

A HISTORY
OF
THE NATIONAL ALLIANCE
FOR THE MENTALLY ILL

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INTRODUCTION

One of the sociological phenomena of the twentieth century has been the unparalleled success of the National Alliance for the Mentally Ill. Since its founding in September 1979 in Madison, Wisconsin, this organization made up basically of parents of persons with severe mental illnesses plus recovering patients and some siblings has grown spectacularly with no signs of slowing down.

Unlike many organizations, National AMI grew from the grassroots upwards. No one person captured the idea of a national body to focus on the needs of long-term mentally ill individuals and their families and then went out to start chapters. There were 59 separate family groups already functioning in their own areas who sent representatives to the University of Wisconsin campus to launch NAMI. From that time on, the exponential growth of NAMI has been generated "back home"; as families felt the need to face their tragedies of mental illness collectively, they established affiliates.

Development of the state groups, composed of three or more affiliates, has followed the same pattern of grassroots origin. The National AMI Office has encouraged states to join together their affiliates but impetus has come from the local groups themselves.

As new affiliates form, one of their first questions is, How did this organization start? References to the founding of NAMI have appeared in several articles, but until publication of this history, no complete history has been written based on archival records in Madison and no synopses of the founding of individual affiliates and state groups have been published.

This volume, then, is an attempt to record beginnings. It is only a beginning. There are, undoubtedly, inaccuracies even though the history of NAMI itself has been extracted directly from minutes of the Board of Directors, from papers and proceedings of the first conference, and from committee and task force reports.

Leaders in affiliate and state groups have sent in the histories of their organizations, and these are still in the process of being compiled. Clearly, in what follows only a fraction of the names of people who have "made NAMI history" appear.

Special thanks are due to Shirley Starr, who filled a gap in official NAMI records with a memoir of her two years as president. The work of Maggie Scheie-Lurie, who composed type, and Lynn Borton, who expedited the publication, both from the NAMI office, should be acknowledged. Finally, the unflagging support of NAMI Executive Director Laurie Flynn helped the editor in this project.

Harriet Shetler
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By Harriet Shetler
NAMI Board Member: 1983-86

A Grassroots Beginning

What started out in the 1940's as tiny candles set against the darkness of unconcern for persons with mental illnesses and their families has in 1986 become a blazing light. The entrance of the family movement into the field of mental illness, combined with the meteoric rise of the National Alliance for the Mentally ill, is a grassroots success story of unprecedented proportions.

It is a story of a handful of families in dozens of cities across the country who found others...it is the story of one small group at a time becoming organized without knowing there was a similar group in any other town or state... it is the story of courageous individuals who braved the stigma of mental illness to come out of the closet in their communities and find other people with the same problem.

Assigning the role of pioneers to any group is fraught with danger, but from the records NAMI has been able to compile, clearly the parents organizations in New York City hospitals appear to be the forerunners of family support/advocacy groups. AMI member Helen Pollack in her master's thesis¹ points out that her mother in the 1940's joined other relatives of mentally ill persons in Brooklyn State Hospital to form an organization that would bring issues of hospital care to the attention of the authorities. Concerned parents who began to meet in the apartment of Max Schneier were the nucleus of the New York Federation of Parents Organization that was founded in the winter of 1971 at the New York State Psychiatric Institute.

¹ "History of Attitudes and Treatment of the Mentally Ill: The Formation of a National Advocacy Movement and Its Implications for Mental Health Professionals," Helen Pollack, Master's Thesis, State Univ. of NY at Stony Brook, December 1983.

Several other family groups started in the 1960's, spawned by the American Schizophrenia Association (ASA) founded in 1963 in New York. Their emphasis was on the biological aspects of schizophrenia, and eventually ASA affiliated with the Huxley Institute for Biosocial Research.

Dissatisfaction with treatment of their mentally ill relatives and lack of communication between professionals and families motivated Margaret Duncan Greene and Evelyn and Arnold Linane to organize Marin County, CA, Parents for Mental Recovery in May, 1972. They had been meeting with other parents for half a year and enlisted two dozen families to create a licensed facility for seriously disturbed young adults. Marin Lodge emerged, and by 1974 there were 36 families on the roster. Eventually the organization decided to become a separate group for purposes of mutual support and advocacy, founding in January 1979 Marin Parent Advocates.

An AMI group of former mental patients that traces its history back to a chartering date of May 7, 1974, is Reclamation, Inc., of San Antonio, Texas. It was started by eight former patients to "help reclaim the human dignity destroyed by the stigma of mental illness,"² and today under leadership of Don Culwell has 22 members who promote operation of a facility patterned after Fountain House, New York City.

The pacesetter, however, of all early AMI-type groups is AMI-San Mateo County, CA, organized in 1974 as Parents of Adult Schizophrenics. Eve Oliphant sent a postcard to a few families whose names she had received from the San Francisco Schizophrenia Association. Ten people attended the first meeting, but in a year the affiliate counted 115 members. After a few months of sharing woes, the group decided to become involved politically and sponsored a housing committee that opened a house in 1976. Fran and Tony Hoffman and Eve Oliphant collaborated with Dr. Richard Lamb in writing an article that appeared in a professional journal.³ One of the group's first public acts was participation in a sit-in in Governor Jerry Brown's office.

² Brochure of Reclamation, Inc., 2502 Waterford, San Antonio, TX 78217.

³ "No Place for Schizophrenics--The Unwelcome Consumer Speaks Out,"
Psychiatric Annals, December, 1976.

Another of the dynamic West Coast organizers has been Marie Hibler. She had heard of the San Mateo family group, met with them and with the Bay Area organization, and ultimately with John Murphy, director of a student advocacy program at San Jose State University for ex-patients from Agnews State Mental Hospital. On April 5, 1975, Parents of Adult Mentally Ill of Santa Clara County was formed with Marie Hibler as coordinator. Marie carried the "gospel" throughout the country, writing encouraging letters to widely dispersed family groups and visiting some of the cities to help found groups.

On the East Coast in 1975, several families founded Pathways to Independence (PTI). The original 13 members met in January at the Social Center of Falls Church, VA, under leadership of Ed Brazill, Ed Weary, Andy Iaderosa, and John Carlton. (PTI's impetus from men contrasts sharply with other family groups, almost all of which were propelled into being by women -- mothers, for the most part.) One of this affiliate's outstanding projects has been leadership in starting trust organizations for families who want to create protective funds for ill family members. Ed Brazill, who attended the NAMI founding meeting, has been the leader in this work.

By 1977 seven local groups had formed in the Bay Area, held joint meetings under the name California Association, Families of Mentally Disabled, and traveled to any part of the state where interest was shown in starting, a new group. May 17, 1978, was a big day for California family members. About 400 people attended a symposium, "Schizophrenia Through the Eyes of Families," held at the College of San Mateo and planned by Eve Oliphant and Terry O'Rourke, college staff person. The next step was a statewide conference held November 4, 1978, in Fresno to organize the state group. Tony Hoffman was elected president of the state organization that included 16 family affiliates.

Some individuals, who later became leaders in NAMI, conducted their own research on the burgeoning self-help movement. Jean Lough of Vancouver, WA, in her paper on the history by the family movement⁴, found that Agnes Hatfield, a professor at the University of Maryland, had surveyed 131 such groups composed of families of mentally ill persons in the spring of 1979. From her 71 responses, Dr.

⁴ Jean Lough, "The Family/Support/Advocacy Movement: Past, Present and Future, Part I"; Vancouver, Clark AMI, 1985.

Hatfield and Carol Howe, of the Threshold, MD, affiliate, found that 77% of the groups were less than three years old: 8% had been formed before 1970, 10% had been formed between 1970 and 1975, 27% between 1976 and 1977, and 50% between 1978 and 1979. Another survey of families was initiated by the San Jose PAMI. The most important finding was that three fourths of the families with mentally ill members were an intact unit.

Peggy Straw of New Hampshire attempted to find other support groups by sending a form letter in April 1977 to all directors of state hospitals throughout the country. Six months earlier Ms. Straw had asked the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) if there were family groups and literature written for families of patients admitted to hospitals. ADAMHA replied that there were no groups or literature that the department knew about. Her letters to the 50 hospital directors were turned over, in every case, to state departments of mental health. Twenty-five states responded, and none of them knew of any such groups except Wisconsin. These 25 sent literature, which for the most part, included client rights manuals, patient handbooks, and hospital guides. Wisconsin sent a booklet that described community services, and Connecticut had published a booklet explaining what families could do to help patients. Peggy Straw didn't hear about NAMI until June 1980, nine months after its founding.

