Nine state hospitals in California eventually closed as a result of the rapid drop in patient census.

Equation 1



Calif State Hospital Census 1855-1990

Advocates of “deinstitutionalization” foresaw community mental health centers providing medications and continuity of care to patients as they were released, but grossly inadequate state funding and insufficient community resources devastated the successful implementation of this well-intentioned vision. Community mental health care services in California remained severely limited.

The effects of these shortfalls unfolded rapidly. Many patients could not adjust to life outside the hospital and were soon living on the streets or caught in a repetitive cycle of arrests, short-term hospitalizations, and incarcerations. Others went home to their families, where parents, grandparents, and adult siblings were forced to take on new roles **as caregivers, service providers, system navigators, gatekeepers and advocates**. They learned how to apply for benefits, interceded with clinicians, and searched for housing and services. They found that their loved ones were often considered low-priority in community treatment programs. Attempts to establish group homes met with local resistance and stigma.

We often hear the community mental health workers say they ‘do not want to baby-sit schizophrenics.’ We need long-term programs staffed by persons who are not only willing to work with schizophrenics, but consider it a worthwhile job. – policy statement of Parents of Adult Schizophrenics, San Mateo County, CA, 1975

We receive our family members back to our homes not necessarily because we want to have our adult-child living with us, but because there are so few places where they can go for treatment, care and possible rehabilitation at whatever level they can function.

We families are unable to meet the needs of our ill members at home but often feel we must serve in a holding role until something can be located that will help his/her situation. – Don Richardson of NAMI, 1988

While patients' families had been significant and highly involved caregivers even before deinstitutionalization, the importance of their role grew as deinstitutionalization unfolded. Many discharged clients would have fallen through the social cracks left by the closure of state hospitals, had not family members acted as primary caregivers, searched for housing, learned to apply for benefits, and advocated with clinicians on their loved one's behalf.

Professional Response to Families

When they turned to psychiatrists for help, families often encountered resistance and disparagement. Some psychiatrists of the 1960s and early 1970s believed that families could contribute little to treatment of persons experiencing mental illness, even that family care was more likely to exacerbate the disorder. The most extreme form of this was the view of psychoanalyst Frieda Fromm-Reichmann, who wrote in 1948:

The schizophrenic is painfully distrustful and resentful of other people, due to the severe early warp and rejection he encountered in important people of his infancy and childhood, as a rule, mainly in a schizophrenogenic mother. During his early fight for emotional survival, he begins to develop the great interpersonal sensitivity which remains his for the rest of his life. – Frieda Fromm-Reichmann, "Notes on the development of treatment of schizophrenics by psychoanalysis and psychotherapy." *Psychiatry* 11 (1949): 263-273.

By the 1960s, some psychiatrists had extended this "schizophrenogenic mother" hypothesis to both parents and even to whole families, referring to the diagnosed individual as the "identified patient," while implying that other family members were hostile, rejecting, or also suffering from some pathology. By the late 1970s, research refuting the validity of the schizophrenogenic theory was more seriously considered, and the theory was eventually largely discredited.

But, in the early deinstitutionalization era, families found themselves disillusioned and stigmatized by clinicians who often considered them to be, at worst, part of the illness, or at best, relatively unimportant participants in their loved one's care. Parents and other family members felt that they were intentionally excluded from discussion and decisions made about treatment and care, yet they often had nowhere to turn in a crisis or to find help with housing, day care, or financial support. The families experienced the perfect storm, confronting an uncooperative and disorienting mental health system, their concern and anxiety about their loved one, and the lack of support and community for themselves.

Mental health professionals...seem to be above being responsible to the public. They surround themselves with a mystique....As parents of schizophrenics, we are told that we are too emotionally involved. – Patricia Feerick, 1975

[My] adult daughter was diagnosed by one of our leading psychiatrists as being undifferentiated schizophrenic. I do not know what that means... only two of the doctors and the sociologist would discuss her condition with me. The others thought I was seeking information from them which she revealed in confidence, which certainly was not my intention. – a mother, 1978

Many schools of psychiatric thought hold the patient's family responsible for aggravating and even generating his illness....Even before their initial contact with the mental health establishment, the family members are usually guilt-ridden and feel a keen sense of failure for having 'produced' a schizophrenic. -- Lamb and Oliphant, "Schizophrenia Through the Eyes of Families." *Hospital and Community Psychiatry* 29 (Dec 1978): 803-806.

