

The Adequacy of Family Support Services for

Families and Individuals Coping with Mental Illness in Maine:

2001 Status Report

Preface

NAMI Maine is pleased to submit this report to the Department of Mental Health, Mental Retardation and Substance Abuse Services. As requested, we have reviewed the current status of family support services and assessed compliance with consent decree standards regarding those services. We look forward to working with the Department and other members of the community to address the issues raised by the findings of this report.

This report describes what services NAMI Maine provides, what mental health service providers provide in terms of family support services, and highlights inconsistencies in perception that exist between mental health providers and family members regarding the availability of and access to Family Support Services in the state of Maine. The report also summarizes over 600 contacts between NAMI Maine and families and consumers who expressed concerns about the supports they were receiving.

Specifically, the AMHI Consent decree requires providers to educate families regarding the consent decree and the availability of family support services. The Decree also requires the Department of Mental Health, Mental Retardation, and Substance Abuse Services to make adult respite services available. NAMI Maine's report addresses areas of potential improvement for family and provider knowledge regarding available services and the linking of families to those services, the education of providers regarding family perspectives, and the availability of education regarding the consent decree.

Purpose and Scope

Pursuant to the work plan that NAMI Maine submitted to DMHMRSAS regarding the completion of this report, a narrative description of family support services provided by NAMI is included in this document. The description of these services includes all family support services available from NAMI Maine and funded or partially funded by DMHMRSAS.

NAMI Maine has also studied compliance with Section I, 109 and 110 of the Consent Decree. Section I, 109 requires the existence of "an array of family support services to include:"

- Education on the terms of the consent decree

- Education on available services, and on mental illness from the perspectives of professionals, other families and mental health service recipients,
- Direct support of family groups through the provision of a facilitator at meetings, if requested,
- Education on treatment, medications, diagnoses, prognoses, and how to care for persons with mental illness,
- Group counseling,
- Psycho-educational programs, and
- Respite services for families who provide class members with intensive supervision and assistance.

Section I, 110 further requires that providers of mental health services include among their services the referral of family members with whom the providers have contact to area support groups. It further requires providers to offer to call the support group on behalf of the family member and gives the means by which the support group can reach out to the family.

This report summarizes information gathered from a survey of family members of persons with mental illness, NAMI Maine Affiliate Leaders, and agencies contracted with DMHMRSAS for the provision of mental health services in Maine. The report makes conclusions and recommendations based on the information gathered from this survey process. The survey was emailed to all members of the Maine Association of Mental Health Services (26 mental health centers and 2 hospitals), a presentation was made to that group regarding the purpose of the survey, and all members of NAMI Maine were mailed a survey (612 members). Finally, NAMI Maine sent the survey to all 80 members on its e-mail list serve.

Family Support Services Provided by NAMI Maine

NAMI Maine receives funding from DMHMRSS to carry out the following family support services:

- Support groups. Technical and financial assistance to family support groups across the state. There are currently 23 support groups – 20 are for family support and 3 are for consumer support.
- Printing of all Family-to-Family training materials. This is a 12-week course for families about coping with mental illness. The course is offered 12 times per year –

six times in the fall and six times in the spring. It is offered across Maine – from Madawaska to Kittery. A summary of this year’s training is attached.

- Information and Referral. NAMI Maine offers telephone and in person support and information to all callers who need help related to mental illness. A 1-800 line is provided Monday-Friday, from 8am –5pm. Information packets are available on all illnesses, their treatment, and any up-to-date research about the illness. Callers are coached on finding the support they need, advocating for services, assisted with identifying resources, and helped to understand the system and what to expect. NAMI Maine mailed brochure holders and NAMI Maine brochures and a poster describing NAMI services to every member of every Local Service System in the state – requesting that they be displayed in their waiting rooms.
- Training. In addition to the Family-Family training, NAMI offers over 20 different training workshops and has provided 83 training sessions to over 800 people between July 1, 2000 and the end of March 2001. A summary is attached.
- Respite. NAMI Maine provides statewide respite services to families who have an adult with mental illness living with them, or who have care giving responsibilities for an adult with mental illness. This program has been underutilized despite multiple efforts to advertise its availability, including the mailing of a poster describing the availability of the service to all members of Maine’s Local Service Systems. (See attached list of advertising efforts under taken during the last two years).