From 1976 on, family groups began to spring up in state after state, but with no good avenue of communication, most of these affiliates "invented the wheel" themselves: Unhappy with the problems of deinstitutionalization, frustrated by absence of any real help in existing mental health organizations, and stigmatized by society and the professionals, small knots of families found each other in their towns.

In the middle and late 1970's scattered family groups heard about similar groups and started to correspond with each other, exchanging newsletters and copying each other's programs and even advocacy efforts. As stated earlier, California had already formed a state organization, but there was no national alliance of any kind that could bring the rest of the support/advocacy groups together.

Two members of one of the most active family groups, Alliance for the Mentally Ill of Dane County, Wisconsin, based in Madison, brought up the need for

a national coalition at the November 28, 1978, business meeting of their board. With the backing of the Board of Directors, Beverly Young and Harriet Shetler were authorized to explore the possibility of inviting representatives from as many groups as they could find to convene at a future date in Madison, with the stipulation that outside funding would be needed.

In January 1979 these two women who had co-organized the group two years earlier sold their idea to Roger Williams, a professor in the University of Wisconsin-Extension Mental Health Department. Professor Williams agreed to seek UWEX co-sponsorship of such a national conference if other family groups responded favorably to the invitation and if a funding base could be secured. Bev Young volunteered to serve as general secretary in writing to groups, and Harriet Shetler went after the funding.

The response to the letter of invitation was overwhelmingly positive. Without exception, the other family support groups encouraged moving ahead with the planning process and pledged support in attending the conference. Lorna Miller, a UWEX employee and administrator of Wisconsin's Title I funds who was supervising an editing project that Harriet was working on, became personally supportive of the idea of convening families of mentally ill persons. The \$5,000 grant that was secured from the Higher Education Act, Title I, enabled the Mental Health Department-AMI Committee to cover most out-of-pocket expenses and keep participant fees at \$10.

The planning committee included the following persons: Professor Williams, coordinator; Donald Kreul, AMI president; Young, Shetler, and Julia Miles, AMI members; Professor Mary Ann Test, UW School of Social Work and co-designer of the PACT program; Patrick Prindle, colleague of Williams; and Sharon Zahradka, Wisconsin Department of HSS.

Stated objectives of the planning group included:

- To foster learning about federal legislation, current research, and recent developments in the treatment of persons with chronic mental illness.
- To encourage sharing what citizens can do through mutual help/advocacy groups in improving the lives of mentally ill persons and their families.

- To create a national federation, coalition, or network of local and state mutual help/advocacy groups.

AMI members on the committee insisted that expenses for participants be kept to a minimum and that many emerging family group leaders have prominent places on the program. The Dane County group opened its homes to any conference participants (30 persons took advantage of this offer), and Coordinator Williams kept expenses down by donating his and his department's time and the conference facilities of UW-Extension.

Agnes Hatfield, co-founder of Threshold, MD, gave the keynote address at the three-day meeting held at the Wisconsin Center, Madison, on September 7-9, 1979. She ended her stirring address with this prophecy that has since been fulfilled: "This movement has been one of the most rapidly developing movements of self-help groups that has ever occurred. We have the vision, we have the will and the energy, and I'm absolutely sure that we will not turn back."⁵

Short addresses by founders of several family groups followed Agnes Hatfield's speech: Irving Berkowitz, chairman, Federation of Parents Organizations for N.Y. State Mental Institutions; Bess Center, chairman, Families of Mentally Disabled, Savannah, GA; Lorelei Glaser, former president, Alliance for the Mentally Ill, Chicago; Marie Hibler, organizer, Parents of Adult Mentally Ill, Santa Clara County, CA; and Eleanor Owen, organizer, Advocates for the Mentally Ill, Seattle.

The program on the second day of the conference was designed to be informative. Speakers included Irving Blumberg, NY; Professor Leonard Stein, M.D., University of Wisconsin; Dr. Samuel Keith and Judith Turner, National Institute of Mental Health, Washington, D.C.; and Max Schneier, president, Transitional Living Centers for Los Angeles County. Dr. Herbert Pardes, director of NIMH, supported the organization-to-be by attending and giving the luncheon address (and bringing on a case of hoarseness when the public address system failed). A mix of professionals, family members, and ex-patients comprised the 20 presenters for seven workshops.

⁵ "Advocacy for Persons With Chronic Mental Illness; Building a Nationwide Network," proceeding of a national conference; editors, Roger Williams and Harriet Shetler; Madison, WI; 1980.

Under Coordinator Williams's skilled leadership, the local steering committee had successfully overcome the problem of providing an open, democratic process for founding a national organization while at the same time arranging a program with enough structure that something concrete could be achieved. The 284 persons who came to Madison from 59 different groups located in 29 states and Canada chose one of five task forces that met late into the night: (1) purpose, (2) structure, (3) program, (4) communications, and (5) funding.

At the final Sunday morning session, a resolution to incorporate the National Alliance for the Mentally Ill was unanimously adopted. The name - AMI - that WELS used by the Madison affiliate and one in Chicago, had been proposed. After discussion and some opposition by some conferees who wanted the name to reflect that most of the members were parents and that schizophrenia was the most serious mental disease, the name was approved.

Task force resolutions, which were adopted in principle, were presented by the following chairs: Eve Oliphant, Committee on Purpose; Shirley Starr, Chicago, Committee on Communications; Edgar LeBlanc, PA, Committee on Program; James Howe, MD, and Don Kreul, Committee on Finance; and Barbara Ledbury, OR, Committee on Structure. George Hecker was elected temporary chairman, and Jean Gump, Chicago, was elected recorder.

Spirited electioneering for places on the Steering Committee produced these results: Marcella Anthone, MN; Irving Berkowitz, NY; Bess Center, GA; Agnes Hatfield, MD; Ethel Rosenfeld, AR; Shirley Starr, IL; Bill Thomas, CA; George Hecker, MO; Barbara Ledbury, OR; Eve Oliphant, CA; Eleanor Owen, WA; and Beverly Young, WI. For the first and only time in the history of NAMI, alternates were also elected, as follows: Ed Brazill, VA; William Breisch, WI; Ann Campbell, OR; Lorelei Glaser, IL; Marie Hibler, CA; Carol Howe, MD; Michael Markotic, AZ; Fred Platte, MI; Carmel Spadola, NJ; John Stegmaier, MD; Isaiah Uliss, MA; and Mary Jean Willis, CO.

After the general sessions were over, the Steering Committee met to choose officers for the first year: George Hecker, president; Irving Berkowitz, first vice-president; Bev Young, second vice-president; Eleanor Owen, secretary; and Shirley Starr, treasurer.

The conferees went back home to their affiliates on a natural high, feeling pleased with themselves and their new-found friends, happy that they had started something very important in three pressured days. Through the windows of the room where they held their plenary sessions, the 284 NAMI founders had watched the sailboats of the Hoofers Club dart around Lake Mendota. Now they were going home to sail uncharted waters.

What contributed to the success of the organizing conference? The conference coordinator, after reading all the evaluations, wrote that timing was the most important factor. "It is just within the past one or two years that local groups realized the national scope of this movement and became interested in reaching out to form a nationwide network."⁶

As all parents know, the birth of a baby is only the beginning! The National Alliance for the Mentally Ill was no exception. With no more than token funds and with no national office, this organization conceived by grassroots small groups scattered from coast to coast had to grow up overnight to fulfill the collective dream of the Madison assemblage. The Steering Committee was equal to the task.

NAMI Is Started

Pledges and gifts of \$4,000 were collected (with Tony Hoffman of California "emceeing") from the persons attending the conference. For the next few months, until NAMI was granted nonprofit status, NAMI monies were kept in a separate account on AMI of Dane County books.

Ten days after the conference President Hecker appeared before the Advisory Council for NIMH. On October 23, 1979, NAMI members met in Washington with Dr. Pardes. Shirley Starr, president of NAMI from 1980-82, tells in her account (see page 10) more about efforts to secure funding from the newly founded MacArthur Foundation.

The new Steering Committee held its first meeting since Madison in Old Orchard Hospital, Skokie, IL, on February 9- 10, 1980. President Hecker reported

⁶ Williams, Roger, UWEX internal paper, "Post-Conference Reflections," 1980.

that the media, professional journals, and other organizations in the mental health field were already recognizing NAMI's entrance. Hecker attended and was recognized at the meeting of the National Mental Health Advisory Council, and NAMI representatives participated in the Community Support Learning conference in Washington. Present at the Skokie meeting in addition to Hecker were Mss. Young, Owens, Starr, Oliphant, Hatfield, and Anthone.

