

July 18, 1985

HISTORY AND ACTIVITIES OF WESTERN MASS, ALLIANCE-MENTALLY ILL CITIZENS, INC.

Before there was an official WMA-MIC, there was the Family Support Group of Holyoke/Chicopee Area. This group, who had met during 1982, was led by a professional Michael Murphy. Michael started up this group because a family person, Josie Mailhott kept insisting that she "would like to meet other families." In the Spring of 1982, Ruth and Harold Stein attended these support meetings and heard families talk openly about their mentally ill loved one and also the families started talking about improving conditions and treatment of care, especially in Northampton Hospital. Ruth Stein discovered NAMI's existence while watching a program from New York in which NAMI family members were being interviewed. On July 14, 1982 this Holyoke/Chicopee group became an affiliate of NAMI and became a family led group having about 20 members. As there is one state hospital in Western Mass., Harold Stein suggested to the members that in order to become more effective as advocates that we broaden this original group to include other families in all of the 5 Dept. of Mental Health catchment areas in Western Mass and not just from the Holyoke/Chicopee Area. Notices were placed in newspapers to try to reach families asking them to attend educational meetings which families started up at Northampton State Hospital. Families came from all the 5 catchment areas in Western Mass. and at the December 1982 family meeting at NSH families voted for the new organization, Western Mass. Alliance for Mentally Ill Citizens. This resulted in dropping our original name. Election officers were also held and Harold Stein became President, Kenneth Landon, 1st VP, Mary Garret, 2nd VP and Barbara Howard, Treasurer. Ruth Stein has served as coordinator since its inception.

During the early stages of WMA, a caring and sympathetic professional, Dr. Michael Hogan, who was at the time Dept. of Mental Health District Manager of Western Mass., came to many of our meetings and worked with Harold Stein to see about the start-up of the monitoring process by families of WMA to monitor Northampton State Hospital. There are now 22 family persons, under the capable guidance of WMA Chairperson Mary Garrett, a retired registered nurse, who have been monitoring NSH on a regular basis. Families, who receive training, fill out a report on the conditions of what they saw in the ward, and this report is responded to by the Director of each ward. For years, patients and staff lived under the dangerous health hazard of exposed asbestos in the hospital. WMA advocacy resulted in this asbestos being removed. (See April 1985 Hospital & Community Psychiatry article "Family Members as Monitors in a State Hospital). Also with Dr. Hogan's approval, the enclosed sample letter is sent out to all families when their relative enters NSH, letting them know how they can get in touch with our Alliance and other understanding families. Unfortunately, this has not been as effective as we thought it would be. Perhaps, the fear and stigma attached to state hospitals and the turmoil and pain families are in when their relative enters a state hospital has kept families from reaching out to us. There are other ways we have tried to reach families, through articles written about the Alliance in newspapers in March 1985, appearance on TV of 3 WMA board members, notices in newspapers about educational and support meetings, distribution of brochures at Mental Health Agencies, attendance and talks about Alliance meetings to professionals. Dr. Torrey's book with our name in the back and his appearance on TV has brought us some inquiries from families. It has been a constant plugging away to reach families who are still suffering from professionals' sin of omission (not giving a family or the patient diagnosis) and professionals who still believe that faulty childhood practices cause mental illness.

Prior to 1983, there were only two support groups for families in Western Mass., the Holyoke/Chicopee group which led by Ruth Stein and now by Betty Johnson and Jeanne Bartley and the one in Westfield area led by a professional. The families started up their own group in the Westfield area and it is led by Harold Stein, and the professionally led one is disbanded. After coming to an Alliance meeting at NSH, professional Mark Keller went back to the Berkshires and helped start up a family group. Now, he and another professional Marjorie Cohan help in whatever way they can, family person Charlie O'Donnell who conducts these meetings. In the Springfield area, we formed a support group which is led by Harold Stein and Jean McNulty. In the Franklin/Hampshire area (Northampton) we also formed this group led by Ruth Stein. Evelyn Russell has brought to every monthly support meeting in Northampton, home baked goodies and drinks from her home and has placed notices in newspapers and on the radio about these support meetings. We invite and urge providers and DMH people to attend these support meetings to hear the families' plight so that they can try to assist the families to obtain better services and help.