Survey Methodology

NAMI Maine used a survey format to assess the compliance of providers with the terms of the Consent Decree as it relates to family support services. Four separate survey formats were used to gather information from a variety of stakeholders.

A survey was distributed via the NAMI Maine e-list serve. Currently the list service reaches 80 people. Members of the list serve are individuals who have asked to be kept up to date regarding the activities of NAMI Maine as they relate to NAMI’s mission. These individuals include family members, consumers, providers, policy makers and members of the press. Individuals were asked to type in their responses and return via e-mail. This survey was posted on the list serve on February 28, 2001

A survey was distributed to family members in the NAMI Maine Affiliate newsletter mailing list. Currently 612 people receive this mailing, every other month. The people who receive this newsletter are consumers and family members who are active members of a NAMI Maine affiliate or support group. Respondents were asked to complete the survey in writing and return it to the NAMI Maine office via mail. The survey was distributed with the March 2001 Affiliate Newsletter.

NAMI Maine Affiliate Leaders (23 leaders) were surveyed via telephone. The NAMI Maine affiliate coordinator completed these surveys during the month of February.

A survey of mental health providers was distributed to all twenty-six (26) members of the Maine Mental Health Providers Association. Providers were given the survey with an explanation of the purpose and the process. They were asked to return the survey to the NAMI Maine office. This survey was distributed to providers on March 8, 2001 via email. NAMI Maine staff also made a verbal presentation to the meeting of these providers on that same day. Providers were asked to return the survey by the last day of April, 2001. By April 23rd only 5 providers responded. At that time a reminder was sent to providers via e-mail and multiple attempts were made to contact a sample of providers via telephone and fax to gather completed surveys.

The following is a breakdown of the number of completed surveys by survey method:

E-List Serve	2 of 80 distributed surveys
Affiliate Newsletter Recipients	8 of 612 distributed surveys
Affiliate Leaders	11 of 23 completed phone surveys
Mental Health Providers	10 of 26 distributed surveys

This reflects a total of 31 participants, 21 representing the perspective of families and 10 representing the perspective of mental health providers. It should also be noted that two (2) of the family respondents indicated that they were also providers of mental health services. The complete responses to the surveys are summarized in Appendix A.

Survey Questions Presented to Affiliate Members

1. Do you have a relationship with the local mental health provider community? Please describe
2. Has your affiliate been invited to talk about “family perspectives” as part of staff orientation?
3. Have local providers referred families to your affiliate?
 - How?
 - How often?

4. How did you learn about NAMI?
5. Have you heard of the Maine Parent Federation?
6. Have you received information/education on the terms of the consent decree?
7. Do you feel mental health providers in your area are “family friendly” by being inclusive of families? If so, in what ways?

Survey Questions Presented to Affiliate Leaders

1. Does your affiliate have a relationship with the local mental health provider community? If yes, please describe.
2. Has your affiliate been invited by local mental health providers to talk about “family perspectives” as part of their staff orientation?
3. Have local providers referred families to your affiliate?
 - How?
 - **How often?**
4. How did you learn about NAMI?
5. Have your heard of the Maine Parent Federation?
6. Have you received information/education on the terms of the AMHI Consent Decree?
7. Do you feel mental health providers in your area are “family friendly” by being inclusive of families? If so, in what ways?

Survey Questions Presented to Mental Health Providers

1. Describe the training your agency offers your staff (in the last year) about (attach information about dates of training and content):

- The AMHI Consent Decree
 - Family Support Services
 - Family Perspectives
2. Describe how you educate families about the services available to them from your agency.
 3. Please list the family support services available in your area, including support groups available.
 4. Describe how your agency links families to support services in your area.
 5. Do you offer group counseling and/or psycho-educational groups for families of persons with mental illness? If so, what do you offer?

Findings from Surveys

Education on the terms of the Consent Decree

- Seventy-three percent (73%) of **affiliate leaders** (affiliate leaders are in most cases family members, and in some cases consumers) report having had some education regarding the consent decree. Of those respondents 75% received that education through NAMI.
- No **affiliate leader** reported having gained knowledge of the consent decree from DMHMRSAS or a mental health provider.
- All of the **affiliate members** (affiliate members are family members who attend support groups, but do not lead them) report having had some education regarding the consent decree. Sixty-three percent (63%) report having gained that knowledge from NAMI.
- Two **affiliate member** respondents reported having gained knowledge from an agency as an employee or board member.
- One respondent **affiliate member** indicated having received information from DMHMRSAS in addition to the information received from NAMI.
- None of the mental health provider respondents indicated that information regarding the consent decree is included in education available to family members.