A voting formula was worked out, with voting for directors to be done each year at the annual conference/convention. Votes would be cast, not individually, but by affiliate, as follows: 5 to 20 members, 1 vote; 21-100, 2 votes; 101-200, 3; 201-500, 4; over 500, 5. Each affiliate was levied a fee of \$25 and contribution of from \$1-5 per member, depending on the affiliate budget. Members at large, who were not affiliated with a local group, were assessed \$10, which included a subscription to the proposed newsletter.

The makeup of the Board of Directors was settled as follows: to consist of 12 members, each serving three years after election of the first formal board at the next convention (terms at that election were to be staggered); no director may succeed himself/herself; no more than two directors from one state; a quorum to consist of six members of the Board.

Income as reported by Treasurer Starr was \$7,188. Marcella Anthone of Minnesota submitted her resignation, and Ed Brazill of Virginia was elected to replace Ms. Anthone.

Reports in affiliate newsletters show that the Steering Committee met again June 30, 1980, at the Garrett Park, MD, home of Carol and Jim Howe. Irving Berkowitz presided in the absence of Hecker. Main discussion centered around plans to open a national office in Washington following NAMI's receipt of a grant of \$78,650 from the MacArthur Foundation.

During the spring of 1980 President Hecker facilitated NAMI's being incorporated under the laws of the State of Missouri as a not-for-profit corporation, with principal office originally designated as Hecker's law office, 500 North Broadway, St. Louis. Also Hecker's firm obtained an IRS tax exempt status and handled the legalities of the first MacArthur grant.

The second summer conference of NAMI, and first since incorporation, was held September 26-28, 1980, at the Bismarck Hotel in Chicago, with Chicago AMI as hosts and Shirley Starr as chairman. The keynote address was given by Dr. Daniel Freedman, president-elect of the American Psychiatric Association and chairman of psychiatry at the University of Chicago Medical School. (But Shirley's account of her presidency gives a more interesting insight into this convention than this factual history can offer.)

Only a brief report from the September 28, 1980, meeting of the Board of Directors is needed before we turn to Shirley's reflections.

A long discussion of the pros and cons of establishing the National Office in Chicago, home of the new president, or in Washington, seat of legislative action, sharpened the debating skills of the novice board. The directors finally decided to authorize the President to consider hiring an executive director, to define such a position and begin a search for the person, and to work on establishing a base in Washington. A search committee for the executive director was appointed: Charles Miles, Bev Young, Mike Markotic, and Agnes Hatfield, with Dr. Miles designated chairman.

Because the NAMI Office has been in four different locations in Washington and some minutes of secretaries have not turned up, Shirley Starr has added to the NAMI archival record with reflections of the first three years of NAMI.

A RECOLLECTION OF THE EARLY YEARS

By Shirley Starr
President of NAMI-1980-82

The weekend in September 1979 that resulted in the formation of the National Alliance for the Mentally Ill was a weekend filled with 18-hour work days and the burning conviction that the 284 individuals present were part of a movement for which the right time had come and that each person was no longer alone in confronting mental illness in the family.

Madison, Wisconsin, was our birthplace; Washington, D.C. would become the arena in which we would work on behalf of the chronic mentally ill. At the close of

the conference, the Steering Committee remained to formulate a strategy to formalize all of the resolutions that had been made and approved and to do it within the bounds of our newly established bylaws.

The unanimity and goodwill of that first meeting augured well for the new organization. Each person on the Steering Committee selected the area in which she or he had the most expertise and assumed full responsibility for that activity. The Committee voted to send me to Washington to seek office space and funds and to announce to the national groups and the Congress that we were about the business of improving the lives of the mentally ill and that we would be a force with which to be reckoned.

There were other people of goodwill present that weekend who did not have mentally ill relatives but knew that a national organization of informed and committed advocates was needed on the national scene. Among them were Irving Blumberg, Dr. Herbert Pardes, Dr. Samuel Keith, and Judy Turner. Together, they comprised an encyclopedia of knowledge about the illness, about the system that served the mentally ill, and the political system in which the decisions were made.

The Steering Committee turned its efforts toward seeking funding for the new organization. George Hecker, Irv Berkowitz, and I, accompanied by our dedicated mentor Irv Blumberg, went to Washington to meet with Dr. Pardes at the National Institute of Mental Health. The questions we asked were: Where, realistically, can we get funding? Who are the people we need to know? What is the political climate in Washington, D.C.? Hecker, Berkowitz, and I came from Missouri, New York, and Illinois and knew our respective states quite well, but the nation's capital was an unknown quantity.

We knew that we needed the federal government in the business of providing essential entitlement funds and funds for basic research, but we didn't know the players. The appointment with Dr. Pardes turned into a two and a half-hour seminar. I had 30 pages of notes when we finally left Dr. Pardes's office. I returned to Illinois somewhat overwhelmed, but I remember well the feeling of excitement and well-being about the challenge ahead for NAMI and for me.

Back home, notes in hand, I began calling people whose names appeared in my notes. As I spoke to each person, telling them about our organization and asking

them to inform me of those who would be valuable allies in our attempt to establish ourselves as a national advocacy movement, a certain pattern emerged in these calls. Some names were mentioned in every call I made. Leading the list, in terms of being mentioned, were Dr. Tom Bryant, the MacArthur Foundation, and Dr. Pardes. We had already met with Dr. Pardes, who offered to contact the MacArthur Foundation on our behalf and who provided us with the name of a key person at the foundation.

While a worthy cause deserves to succeed on its own merit, luck and contacts increase the probability of success. NAMI was blessed with both. The key person at the MacArthur Foundation -- newly established with a known interest in mental illness -- was Dr. John Conger, a college classmate of George Hecker. George was able to call the foundation and speak to him immediately and thereby facilitate my efforts in preparing a proposal for submission to them.

Dr. Conger, a man of great vision and intelligence (and a poet), immediately grasped the importance of the new movement and was from the beginning our advocate within the foundation. We were lucky in other ways, also. Dr. Bryant turned out to be the chairman of the President's Commission on Mental Illness, a commission enacted in the Carter Administration to address the critical needs of the mentally ill. As advisor to President Carter, he showed vision and intelligence and became our advocate in the halls of Congress and with the established mental health organizations.

In the middle of October 1979 I began my weekly treks to Washington, D.C. Each day was spent calling upon the executive directors of the many mental health organizations and informing them of our hopes for our organization and our willingness to work together with them in making significant change in government policy and public attitudes about mental illness and the mentally ill. At the same time I was informing them about our plans, I was being informed about recent legislation, the climate in the federal government, and the important legislators, both friendly and unfriendly.

When I had exhausted that list, I turned my efforts toward Congress. Whenever Steering Committee members were in town, they accompanied me on my visits, which made the work more effective. We would drop the name of that person's state and then mention all the other states that were part of our

organization. Always vague when we spoke of numbers, we presented the illusion of a national organization with constituents in every state. While it wasn't true in October, November, and December 1979, we always knew it would be true, and we suffered little for our transgressions.

The first hurdle encountered was the issue of membership in the Mental Health Liaison Group, a group composed of all organizations that dealt with mental illness. The Group had certain criteria for membership, but one, in particular, would have barred us from membership if enforced. That provision required each organization to have been a national organization with offices in Washington, D.C. for at least three years. I argued for inclusion because many of our affiliates had been in existence for at least three years and because we were the only organization that was truly a consumer group. Dr. Tom Bryant supported that position and conveyed his valued opinion to all of the groups. In the background, Irving Blumberg quietly but forcefully spoke to individual organizations to gain their support for our inclusion. Finally we were accepted after three months of consideration and deliberations.

We became members at an important time. It was the time in which the passage of the Mental Health Systems Act was before Congress. The passage of the bill was achieved when it was signed in October 1980. Our euphoria vanished when the Reagan Administration's budget eliminated funding for the Act. Congress delivered the fatal blow when they rescinded it in the Reconciliation Act in spring 1981. All of the hopes that the Act held for improving the lives of the mentally ill were extinguished by this act of Congress. The Mental Health Liaison Group turned its efforts to salvaging something from the wreckage and to developing new agenda.

For the first two months of my Washington five-day weekly visits I stayed at a hotel that was centrally located in terms of Congress, Georgetown (where Tom Bryant's office was located and where I had the use of a telephone and a desk), and close to the downtown offices of the many mental health groups with whom we were working on coalition issues. That meant being downtown. After a month of hotel rates that I believed to be exorbitant but which Washingtonians assured me were quite reasonable, I found space just south of the downtown area in an apartment building at 1234 Massachusetts Avenue, N.W.

I had established contact with the National Society on Autism at the suggestion of Chuck Miles because we knew they were a low-budget, not-for-profit family

group also. They welcomed us because of our goals and because they needed to cut down the cost of their rent. I rented a one-room studio apartment on the fifth floor and desk space in the basement of the offices of the autism group. We had our offices: a two-mile walk from Congress, short Metro ride from the rest of the mental health constituencies, and a one-block walk to the heart of the red light district! I was unaware of the notoriety of 14th and Mass., N.W. – only my nightly walks informed me of that fact.