Genesis of the Family Movement

Early family organizing occurred in **eight different states, with New York and California** the most prominent. As early as the 1940s, family members of people with mental illness were working to improve conditions at Brooklyn State Hospital. The American Schizophrenia Association (ASA) was organized in New York in 1963 to support research on the biology of schizophrenia, and small groups of parents affiliated with the ASA met to share information and support each other in the San Francisco area. Parents for Mental Recovery was organized in Marin County in 1972.

A major catalyst of what would become the Family Advocacy Movement was the work of Eve Oliphant and Fran and Tony Hoffman in **San Mateo County, California**. In 1973, Oliphant began a series of meetings in her home with other parents of adult children with schizophrenia, "to cry on each other's shoulders." Oliphant and the Hoffmans disagreed with the ASA's theory that schizophrenia could be treated with vitamins and minerals, to correct "imbalances...at the [cellular] and molecular level".

New Group to Aid Mentally Ill

By VERA GRAHAM

A new organization — The California Association, Families of Mentally Disabled — which had its origin in San Mateo County, met in its first state-wide conference recently and elected Tony Hoffman of San Mateo as its president.

Hoffman is chairman of the San Mateo County Mental Health Advisory Board and represents the San Mateo Labor Council and San Mateo County on the West Bay Health Systems Agency. Hoffman is also the business representative for Bay Area District Lodge 113 of the International Association of Machinists and Aerospace Workers.

Joining him as an officer is his wife, Fran Hoffman, who is the corresponding secretary. Mrs. Hoffman, together with her husband, have long been active in mental health advocacy locally and state-wide.

Aim of the new organization will be to oversee improved care for the mentally ill and expanded public education as well as providing support for those agencies seeking new methods of treatment.

The idea was born during the special conference held in May on the subject of "Schizophrenia, Through the Eyes of Families," held at the College of San Mateo. Organized by Mrs. Oliphant, it was attended by several hundred people.

Mrs. Oliphant is also the prime mover and founder of the Parents of Adult Schizophrenics, which has become not only a recognized state-wide, but nationwide agency.

She attended the first session of the new association which she was instrumental in forming as a dele-

gate. Hoffman said that it was reported demonstration projects will be started at the state hospitals and applied and scientific research will be done. A long-awaited orthomolecular treatment project is to be started at Napa and a project for the neurologically handicapped is expected to get underway at Camarillo.

As for local community care, Dr. Parabee expressed the hope that county (Short-Doyle) funds, will be used more efficiently.

The state mental health chief noted that California has enormous resources and is a progressive state. The need is to utilize resources and forces.

Hoffman today said that is the purpose and drive of the new California Association, Families of Mentally Disabled.

TONY HOFFMAN

FRAN HOFFMAN

EVE OLIPHANT

In 1974, they formally organized Parents of Adult Schizophrenics (PAS) of San Mateo County. While PAS members had been brought together by schizophrenia, **they worked on improving** care facilities, crisis care, and treatment services for all people with mental illness, promoting research, and on providing mutual support and education. By early 1975, 115 parents had joined PAS in San Mateo County, and by 1976, there were affiliated chapters in ten neighboring counties. PAS began to receive significant media attention. The group was featured on a TV talk show, in news stories, and on radio spots in 1976; and late that year, Oliphant spoke at the American Psychiatric Association's annual meeting.

PAS formed an alliance with a sympathetic psychiatrist, Richard Lamb, then Director of Psychiatric Rehabilitation in San Mateo County, and he and Oliphant published an article together in 1978.



Families of schizophrenics have received too little help from mental health professionals, even though in many cases families are the real primary care agents for long-term patients released from mental hospitals. – Lamb and Oliphant, “Schizophrenia Through the Eyes of Families.” Hospital and Community Psychiatry 29 (Dec 1978): 803-806.

H. Richard Lamb, M.D.

State and National Organizations

In Los Angeles, meanwhile, parents of children with mental illness had organized in the 1970s under the leadership of Don and Peggy Richardson and Stella March; groups included the Los Angeles County Parent Coalition and Advocates for the Mentally Ill, an umbrella group composed of 33 others.