There is a vast DMH and Provider Empire in Western Mass. with much staff as a result of the NSH Consent Decree in 1978. Although patients are supposed to have an Individual Service Plan on their release from NSH, there are patients who are released without such a plan in place or an adequate plan as there are not enough psycho-social rehabilitation programs and an appalling lack of residential programs for those in need. Long waiting lists exist and as a result, many families have

become the care takers, or the client lives in rescue missions, the streets, or run down hotels (See newspaper article, June 9, 1985). The DMH Holyoke/Chicopee Area Director and its big provider, Mt. Tom Institute like to advertise themselves around the country and at conferences as a model for the country, a la Madison, Wisconsin. (Please see copy of article, pg. 57 of U.S. News and World Report, July 1, 1985). If conditions were that great for the mentally ill in Western Mass., there would be no need for Western Mass. Alliance. When you look at the DMH budget for Western Mass. it seems large compared to other areas of Mass. and of the country, but much money is allotted and spent for old time talking therapies for families and clients and for many service coordinators in the community who cannot coordinate and follow through, because there is not sufficient supervised housing and very few social rehab programs to send clients to. Families whose relatives have never been to NSH do not stand a chance to have their relative get into any supervised housing program unless they pay an "arm and a leg" for it, themselves. There is a crying need for retraining and education of professionals in clinics and programs who waste precious time and money with talking therapies and rehashing with families and clients, what happened when they were "3 years old." We hope to have knowledgeable professionals, such as Dr. Ken Terkelson and Dr. Kayla Bernheim, come to educate professionals and families in Western Mass.

Our legislative committee, led by Kenneth Landon, has worked diligently on state and national issues. We have rented buses to go to Boston, which is two hours away, to testify on state mental health bills, one of which was initiated by WMA, and to rally to save state hospital lands which the state wants to sell for commercial purposes. Ken Landon has set up a network of families to call and write on important bills. Legislative socials were held in 1985 on Saturday mornings in members' homes in various areas of Western Mass. Our state representatives came to hear families talk about what mental illness is and is not, what families have had to endure, about certain bills we are concerned about. One representative said "I always hear the DMH side and the provider's side, this is the first time I am hearing the families' side." Mary Garrett and Ken Landon have served in 1985 on Gov. Dukakis Mental Health Action Project to help revise the chaotic mental health system in Mass. Our executive board members have met with Gov. Dukakis, DMH Commissioner of Mass. James Callahan (who just resigned after two years) and other officials in the state administration.

We have 9 educational meetings a year held at Holyoke Community College since March 1983. Prior to that time, these meetings were held at NSH. Some of the speakers have been William Anthony, Commissioner Callahan, and Congressman Conte (at a Luncheon Social in a museum). Psychiatrists from state and private hospitals to talk on schizophrenia and manic-depression, etc. Our newsletters are sent to professionals, all over Western Mass. State legislators, members and prospective members. Ruth Stein has been doing this newsletter since Oct. 1982 when the nucleus of WMA was Holyoke/Chicopee Family Support Group. The newsletters contain announcement of educational meetings, the 5 support groups where and when they are held, legislative up-date, listing of books available in our library and whatever else can be squeezed in about the latest research findings on mental illness. We do not have an office and operate out of our home in Agawam.

In July 1985 we have membership of 230 families, but we realize there are still hundreds of families out there in Western Mass. who are still struggling by themselves to survive without the help of other understanding families. We hope to reach more of them by having some of our newer members become involved; as the original Executive Board of WMA is now still the same, Harold Stein, President, Ken Landon, First VP, Mary Garrett, second VP, Barbara Howard, Treasurer and we are aware of the term "burn-out."

We have joined the State Alliance, AMI of Mass., and Mary Garrett is member of the board. We have worked with the State Alliance in every way we can to help improve the quality of care for all the mentally ill in Mass. Harold Stein and Ken Landon participated in workshops at the 3rd Annual AMI Convention in Boston on May 4, 1985.

NAMI can help all affiliates and the mentally ill by convincing prominent persons across the country that have mentally ill relatives to "come out of the closet." That is how the stigma of Alzheimer's is being eliminated. We also hope that you can obtain more funding for ads on TV and arrange for programs that feature families.

Ruth Stein

Coordinator