My studio apartment had a large walk-in closet, and that served as an extra bedroom when NAMI members came to Washington. With a bedroll on the floor and a couch that converted to a bed, NAMI could accommodate any member who wanted to come to Washington and lobby in Congress. A second bedroll could accommodate a third person, but no one ever took me up on the offer.

The National Society for Autism provided me with a receptionist, a desk, a telephone (no service), and the use of a copier machine. Appointments with other advocates and NIMH personnel were held in my apartment. My typewriter was carried up and down in the elevator daily -- in the morning down to the basement; at six in the evening, up to the apartment. The typewriter and I survived, with the typewriter moving up to better quarters when we moved into a two-room suite on the seventh floor of the same building. We were out of the basement and moving up in the world!

Our convention in Chicago in September 1980 brought more than 600 persons to the Bismarck Hotel: family members, professionals, and many ex-patients. Ann Landers (who was to play a continuing supportive role to NAMI in the future) was the speaker at our first luncheon; George Wald, the Nobel Prize biologist, was the keynote speaker at the Saturday evening program. Dr. Daniel Freedman, chairman of the Department of Psychiatry at the University of Chicago, secured a \$10,000 grant for the Chicago AMI group to enable us to put on the convention. He was another of the illustrious speakers and opened the program with a keynote speech: "Families and Mental Health Professionals: A New Partnership."

At the convention we were heady with our success, certain that there was nothing we could not accomplish. However, we could not accomplish overcoming the problems with the sound system for the meeting at which Ann Landers spoke.

She solved the problem for us by insisting that everybody move chairs from the far end of the ballroom closer to the podium.

The election of individuals to serve on the Board of Directors to replace the Steering Committee was another problem. The problem did not lie in finding the people to serve on the national board -- the problem lay in the logistics of electing that board. We wanted to be a democratic organization, in which all member affiliates could nominate somebody for the board. And we wanted to make it possible for those who had just joined at the convention to be able to make nominations from the floor. And they did! By the end of the evening there was not enough room across the width of the large ballroom to handle the nominees, and so the line of nominees curved around the front of the ballroom into a half-circle.

George Hecker ruled with a firm hand and limited each nominee to three minutes in which to present ideas to the audience. Somehow, to the amazement of us, choices were made and 12 persons were elected to the first NAMI Board of Directors: Clara Davis and Porter Warren, NY; Agnes Hatfield and Carol Howe, MD; George Hecker, MO; Tony Hoffman, CA; Mike Markotic, AZ, Chuck Miles, UT; Eleanor Owen, WA; Shirley Starr, IL; Sheldon Rein, KY; and Beverly Young, WI.

If anybody had any doubts about whether the right persons were selected, they were put aside. We believed that every family member who came to that meeting was qualified to be a board member. If we were going to make mistakes, we were going to make them together. At completion of the convention, the new Board, with terms staggered from one to three years, elected its officers: I was honored by being elected president; Eleanor Owen, vice-president; Carol Howe, secretary; and Sheldon Rein, treasurer.

I returned to Washington as president, this time to a two-room suite mentioned earlier, as a result of our having received a \$100,000 a year grant from the MacArthur Foundation. In May 1981 we hired an executive director and an administrative assistant. We now had three telephones and three lines and had purchased a typewriter far superior to the one I had brought from Chicago. We were ready for the expansion that was inevitable if we did our job correctly.

We were fortunate in our choice of executive director. Bernie Smith was a kind, dedicated individual who responded to every call for help that reached the NAMI office. He played an important role in our expansion-from a fledgling organization to very respectable size for a relatively new organization. He also had the consummate wisdom to hire Lynne Saunders as his administrative assistant. Together Lynne and Bernie provided an environment in which NAMI was perceived as being an important mental health organization and a catalyst for needed change.

We had accomplished much in two years. We had received a significant grant from a major foundation. We had moved into larger quarters. We had expanded our staff and had increased the number of volunteers 200%. We were an essential member of the Mental Health Liaison Group and we were represented on the President's Committee on Employment of the Handicapped and on the American Psychiatric Association's Committee on the Chronically Mentally Ill. Our membership had grown from the original 284 present at Madison, Wisconsin, to over 5,000.

Every president looks back upon the period in which she/he served and remembers certain highlights and events. During my two terms there were many things that provided me with much gratification. Certainly our rapid growth in membership was one such area. Another source of satisfaction was our increasing capability to respond to the calls for help that were coming into the office in ever-growing numbers. I take particular pride in having served on the Steering Committee/Board for four years and having played a contributing role in the following:

1. The establishment of a voting formula that protects the interests of the minority, affiliates with a small number of members. This is a well-established principle in constitutional law, and it was good that NAMI codified that principle very early in its existence.

2. The recognition the MacArthur Foundation gave NAMI when they awarded us the three-year grant. It was a statement of their belief in us and in the importance of our movement.

3. The naming of Chuck Miles as the NAMI representative to the Advisory Council of NIMH. This represented another significant recognition of the importance of the family movement in improving the lives of the mentally ill.

4. Our being a moving force and co-founder of the Council for Understanding Mental Illness, a council whose main thrust is to reduce stigmas toward the mentally ill. While the Council has had difficulties in securing adequate financial support, the concept of a coalition of all the national mental health organizations developing national educational antistigma campaigns is important.

5. NAMI's acceptance as a health agency in the Combined Federal Campaign (CFC). Again, the importance to me was the fact of NAMI's being accepted as an organization that provided mental health support and information and was, therefore, worthy of being supported as much as the American Cancer Society or the Heart Association. More importantly, it represented an acknowledgment of mental illness as a health problem and not social deviation.

6. The formation of a Curriculum Development Committee during my presidency. I believed that NAMI knew much about the illnesses and ways in which the mentally ill and their families could be better served. Also, I believed that within our ranks were some of the most capable individuals whose education and training were grounds enough for being the experts in the field. But they possessed something that other professionals did not have: the unique experience of being the relative of a mentally ill person and of having coped with all the complexities of the illness. When Agnes Hatfield agreed to act as chairman of the new committee, we were on the way to being one of the best resources for families and professionals alike.

Out of the Mom and Pop Stage

After Shirley Starr's fine review, we resume the story, with dates, names, places, and other archival facts, of NAMI's emergence as the leading organization concerned about mental illness.

The Board of Directors met January 9-11, 1981, in Scottsdale, Arizona. Discussion centered largely on qualifications needed and possible candidates for the position of executive director of NAMI. The Program Committee indicated that

NAMI's top priorities should be building the organization and promoting the Mental Health Systems Act. The Board requested that newsletters, which had been sent out intermittently to all members, be published on a regular bimonthly basis. Editing of the newsletters was to be done by the executive director. The Board discussed opening of the national office, which took place February 1, 1981, a "first" that Shirley recounted earlier.

The full Board met again May 22-24, 1981, at International Inn, Washington. The Finance Committee recommended that Board members be given airfare plus a flat fee of \$200 for living expenses at Board meetings. At this meeting, the Board selected H. Bernard Smith as the first executive director and authorized the hiring of Lynne Saunders as assistant. Smith had extensive experience in mental health and administration fields, having served as executive director of the Cuyahoga County, OH, Community Mental Health and Retardation Board in Cleveland, and as executive of a community mental health board in Arlington, VA. He started work with NAMI June 1, 1981.

It was seen early on that newsletters could be a good link between affiliates and between the grass roots and the national office. Eleanor Owen had edited several newsletters, and Shirley Starr also wrote and distributed several issues. Bob Hartigan, one of the early supporters of the family movement from Michigan, kept lines of communication open with a newsletter called Anawam, which was mailed to NAMI members twice but ceased publication for lack of funding.

One of the first public references to NAMI came in the April 1981 issue of Women's Day. Carol Howe, secretary, who had temporarily moved with her husband to Colorado, handled the great influx of mail. Later that year the Howes moved back to their residence in Garrett Park, MD, and turned out to be the hosts for the winter Board meeting (December 4-6, 1981) at their home even though Jim was overseas on business and Carol had been called away by a family emergency. (Through subsequent years the Howes have entertained as house guests so many NAMI leaders that their home is fondly known as the Howe Motel.)

The third NAMI conference/convention was held in Seattle, August 13-16, 1981, hosted by Washington Advocates for the Mentally Ill. (The argument of what to call NAMI's annual summer meeting has never been settled. Is it a conference or a convention? Probably it should be called both because information is disseminated

through lectures and workshops - a conference, and the official business of the organization is conducted - a convention.)