Education on available services and on mental illness from the perspectives of professionals, other families and mental health service recipients

- Eighty percent (80%) of mental health provider organizations report training their staff regarding available family support services.
- Seventy percent (70%) of responding mental health provider organizations reported providing their staff with training on family perspectives.
- Forty percent (40%) of the responding organizations indicated that family members provide the family perspectives training to staff.
- Twenty-seven percent (27%) of **affiliate leaders** indicated that their affiliate has been invited to talk to local mental health providers about family perspectives.
- Sixty-four percent (64%) of NAMI **affiliate leaders** had learned about NAMI from a non-provider resource.
- Sixty-three percent (63%) of **affiliate members** learned about NAMI from a non-provider resource.

Direct Support of family groups through the provision of a facilitator at meetings, if requested

- The relationship between local family support groups and mental health providers varies significantly. Forty-five percent (45%) of **affiliate leaders** reported **no relationship** between the local NAMI affiliate and the mental health provider community. Thirty-six percent (36%) reported a relationship does exist. Eighteen percent (18%) of affiliate leaders gave a qualified “yes” response to this question.
- **Affiliate leaders** responding positively to this inquiry cited examples such as sitting on the board of directors of the mental health center, sitting on committees with providers, being able to “pick up the phone” to talk with a director, calls from providers to see if the group still meets, referrals from the local providers.
- One hundred percent (100%) of **affiliate members** surveyed reported they have a relationship with the local mental health provider community.
- **Affiliate members** cited examples of developing cooperative relationships regarding their individual family member’s treatment, participating as board members, participation in the local QIC and /or LSS meetings and as being providers of mental health services themselves.
- One **affiliate member** indicated that members of the local provider system meet with the consumer group “from time to time.”

Education on treatment, medications, diagnoses, prognoses and how to care for persons with mental illness

- ? psycho ed groups

Group Counseling

- None of the mental health providers indicated they are currently offering group counseling as a family support service.

Psycho-educational Programs

- Seventy-one percent (71%) of the responding mental health providers report they are currently providing psycho-educational groups for family members of persons with mental illness.
- Two affiliate leaders (18%) indicated awareness of the psycho-educational groups.

Respite Services

- None of the responding providers indicated any understanding that respite is a support service available to family members of persons with mental illness.

Referral of family members with whom the providers have contact to area support groups

- Sixty-four percent (64%) of the **affiliate leaders** reported that local providers refer family members to the local NAMI affiliate. Twenty-seven percent (27%) deny any such referrals occur.
- Only one **affiliate leader** reports receiving calls directly from a provider “rarely.”
- The frequency of referral from providers ranges from several times a month to once every 6 months.
- All of the responding providers report that they refer family members to local NAMI and other family support organizations. Thirty percent (30%) of responding providers indicated they offer to make the direct contact for the family.
- The methods of referral commonly listed by both affiliate members and leaders and provider organizations are giving the phone number of the local affiliate to family members, posting flyers/posters, and handing out brochures.

Other Findings

Family Perspectives Training

NAMI Maine’s training curriculum includes a course on Family Perspectives. A NAMI staff person teaches the course in conjunction with a family member of a person who has mental illness. The availability of this course is advertised to all mental health providers in the Maine. Between April 2000 and April 2001 eight mental health provider organizations requested this course be presented to their agency staff. The course was also presented in two university settings where providers and family members were invited to attend. In the university settings the majority of participants were family members. A total of 193 staff people from mental health provider organizations attended the NAMI Maine ‘Family Perspectives’ training between April 2000 and April 2001.

The response to this training from staff people of mental health organizations is overall positive. The specific comments about the training are summarized in **Appendix. The comments however, indicate a lack of understanding on the part of mental health providers regarding the perspective of family members coping with mental illness in their lives. For example staff have commented about how it was not helpful to have an angry family member talk about his/her experience, when part of the point of the presentation is that family members do get angry.**

Family Support Services for Parents of Children

The survey to affiliate leaders and affiliate members included a question regarding their knowledge of the Maine Parent Federation. The Maine Parent Federation is the largest family support program in Maine for families of children with mental illness. Less than 50% of the respondents to this question knew about this organization. This indicates that families are not being fully informed about the supportive services available around the state.