Peggy and Don Richardson (center) 1981

As the family movement gained momentum, local leaders saw the potential for a statewide organization. In 1977, representatives from the Northern California parent mental health support groups met in Oakland. The ensuing group soon adopted the name **California Association, Families of the Mentally Disabled (CAFMD)**; Tony and Fran Hoffman were elected president and corresponding secretary. In 1978, Tony Hoffman met Los Angeles mental health family leaders Don and Peggy Richardson and Stella March at the LA airport and Southern California groups soon allied with CAFMD. Like PAS and other precursor groups, CAFMD focused on supporting families, raising community awareness of mental illness, and advocating for improved community treatment and housing facilities. One of CAFMD's early victories, shared with client advocates, included the 1978 passage of a law sponsored by Assemblyman Thomas Bates of Berkeley that mandated the inclusion of mental health consumers and family members on the influential Citizens Advisory Council, which advised the governor and legislature on mental health policy.

In 1979, **a pivotal conference in Madison, Wisconsin**, “Advocacy for Persons with Chronic Mental Illness: Building a National Network,” convened 280 representatives from 59 groups in 29 states and Canada and led to the formation of the **National Alliance for the Mentally Ill (NAMI)**. (The group later changed its name to National Alliance on Mental Illness, retaining the NAMI acronym.) Existing family groups could affiliate by becoming local or state AMI chapters;

CAFMD became the California Alliance for the Mentally Ill (CAMI) in 1982. In the first 12 years after it was formed, NAMI grew to include about 150,000 members, and, in 1986, registered its 600th affiliate chapter.

Ongoing Advocacy and Influence

As NAMI grew, California members played major roles. Don Richardson served as the first Executive Director of the national organization and Stella March was a NAMI lobbyist in Washington. NAMI's initial emphasis on advocacy for research funding and improved community services expanded to include public education and stigma reduction. These four **major areas of focus** – stigma, education, advocacy, and research – came to be known by the acronym SEAR.



Stella March

Combating stigma has been one of NAMI's most visible programs. NAMI's *Living with Schizophrenia* program allowed those in recovery to tell their own stories in face-to-face and video presentations. As the project grew and people with other mental illnesses became involved, the name was changed to **In Our Own Voice**. In 1995, Stella March launched the *StigmaBusters* project to monitor and dispel inaccurate and disparaging depictions of mental illness in movies, television shows and the news media. When a NAMI Stigma Buster spotted a negative image, she would call for floods of letters to the editor or producer.

An early StigmaBusters victory removed the Madame Alexander "Psycho" doll from store shelves.

Both NAMI and CAMI have played key advocacy roles in many areas directly and indirectly related to mental health. The national organization has been active in working for better housing and more housing sites for the homeless mentally ill and to combat landlord discrimination and neighborhood opposition. On the local level, CAMI fought to prevent incarceration of the mentally ill. The large population of Los Angeles jail inmates with mental illness was widely seen as a consequence of inadequate community resources awaiting patients who had been discharged from state hospitals.



Family and client advocacy groups have collaborated on these issues with much success, and family advocates have supported **client-run centers and groups**.

Other issues have been contentious. For example, NAMI advocates the enforced use of psychotropic medication in treating major mental illness, **a position often opposed by mental health client groups** and has supported involuntary treatment, or assisted treatment, laws for individuals who repeatedly refuse treatment or are considered a danger to themselves or others, such as **Kendra's Law in New York and Laura's Law in California**.

Law a matter of life and death



Al DeWitt and his relatives comfort each other after affording the arraignment in an Oakland court Feb. 22 of his son, Daniel Jordan DeWitt, who was charged in the bidgopping death of Peter Cukor at his home in the Berkeley hills. Al DeWitt says his son was diagnosed with paranoid schizophrenia.

By Carla Jacobs and Kristina M. Hagata

Hardly a day seems to pass lately without a killing in which untreated mental illness was a factor making headlines, the most recent being the beating death last month of a popular businessman by a young man with untreated mental illness.

The death of 67-year-old Peter Cukor of Berkeley is a timely but tragic illustration of why a bill before the Legislature needs to be enacted and why the mental illness treatment option it supports needs to be implemented in the Bay Area right now.

Santa Rosa Assemblyman Mike Albi's AB 929 would extend California's court-ordered outpatient treatment law for six more years. Known as Laura's Law, it is scheduled to expire at the end of this year. It should — and could — be saving lives if only counties would implement it.

Chances are that accused killer Daniel Jordan DeWitt, 24, would have qualified for court-ordered treatment at the community under Laura's Law. Al DeWitt says his son was diagnosed with paranoid schizophrenia at 18 and has been hospitalized at least nine times for treat-

ment in the four years since then. Each time, Daniel DeWitt was released before stabilizing fully, went off his medications, relapsed, was arrested or re-hospitalized, was stabilized and was released again. His family calls Cukor's death "a failure of the mental health system."