Eleanor Owen, conference chair, brought off a great coup in enlisting as speakers a psychiatrist who was beginning to be known as a champion of families, Dr. E. Fuller Torrey of Washington, D.C., and a reporter from the New Yorker, Susan Sheehan. Her enthralling true story of a schizophrenic woman in New York, Is There No Place on Earth for Me?, had just been published in four installments in the magazine. (Eventually, Sheehan won a Pulitzer Prize for the book.)

Approximately 450 persons attended the conference held on the campus of the University of Washington, a beautiful site but NAMI lucked out to encounter the only excessively hot week in recent memory of Seattle natives. Board members elected included two incumbents who had served only one year on the staggered terms set up at the Chicago convention: Chuck Miles and Porter Warren. Merion Kane of Washington, D.C. and Peggy Langdon Straw of New Hampshire also were elected. The Board reelected Shirley Starr president and the following: Eleanor Owen, first vice-president; Beverly Young, second vice-president; Peggy Straw, secretary; and Sheldon Rein, treasurer. The Board directed Executive Director Smith to serve as editor of the NAMI newsletter, to be published bimonthly. (He was later assisted by Nancy Schaefer, a volunteer from the Washington area.)

During the famous December meeting at Howes, the Board set top priority for the new executive director as (1) publishing the newsletter regularly, (2) developing membership, (3) constructing a five-year fund-raising plan, and (4) supporting families. Mr. Smith reported that the mailing list comprised 5,000 names.

In October 1981 the MacArthur Foundation had approved a \$200,000 grant to NAMI to be allocated through September 30, 1983. Although a stable source of funding guaranteed continuation of the Washington office and small staff, the Board and executive director searched for additional grants and for better support from NAMI members.

Dr. Chuck Miles, cochairman of NAMI'S Research Committee, was appointed to the National Advisory Council of NIMH, culminating a successful drive to land a family consumer representative on the committee that passes on applications for research grants.

The Board met again in Washington on April 16-18, 1982, with development of affiliate antistigma and organizational kits dominating discussion. Later that month, Carol Howe, Director Smith, and Phebe Cook of Philadelphia met with Health and Human Services Secretary Richard Schweiker in a productive discussion of the problems confronting persons with chronic mental illnesses. As a result of the meeting, NAMI was invited to send to the secretary a list of action desired from NIMH and from the Health Care Financing Administration. In addition to this national recognition, President Starr gave testimony before the HHS Subcommittee of the House of Representatives.

NAMI had learned to extend its advocacy efforts by joining with other mental health organizations and coalitions: an SSI-SSDI coalition of 11 disability groups, the Mental Health Liaison Group, the National Community Support Advocacy Network, and the Council on Understanding Mental Illness.

For the first time, a prominent European psychiatrist, Dr. John K. Wing of Great Britain, was featured speaker at a NAMI conference. The fourth annual meeting, which attracted 600 members and guests to Washington, D.C., was held in a new Marriott hotel on August 5-8, 1982. Dr. Wing lived up to advance billing, presenting two lectures and making himself available to conferees during the entire conference. For the first time, through his clear British-accented explanation, NAMI members learned the difference between positive and negative symptoms in schizophrenia. Other speakers who carried out the theme, "Empowering the Consumers of Mental Health Services" were Dr. Milton Shore and Dr. Fred Goodwin, NIMH; Dr. Richard Lamb, University of Southern California; and Dr. John Talbott, editor of Hospital & Community Psychiatry, American Psychiatric Association publication popular with AMI affiliates. Convention coordinators were Ed Brazill, Carol Howe, Mary McClure Carter, and Agnes Hatfield, who served as program chair.

During the convention, Director Smith reported that the mailing list now included 8,000 names, with over 160 affiliates on the roster. New NAMI publications included a NAMI brochure, a directory of affiliates, two guides for legislative action, an antistigma handbook, a pamphlet of model programs, and a booklet for organizing new AMI groups. Shirley Starr concluded her dedicated two years of the presidency as the Board chose Agnes Hatfield president and continued in office the other Board members chosen at the Seattle convention. New Board

members were Phebe Cooke, Philadelphia; Felice Dickson, Miami; Ann Sheehan, St. Louis; and Helen Teisher, San Diego.

Conferees divided into five issue groups, and in the group studying the issue of guilty but mentally ill (as enacted in several states) members were able to compose a resolution passed by the assembly. The resolution read: "We support the plea of 'not guilty by reason of insanity.' We oppose the pleas of 'guilty but mentally ill.' We support the concept that the burden of proof be on the defendant."

NAMI instituted a Distinguished Service Award, which for the first year was presented to Congressman David Obey of Wisconsin for his advocacy for community support programs for persons with mental illness. The congressman at that time was chairman of the Budget Committee Task Force on Economic Policy and was also on the Appropriations Subcommittee on Health, Education and Labor.

1982 saw the formation of HELP (Help Exists for Loved Ones in Prison), the first subgroup within NAMI. Madeleine Goodrich, organizer of HELP, started the group for NAMI members who have experienced a death in the family because of mental illness or who have mentally ill family members serving a prison sentence.

At the December 3-5, 1982, Board meetings held in Washington, the director reported that there were 168 affiliates. Ed Brazill of Virginia was designated lead person in studying possible guardianships and trusts for mentally ill family members. The first official NAMI antistigma campaign was designed around the release of the movie, "Psycho II," with boycotts encouraged.

As AMI affiliates across the country devoted increasing efforts to advocacy for services, they discovered that the locus of action was their own state. The new administration in Washington was withdrawing as fast as possible from providing services for disabled persons. The NAMI office was coordinating advocacy efforts to support continuation of the Community Support Program Office in NIMH, to protest Social Security disability reviews, and to urge greater research funding.

There had been state AMI organizations even before NAMI was officially launched in 1979. California was the earliest with seven Bay area groups united under the name California Association, Families of Mentally Disabled. Wisconsin was next, joining seven county AMIs into AMI of Wisconsin in the spring of 1981.

In 1982 and early 1983 five other state AMI organizations emerged: Colorado, Ohio, Massachusetts, New York, and Maryland.

The NAMI office was moved from 1234 Massachusetts Avenue, N.W., to a fourth-floor suite in a building housing other nonprofit health organizations at 1200 15th Street, N.W. Additional office staff to help Smith and Saunders were Richard Greer, a former congressional aide and AMI member from Virginia - legislative liaison person at three-fifths time - and Susan Woods, information specialist.

At the NAMI Board of Directors' meeting April 22-24, 1983, in Crystal City, Arlington, President Hatfield reported there were 199 affiliates in all but eight states: Delaware, Idaho, North Dakota, Rhode Island, Tennessee, Vermont, Wyoming, and West Virginia. Ginnie Krumdieck, OR, was appointed to a position on the Board, replacing Felice Dickson who resigned. Ginny was to serve until the annual meeting in St. Louis.

The stability and growth of NAMI was reflected in the increased attendance at the fifth annual summer convention held August 4-7, 1983, in St. Louis. Over 650 persons attended the sessions held on the campus of Washington University. The theme, "Coping with Mental Illness: Progress Through Research/Rehabilitation," seemed particularly appropriate for a conference held on this campus because the biological approach to mental illness was largely kept alive during the days of America's capture by psychoanalysis through the efforts of professors and researchers at Washington University. Host group was AMI of St. Louis, with Ann Sheehan as general chairman.

Plenary speakers included NAMI President Agnes Hatfield; Dr. Samuel Guze, president of WU Medical Center; Dr. Boyd Hartman, professor of psychiatry at WU; Dr. Herbert Pardes, NIMH; and Alan Barry, Ph.D., director of the St. Louis Planning council. NAMI's Distinguished Service Award was presented to Dr. Eli Robins, former Head of Psychiatry at WU, for his work in helping to compile the Diagnostic and Statistical Manual of Mental Disorders, 3d Ed., and for his efforts to keep American psychiatry in the field of medicine.

Mr. and Mrs. Jack Hinckley of Colorado, parents of John Hinckley who attempted to assassinate President Ronald Reagan in 1981, "came out" for the first

time at this convention.⁷ Media were heavily in evidence as the Colorado couple told of the shocking events that changed their lives.

Membership Chair Beverly Young reported to conferees that there were 230 affiliates, located in every state except West Virginia, Idaho, North Dakota, and Wyoming. Some of the growth was attributed to the appearance of Dr. E. Fuller Torrey on the Phil Donahue TV Show, with his repeated references to NAMI, and to publication of his popular book, Surviving Schizophrenia: A Family Manual. Dr. Torrey, who had been a speaker at the Seattle conference, was helping stabilize the NAMI budget by turning over all royalties from sale of his book to NAMI.