Licensing and Contractual Obligations

DMHMRSAS has included compliance with components of the consent decree as part of mental health providers licensing and contractual obligations. Rider D-2 #15 of the standard mental health provider contract requires that all new clients of the system be given information about services available through NAMI and peer support organizations/groups.

The Mental Health Agency Licensing Standards include in required staff orientation “the perspectives and values of clients of mental health services conducted by a consumer of mental health services” (SD.1.A.11) and family support services (SD.1.A.14). The

survey responses from mental health providers do not indicate a clear understanding of these obligations.

Conclusions and Recommendations

Compliance with Section I, 109 and 110 of the Consent Decree is inconsistent and many providers of service offer non-specific descriptions of the manner in which they comply with this section of the Decree (see chart Appendix ?). In addition:

Broad conclusions:

- A majority of mental health providers fail to comply with Section I, 109 and 110. Specifically, they fail to include regular training regarding family support services in their staff orientation, lack an adequate understanding of what family support services are available, do not maintain relationships with family support groups, and do not attempt to improve their understanding of existing resources. We conclude, therefore, that a majority of families do not know where to get help and are not informed by their mental health providers.
- Mental Health providers do not take specific actions required by the consent decree to link families with supportive services. This indicates an inherent lack of understanding about the family perspective when coping with mental illness in the family.
- Most families receiving supportive services have learned about these services from resources other than mental health providers.
- A small minority of individuals providing mental health services has had current training in family perspectives from a family member.
- Mental health provider agencies do not provide information to family members about the consent decree.
- A majority of mental health providers say they offer psycho-educational programs for families but few family respondents indicate an awareness of these services.
- There continues to be a division between families and providers including a lack of understanding of each other and difficulty bringing the two groups together to improve this.
- There is almost no recognition of family support services for families of children.
- Largely the onus has been on family members to develop positive working relationships with providers regarding the care of their individual family member.

Recommendations:

1. Performance measures related to family support services be established which require providers to report how they link families to support services.
2. NAMI Maine continues to assess compliance with this section of the statute every year.
3. NAMI Maine mail a copy of this survey to all providers along with a list of available training and a reminder about the brochure holders.
4. LSS groups be used as a tool to educate providers about the terms related to family support services and the services available from NAMI, including respite services, and other family support groups.
5. Providers and NAMI Maine affiliates that do have successful relationships should be further studied to give guidance to other provider organizations.

NAMI MAINE PUBLIC RELATIONS ACTIVITIES

- Annual meeting with Maine Association of Mental Health Services to describe NAMI Maine's programs and hand out information about training.
- 2000 mailing to all LSS members state-wide – brochure holder, brochure, and poster for waiting room.
- Purchased state-wide radio advertising in 2001 (3 months) describing NAMI Maine and services available. Time slot – 7am to 8am.
- Purchased Bangor area radio advertising (3 months) availability of NAMI Maine respite services.
- Circulation of 4,000 newsletters to providers, families, press, and interested others – four to six times per year.
- Website established in 2000.
- Mailing to all substance abuse agencies in 2000 regarding services available from NAMI Maine.
- Mailing to all law enforcement agencies in 2001 regarding training available from NAMI.
- Annual Mental Illness Awareness Week activities.
- Purchased advertising in local press regarding each Family-to-Family Course.
- Listing of all support groups in local support group section of newspapers.
- Annual mailing to all LSS members regarding becoming a member of NAMI. Organizational membership offers unlimited free training for staff.
- Meetings with Maine Special Education Directors to disseminate information about NAMI.
- Hosting booths in 2000-2001 at Common Ground Fair, Mental Health Fair – Portland, Maine Bar Association, Maine Social Workers Association, Maine Disability Rights State House Day.
- Annual NAMI meeting – mailing regarding the workshops available to over 8,000 people.

- NAMI pens and magnets handed out at NAMI training sessions.
- Publication and distribution of NAMI Maine Family Resource Guidebook.
- Presentations and training workshops – delivered across the state more than once a week.