In mental health circles, the cycle that led to it is known as the "revolving door."

Laura's Law was passed by the Legislature in 2002 to stop the revolving door. Named for Laura Wilson, one of three victims of a Crain Valley campaign shooting by a man with untreated schizophrenia, the law provides counties

city-based, assisted outpatient treatment to a small population of individuals who meet strict legal criteria, such as the repeated hospitalizations and arrests that DeWitt underwent. Participants also need to be unable, as a result of their mental illness, to seek community mental health care voluntarily.

Every one of California's 58 counties is eligible to implement Laura's Law, but the law requires each county board of supervisors to pass a resolution opt-in to the law. Only two have done so to date. Nevada County was state and national award for its program, which the county has successfully integrated into its existing mental health delivery system. Los Angeles County operates a small pilot program that has produced impressive outcomes, including a 28 percent reduction in hospitalization among participants.

In the wake of a series of high-profile tragedies, advocates in additional counties throughout the state have been pleading with their county officials to implement Laura's Law. Among them

What you can do

- Learn more about Laura's Law: <http://lgf.ly/2WYUu>
- Sign up for news and alerts about developments in Laura's Law by e-mailing CTAC@treatmentadvocacycenter.org.
- Contact your state legislators (ask for CA legislators) and let them you support AB 929 (<http://lgf.ly/2O7C7VY>) to extend Laura's Law.
- Contact members of your board of supervisors and let them you support the implementation of Laura's Law in your county: <http://lgf.ly/2D81D8H>
- Join the "Advocates for Laura's Law" Facebook community: <https://www.facebook.com/afg.ly/2uA7U3d>

are Mendocino County, where two killings by a man with untreated schizophrenia led to a month-long manhunt last summer, and Orange County, where the police beating death of a homeless man with untreated schizophrenia resulted in two officers being charged with murder.

The San Francisco Board of Supervisors considered a resolution Aug. 3, 2006, to implement Laura's Law, but the measure was ultimately withdrawn after opponents started an effective misinformation campaign against it.

Assisted outpatient treatment is being used from coast to coast to save lives and families and to reduce the costly consequences — arrest, incarceration, hospitalization and homelessness among them — that occur when severe mental illnesses are not treated. California has a good law that California counties are refusing to implement. Until they do, individuals like Daniel DeWitt will remain trapped in the revolving door, and people like Peter Cukor and all those whose lives he touched will continue to pay the price.

Carla Jacobs is the coordinator of the California Treatment Advocacy Coalition. Kristina M. Hagata is the legislative and policy manager of the Treatment Advocacy Center. Send your feedback to carla@nami.org or kristina@nami.org.

2001 editorial in support of Laura's Law

NAMI also lobbies at all levels of government for mental health funding, particularly for research. In California, it provided key support for the 2004 passage of Proposition 63, which became **the Mental Health Services Act**.

But NAMI's most important role is probably still the education and support its members provide to other families struggling with the care of a loved relative diagnosed with a mental disorder. Its Family-to-Family sessions, offered throughout the year, explain the basics of diagnoses and treatment, the resources families can draw on, and the importance of family support to mental health and recovery.



Sharon Dunas of Westside LA NAMI leads a Family-to-Family training session.

While this history has focused on NAMI and its affiliates, other prominent groups advocate for and represent families. **Mental Health America (MHA)** (formerly called the National Mental Health Association), created in 1909 by the reformer and patient Clifford Beers, has played an instrumental role in the passage of legislation protecting and asserting the rights of patients and their families. The **Federation of Families for Children's Mental Health (FFCMH)** supports children and their families, advocates for policy, and supports other family-run organizations.

Together with consumer advocates, families have exerted and established considerable influence on mental health services. **The Surgeon General's 1999 report on mental health**

cited NAMI's successful advocacy for increased funding for federal research, federal legislation mandating family inclusion on mental health planning boards, the passage of the Mental Health Parity Act in 1996, and NAMI's training programs for clinicians and families. The report also identified families as important sources of support for people with mental health problems. The **2003 President's New Freedom Commission on Mental Health** noted the need for family involvement in care and treatment for people with mental illness, and recommended that families and consumers play central roles in designing a recovery-oriented mental health system.

"I propose that we combine an ability to educate with an ability to learn; a giving of support with an acceptance of support; a need to understand with a need to be understood. I think if we can perpetuate this approach, we will continue our journey toward amazing and positive results."

Don Richardson, Los Angeles, 1988