For this national media exposure on the Donahue program and for all subsequent appearances by Dr. Torrey and following references to NAMI in the Ann Landers column, many volunteers from nearby AMIs in Maryland and Virginia put in thousands of hours answering the NAMI phone, or writing letters to families in pain. Several Board members, especially Peggy Straw, also helped with the inundation of mail during 1983.

New Board members elected in St. Louis, were James Howe, Ginny Krumdieck, Harold Martin, and Harriet Shetler, three-year terms, and Nancy Masland, two-year term. Agnes Hatfield concluded her term as president, a successful period of explosive growth and good communication through her monthly letters to affiliate leaders. The Board chose Charles Miles, president; Helen Teisher, first vice-president; Peggy Straw, second vice-president; Harriet Shetler, secretary; and Merion Kane, treasurer.

A second subgroup, Siblings, was added to NAMI at the convention. Julie Johnson of Minneapolis, who had started the first NAMI Sibling group while a member of Dane County AMI, WI, was recognized as chair of this group who had mentally ill brothers or sisters.

A special interest group that emerged at the Washington, D.C., convention and gathered steam at the St. Louis convention is the Ethnic Minority Concerns Committee. This task force has been providing direction to NAMI outreach to ethnic minority families who have mentally ill relatives. Merion Kane, first minority

⁷ Breaking Points, by Jack and Jo Ann Hinckley, Zondervan; 1985.

member elected to the NAMI Board of Directors (in 1981) serves as chair and Lynne Saunders, director of the Office of Affiliate Relations, serves as staff liaison. Others on the committee at present are June Bland, John and Natella Colbert, Kathy Jackson, Cynthia Lewis, and Camilla Miller, NAMI Board liaison. The group has developed an information brochure and presented a workshop, "Effective Outreach to the Community," at the Boston convention, along with encouraging growing participation of minorities in AMI affiliates and on national committees.

Finances continued to be a major concern in 1983 for the Board and Executive Director Smith. Few members were sending in voluntary dues of \$5, although most affiliates were submitting \$1/member after their first-time affiliate admission fee of \$25. A three-year renewal of the MacArthur Foundation grant was sought; the large amount accruing from royalties and sale of Dr. Torrey's book helped keep the organization afloat.

NAMI joined the Combined Federal Campaign, similar to United Way, in the fall of 1983, with a first-year thrust into large cities where the greatest number of federal employees were located. The Board-voted to allocate 70% to NAMI, 30% to the affiliate for the first year, 60% and 40% for the second year (later changed to 50-50), and 50-50 for subsequent years.

One of the outstanding projects of the Miles presidency was submission of a proposal, largely written by Finance Chair Jim Howe, to the Pew Foundation. This subsequently became the office of Affiliate Relations when funded. The three-year project for \$200,000 awarded by the Pew Memorial Trust involved hiring Dr. Hatfield as project director at half-time salary and appointing Carol Howe as assistant director, serving without compensation. The office staff at NAMI expanded again with the addition of Adeline Marsicano as administrative assistant and Carol Grant as bookkeeper.

During the meeting of the Board of Directors at Tucson, AZ, February 2-5, 1984, voluntary dues of members were raised to \$10 and affiliates were asked to pay a yearly fee of \$25 except for groups smaller than 20. The Board continued to discuss establishment of a NAMI research fund to carry out the research resolution adopted at the St. Louis convention. Explorations were conducted with Jack Hinckley, president and founder of the American Mental Health Fund, and with Ted

Wolf, president of the National Mental Health Association. In the meantime, NAMI set up an escrow bank account to receive funds designated for research.

In the winter of 1983/4 two meetings were held with the National Mental Health Association, Jack Hinckley, president of the American Mental Health Fund, and NAMI Board members to see if we could unify our plans to establish a privately financed program of research on major mental illnesses. Mr. Hinckley proposed that NMHA and NAMI submerge their efforts into his. He offered seats on his board of directors in exchange for the mailing lists of both associations. NMHA and NAMI declined, and NAMI inquired whether he would be willing to serve as executive director of a unified effort, reporting to a board of directors composed of equal numbers from each of the three organizations. Mr. Hinckley declined. More detail appeared in the April 1984 issue of the NAMI Newsletter.

The first-ever public service announcements were produced in early 1984 by the Communications Committee (Ann Sheehan, Harriet Shetler, and Peggy Straw) under supervision of Bernie Smith and Joshua Hammond, executive director of CUMI. Two PSAs were distributed to ABC, CBS, and NBC for national network viewing, and affiliates were able to purchase these for their local stations. The tapes, entitled "Shattered Dreams" and "Scrapbook," featured AMI members Nancy Schaefer and Richard Greer and family.

To the West Coast went 1,152 persons for AMI's sixth annual conference, held July 5-8, 1984, on the campus of University of California-Irvine, which cooperated with AMI of California in hosting the event. Conference Chair Ramona Schneider and Program Chair Helen Teisher arranged plenary and workshop sessions around the theme, "Surviving Mental illness: Families Face the Challenge."

Plenary addresses were given by Dr. William Bunney, Jr., Chairman of the Department of Psychiatry, UC-Irvine; Dr. Robert Gerner, chief of psychiatric research, VA Medical Center, Long Beach; Dr. Floyd Bloom, neuroscientist at Scripps Research Institute; Dr. David Janowsky, UC-San Diego; Dr. Monte Buchsbaum, UC-Irvine; Dr. Bert Pepper, executive director, Spring Valley, NY, Center; Dr. Lawrence Sporty, UC-Irvine; Commissioner George Conn, Rehabilitation Services Administration; Dr. Donald Lunde,, Stanford University; Dr. George Solomon, UC-Los Angeles; and Dr. Pardes, director, NY State Psychiatric Institute.

NAMI's Distinguished Service Award was presented to Dr. Seymour Kety, famous research scientist who pioneered in twin studies to show genetic configuration in schizophrenia. Dr. Kety has had a long career with NIMH and with the schizophrenia research funded by Scottish Rite Masons. A NAMI Special Families Award went to Dr. Torrey, who was unable to attend the convention.

A reporter from a biweekly Washington, D.C. newsletter who covered the convention for his periodical summed up the meeting this way: "In dramatically increasing number, relatives of the chronically mentally ill are coming out of the closet and marching headlong into the world of mental health advocacy 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."⁸

Four directors were elected for three--year terms: Laura Guilfoyle, IL; Liselotte McMillan, MA; Davis Pollack, NY; and Donald Richardson, CA. Officers chosen by the incoming board were: Jim Howe, president; Helen Teisher, first vice-president; Ann Sheehan, second vice-president, Laura Guilfoyle, secretary; and Hal Martin, treasurer.

Chuck Miles's presidency had ended on a note of optimism about start-up of the long awaited research foundation, one of Dr. Miles's main projects. He was asked to serve as chair of the Research Committee, empowered to continue discussions about a foundation with related groups. In September 1984, he met in Chicago with Phil Ardery of Louisville, KY, and Gwill Newman of Chicago to link NAMI and the Schizophrenia Research Foundation that they represented into a research merger.

At the Board meetings held during the California convention Membership Chair Masland reported that there were 307 paid affiliates and 15 state groups. One of the highlights of the conference's ethnic dinner was an announcement by Robert Walker of Casper, WY, that they had just formed an AMI affiliate, thus completing a sweep of all 50 states. Two conference resolutions passed called for establishment of a committee of ex-patients, and charged the federal government to make a

⁸"Membership of Fiery Family Advocacy Group Mushrooms," Mental Health Reports, Patrick Rogers, reporter,, Arlington, VA; July 18, 1984.

commitment to seek the causes and cures for serious mental illnesses through adequate research funding, similar to efforts expended for other major illnesses.

The financial outlook improved in late September 1984 when the MacArthur Foundation approved a second three-year grant of \$300,000 extending to September 30, 1987. When Executive Director Smith announced his resignation, President Howe appointed a search committee consisting of Board Members Howe, Richardson, and Shetler; Bob Kushell, AMI member from New York City; Dr. Hatfield, former NAMI president; and Dick Greer, current NAMI staff. After screening 125 applications, the committee selected Laurie Flynn of Alexandria, VA. Ms. Flynn was experienced in national advocacy with a distinguished background as executive director of the North American Council on Adoptable Children.

Expressions of appreciation for Bernard Smith's work poured in from NAMI members, who had benefitted from his sensitivity to families in pain and who especially approved of his thoughtful relationship to clients of the mental health system.

The Board requested Harriet Shetler, a journalist recently retired after 35 years experience in print media, to assume editorship of the NAMI newsletter on a voluntary basis.

At the October 5-7, 1984, Board meeting in Arlington, the members unanimously voted to accept the recommendation of the Search Committee. Within two weeks, Laurie Flynn was behind the Square Desk as Executive Director in the Rectangular office of NAMI. A budget of \$453,125 was approved for FY1985. By November, the number of affiliates had risen to 356, an addition of 100 in less than a year.

NAMI's main efforts in the fall of 1984 were directed to implementing the 1983 convention resolution directing NAMI to establish a research foundation. At the September 20th meeting mentioned earlier when the Louisville group and NAMI effected their merger, it was decided that there should be a scientific board as well as a lay governing board.

As members expressed difficulty in securing books in the field of mental illness, the NAMI Office expanded its offering of selected titles to be sold, often at

reduced rates. Raymond Barrett, a part-time book clerk, was added, while the Book Selection Committee from the Board scoured library and professional journals for additions. Book prices and an order form became standard on the back page of the newsletter. One of the new columns, which offered reflections by authors of these books and was entitled "After Two Years," featured writing by Phyllis Vine, Mona Wasow, Dr. Torrey, Kayla Bernheim and Richard Lewine, and Maryellen Walsh (one year after publication). Dr. Richard Wyatt, chief of the Neuropsychiatry Branch, NIMH, wrote a regular column in which he answered technical questions from readers.

The Board held its spring meeting February 1-4, 1985, at Tulane University, New Orleans, site of the 1985 summer meeting. The outstanding decision from that meeting was agreement for a bylaw change, to be voted upon later by the assembly, setting up a NAMI Client Council. Each state AMI, or when none existed an affiliate in that state, was to select one client to be a delegate to a Client Council. At the 1986 convention, the Council was to choose one representative for a three-year term on the Board of Directors.

A breakthrough in NAMI's antistigma efforts came suddenly in the late winter and was reported at the Board meeting. Hasbro-Bradley Toy Company, after reeling from a deluge of letters and calls by NAMI members upset by a doll that stigmatized persons with schizophrenia, generously donated \$30,000 for a two-year antistigma campaign and also offered access to its public relations department.

The increasingly active government relations sector of NAMI, under staff member Dick Greer, held its first legislative seminar in Washington. Legislative Chair Davis Pollack also helped with planning the seminar, March 11-13, 1985. Participants convened for a two-day crash course in advocacy, with many staying for a day on "The Hill," opening paths to congresspeople and mending fences. Stella March, vice-president of California AMI, summed up her reaction in an article in the April 1985 newsletter: "NAMI has more than met its goal and our expectations at this first Legislative Seminar We met with good fellowship, networked our state successes and projects, and learned the impact of decisions made by Congress and the President in Washington on the daily life of our family member back home."⁹

⁹ "NAMI's Legislative Seminar: First Impressions," Stella March, NAMI Newsletter, April 1985.

After a year of operation of the Office of Affiliate Relations (OAR), Director Hatfield issued a report to the Pew Memorial Trust, funders of the project. She stated that the goal of increasing membership had been reached (400 affiliates by April 1985), a bimonthly packet was being issued to all affiliates, and publications on a variety of subjects had been drawn up.

OAR and Agnes Hatfield wrote or sponsored the following booklets: "Consumer Guide to Mental Health Services"; "The Role of Professionals in the National Alliance for the Mentally III"; "The National Alliance for the Mentally III: Five Years of Progress"; "Primary Affective Disorder"; "What Is Tardive Dyskinesia?"; "Mental Illness is Everybody's Business." NAMI also reprinted a useful book with questions and answers about the unsolved problem of tardive dyskinesia originally compiled through Ginny Krumdieck's efforts in Lane County, Oregon AMI. Harriet Shetler and Ginny used Board input in compiling a reading list booklet of books and periodicals most helpful to NAMI families.

After a brief absence, Lynne Saunders returned to NAMI staff, eventually becoming director of OAR. Maggie Scheie, administrative assistant, and Don Mackay, clerk, were added to the OAR, Alida Kimer became receptionist, and Rino Aldrighetti joined NAMI as director of development.

On April 15, 1985, NAMI moved its office to the present location, near the Rosslyn Metro station, on North Fort Myer Drive, Suite 500. As soon as the address was firmed up, the new financial development director began to explore ways to secure solid finances through direct mail, foundations, corporate giving, extension of the Combined Federal Campaign, planned giving via wills, and marketing of members' benefits.

Louisiana AMI affiliates with Hal Martin, general chairman, and Marilyn Rosenson, program chairman, were hosts to NAMI's sixth annual convention held on the campus of Tulane University. The fascination of New Orleans and the excellence of the program drew 1,448 conferees to the Mississippi site on June 27-30, 1985. Keynote speaker Dr. John Talbott told the organization that honored him with its Distinguished Service Award that "NAMI is simply the most important force in our field." Dr. Torrey reported on his survey of 2,700 NAMI families, and the following professionals gave plenary addresses: Dr. Shervert Frazier, Dr. Wallace Tomlinson, Bonnie Spring, Ph.D., Dr. Frederick Goodwin, Dr. Samuel

Keith, Dr. Jan Fawcett,, Dr. John Strauss, Dr. Ken Terkelsen, and Educators William Anthony, Courtenay Harding, Sue Estroff, Kayla Bernheim, and Agnes Hatfield. A distinguished group of men and women led medical-scientific seminars during one afternoon, and on the second afternoon workshop leaders from NAMI ranks and guest speakers presented community rehabilitation and family coping workshops.

Voting at the convention resulted in four new members for the Board of Directors: Dale Johnson, Houston; Brenda Lyles, West Palm Beach; Camilla Miller, Richmond; and Herbert Reisenfeld, Cincinnati. The change in the bylaw, to add one seat held by a client on the Board, passed with the required two-thirds majority. Another bylaw that passed stated that state AMI groups must be composed of at least three local geographically dispersed affiliates.

At the meeting of the Board after the convention, Jim Howe's dynamic leadership of NAMI during 1984-85 was rewarded by election to a second term for the Threshold-AMI member. Donald Richardson was elected first vice-president, Ginny Krumdieck, second vice-president; Laura Guilfoyle, secretary; and Hal Martin, treasurer. The Board gave approval to an FY1986 budget of \$642,463.

On June 26, 1985, preceding the convention, the newly created National Alliance for Research on Schizophrenia and Depression (NARSD) held its first meeting. The governing board took the following actions: (1) elected Gwill Newman president and Chuck Miles vice-president; (2) adopted bylaws that among other things requires a majority of members of the governing board to be family members of persons with mental illness or those persons themselves; (3) specified that the main focus of research be serious mental illness with emphasis on brain diseases. Other NAMI members on the governing board included Jim Howe, Sheldon Rein, Ira Rose, and Helen Teisher. Twenty-two prestigious psychiatrists or researchers were enlisted to serve on the Scientific Council.

In addition to Dr. John Talbott, other persons honored at the convention were: Daniel Weinberger, M.D., Young Scientist Award; Agnes Hatfield, Outstanding Member of NAMI; Phil Donahue, Outstanding Public Educator Through the Media; and Brenda Lyles, Ph.D., Local Convention Host Award for Exceptional Service. The newly established Krementz Antistigma Award was won by AMI of Southern Arizona for its presentation "The Forgotton." The entry included a 30- minute

documentary videotape, two 60-second public service announcements, and an informational pamphlet.

In October 1985 the 500th affiliate was enrolled, shortly before the Board of Directors met at the Arlington office, October 11-13. Two task forces of NAMI that came in for attention by Board members were the growing antistigma effort spearheaded by Davis Pollack and the successful advocacy effort in Congress led by Dick Greer. Nancy Domenici, wife of the New Mexico senator who headed the budget committee, was recognized for her enlistment of other congressional wives in testifying for the NIMH budget and in helping to host a NAMI seminar on schizophrenia attended by congresspeople and their aides.

Executive Director Flynn reported addition of three staff members: Charles Harman, public relations and eventually newsletter editor; Patricia Brady, government relations assistant; and Lynn Borton, executive assistant. The staff was now meeting once a week to discuss goals and problems, and individual staff persons were turning in monthly reports. Office procedures were worked out to handle the thousands of incoming calls and letters following a second appearance by Dr. Torrey on the Phil Donahue Show and an Ann Landers column praising the work of NAMI. Volunteers from nearby AMI affiliates greatly augmented the staff that was trying to stay on top of the wave of the strong NAMI tide. As Director Flynn supervised her staff, handled communications, and teamed up with President Howe in overseeing a host of new NAMI projects, the Board expressed approval of the way its new director had "taken hold" in just one year.

Prior to the October Board meeting, members and several guests spent the morning of October 10 at a briefing day given by NIMH at its Bethesda offices. Top researchers and department heads "walked" NAMI members through the reorganization of NIMH, explaining their goals and their operation. After this session, NIMH hosted open exchange programs for subsequent Board meetings and for NAMI members who attended the second Legislative seminar held in March 1986. Before the second Board invitation to NIMH in February 1986, the Board perused descriptions of research funded and was able to elicit answers to hard questions about the relevancy of certain research in areas unrelated to serious mental illnesses.

On January 20, 1986, the Board of Trustees of NARSD convened in Chicago. Also present was the newly elected chair of the Scientific Council, Dr. Pardes. Treasurer Jim Howe reported \$120,000 received from NAMI members and over \$30,000 from the former Schizophrenia Research Fund. Negotiations with the National Mental Health Association were reviewed. (Later this year, NMHA voted to participate as a partner, as well as the National Depressive Association, and by the Boston convention, NARSD published a brochure listing the trustees with members from all organizations in the research merger.)

As mentioned earlier, the second legislative seminar was held, this time almost doubling attendance with 150 persons flying in from all over the country. Acting Assistant Secretary of Health and head of ADAMHA Dr. Donald Macdonald and Senator Pete Domenici spoke. Plenary sessions on the topics of NIMH and Medicaid laid groundwork for more individualized workshops on social security disability, NIMH programs, housing, right to treatment, rehabilitation, insurance, use of animals in research and recognition of the growing problem of animal rights supporters, homelessness, and protection and advocacy.

When the Board met February 13-16, 1986, in Washington, members heard Treasurer Hal Martin and Richard LeBus, newly hired director of finance and administration, outline a fiscal year projected budget of approximately \$750,000. NAMI's department of development, which now had an assistant director, Jerry Ernst, was raising funds for this budget by periodic letters to members, through appeals to various businesses, and by substantial grants from Van Amerigen, Pew Trust, MacArthur, and Ittleson foundations. Director Aldrighetti was gearing affiliates for the fall Combined Federal Campaign, but warned that confusion in campaign regulations and lawsuits made the future of CFC funding uncertain.

Executive Director Flynn reported that the NAMI office staff comprised 14 persons, including Chris Kitzmiller, information specialist, and Stephanie Smith, secretary.

The expanding organization was reaching out in all directions. Task forces were convened at the NAMI office on insurance and Medicaid, while the Curriculum and Training Committee cosponsored a conference February 26-28 at NIMH, "Educating Professionals to Work With Families of the Long-Term Mentally Ill." Chaired by Harriet Lefley, co-leader of the NAMI committee, major papers

were presented by Lefley, Dale Johnson, Mona Wasow, Agnes Hatfield, Gerda Cohen, Evelyn McElroy, Kayla Bernheim, and Ken Terkelsen..

Ed Brazill, chair of the Guardianships & Trusts Task Force, reported to the Board on results of his committee's questionnaire. A response from 535 families indicated that relatives of mentally ill persons are concerned about the future of their relatives, with 85% interested in locating a trustee to take responsibility. Brazill's committee is helping local affiliates set up trust associations.

The new public relations department prepared public service announcements and developed a packet of materials to use in connection with CBS's TV-program on Marie Balter, "Nobody's Child." Ginny Krumdieck worked on an updated version of a booklet covering public sector housing, and Peggy Straw and Harriet Shetler co-edited a booklet of client writings entitled "A New Day."

The 600th AMI affiliate was added in May 1986, completing a sweep of all 50 states, Puerto Rico, Canada, and Guam. Almost weekly, prominent print media publicized NAMI, with the most outstanding support coming from a series of four articles in the New York Times and with publication of Care of the Seriously Mentally Ill: A Rating of State Programs by Dr. Torrey and Sidney Wolfe, M.D., members of the Public Citizen Health Research Group. President Howe, Client Member Esso Leete, and NIMH Researcher Dr. Samuel Keith appeared on a substantial segment of the ABC morning news program, "Good Morning America," at about the same time that Parade Magazine published an article on schizophrenia, giving a prominent space to NAMI.

Riding the wave of activity on all fronts, 1,650 persons attended the eighth annual NAMI convention/conference July 3- 6, 1986, at the Park-Plaza Hotel, Boston. Despite the Independence Day holiday and dedication of the reopened Statue of Liberty, members, guests, and speakers overflowed the huge ballroom, the "Castle" (nearby auditorium), and individual workshop rooms.

Preceding the conference, the Board convened for one day, compressing agenda into "taking vital signs," hearing administrative and financial reports, and flexing the muscles of the family movement, opting for concern for mental illness rather than mental health. NAMI agreed to cooperate with NIMH in its D/ART

campaign, focusing on depression as an illness: Depression/Awareness/Recognition,/Treatment.

The Board agreed that although NAMI has 41 state associations, the strength of the association is still grass roots and the governing base and election power lies in the affiliates. A decision was made to give past Board members emeritus status, involving them from time to time on volunteer tasks. Dick Greer reported that 800 persons in AMI have volunteered to be national advocates. Lynne Saunders, director of OAR, said that her office sends out 12 start-up packets each week to prospective affiliates. Budget projected for FY1986-87, which began July 1, 1986, is \$862,844, with personnel expenses listed at \$483,594.

The day before the Boston convention opened, state leaders and other interested NAMI members convened for a whole day of information exchange, followed in late afternoon by a reception for Board and state presidents and for honored guests of the NAMI Fundraising Committee and the department of development.

NAMI's 1986 convention, fondly nicknamed the Boston Marathon, opened on a lively note Thursday afternoon, July 3, with seven candidates for the four Board of Director openings telling about their qualifications. At the evening session, Anita Pyatt, president of AMI of Massachusetts, enthusiastically dislodged the head from her gavel in getting the plenary sessions off to a rousing start. Speaker Dr. Thomas Bryant praised NAMI for its leadership, saying it was badly needed in view of how easily the Mental Health Systems Act disappeared in 1981.

Chair Nona Dearth and Program Co-Chairs Lilo McMillan and LeRoy Spaniol, of the host AMI of Massachusetts group, introduced a distinguished array of psychiatrists and research pioneers for the July 4 program: Drs. Solomon Snyder, H. Richard Lamb, Steven Matthysse, Shervert Frazier, and Samuel Keith. On July 5 speeches were given by Governor Michael Dukakis, Dr. Carol Nadelson (former president of the American Psychiatric Association), Dr. William Anthony, Dr. Donald Macdonald, and Senator Pete Domenici. A full battery of workshops, practical and theoretical, filled the afternoons of July 4-5. The conference concluded Sunday, July 6, at noon with Dr. Torrey's speech on possibilities for change.

New members elected to the Board were as follows: Don Culwell, client representative, TX; Eleanor Schorr, AZ; William Snavely, VA; Caroline Sneed, AR; and William Uhlhorn, OR. Bylaw changes and two resolutions passed: request for a commemorative stamp honoring persons with mental illness and the family advocacy movement (presented by Washington AMI), and a petition to the World Health Organization to establish a schizophrenic institute and to change wording in its publication, International Classification of Diseases (presented by Ohio AMI).

Awards presented during the convention went to the following persons: Outstanding AMI Member(s), Jim and Carol Howe; Young Scientist, Dr. David Pickar; Krementz Antistigma Award, Rock Island-Mercer County, IL, for their Project Employment; AMI's Distinguished Service Award, Nancy Domenici; Public Education Through the Media, New York Times, Good Morning America, and the Today Show; Friends of the Family, Hasbro-Bradley Company and the MacArthur Foundation; Special Commendation, Scottish Rite; Special Award, Marie Balter; Outstanding Advocacy, Affiliate -- Montgomery County, MD; Outstanding Advocacy, State -- California. Best newsletter awards went to AMI-Wisconsin, state; AMISA, Tucson, large affiliate,- and AMI of LaCrosse County, WI, small affiliate.

New officers were elected by the Board at a meeting following the convention. President Jim Howe concluded his two years, having seen NAMI double the number of affiliates during his term, and having provided much of the leadership that propelled the organization into the front ranks of fighters trying to overcome mental illnesses. Donald Richardson was elected president; Davis Pollack, first vice-president; Brenda Lyles, second vice-president; Laura Guilfoyle, secretary; and Herbert Reisenfeld, treasurer.

The first chapter in the history of NAMI ends at the Boston conference, as the hundreds of family members and clients went back to the grass roots where AMI started and where it continues to flourish with a spectacular combination of support for each other and determination to change the public and private system of treating the ancient scourge of mental illness. Five talented presidents --- George Hecker, Shirley Starr, Agnes Hatfield, Charles Miles, and James Howe -- and a strong NAMI staff have brought us to this point, poised on the cutting edge of the great breakthrough to discovery of the causes and cure for long-term mental illnesses.