



The Nation's Voice on Mental Illness

Future NAMI Leader:

Thank you for your interest in joining the NAMI family by contributing to meet the NAMI mission in your community or within your selected needs group. You have learned about the exciting, effective family/consumer movement for people with mental illness and you want to start a NAMI support, education, and advocacy group in your area. Now you are wondering how to begin.

Everyone is part of the "family": parents, children, adolescents, spouses, siblings, and consumers. Perhaps you belong to a small group of individuals and families and you're feeling isolated and alone in trying to solve an array of problems because of a major brain disorder in the family. You may be deeply concerned by society's failure to respond to the needs of those affected. You may want to learn more about mental illness, and the options available for treatment and rehabilitation. Like the rest of us in NAMI, you may feel the only hope lies in organizing and working together to create a better life for you and your relatives while also helping to accelerate our research efforts. The question, then, is how do you start a NAMI Affiliate or Support Group? What is the best way to begin?

The following pages are intended to provide guidance and recommendations to you as you move through this initial planning process. Please review them and contact us if you have any questions or need assistance of any kind. Your state organization and NAMI national work in partnership to support NAMI grassroots leaders in meeting the NAMI mission.

-- *NAMI National Center for Leadership Development*
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Starting a New NAMI Affiliate or Support Group

Step I. Contact your State Organization and NAMI National

Step II. Assess Your Situation

This is an essential step because it will help you think through the leadership process you are initiating. Examine your motivation for starting an affiliate (group). This will help you decide what kinds of options you want to look at (i.e., support groups, or advocacy for better services or educational programs) as well as clarify what your role will be.

Questions to Consider in Making Your Assessment

Q: *Why do we want to start a group? What do we want to accomplish?*

A: The following reasons for forming a local affiliate will provide a sound basis for your planning decisions:

- To help ourselves and others through mutual support and education
- To pool resources and talents with others to improve services for people with mental illness and their families
- To improve the health of our community
- To build an organization with enough clout to be effective in advocating for people with mental illness
- To educate the community about serious mental illness
- To end the loneliness we feel when there is no one to talk to who understands the problems of coping with serious mental illness
- To address the need for an advocacy/support group in a community where no such group exists or where the nearest group is many miles away or otherwise inaccessible

Also, consider these questions:

Q: *Are there enough people to form and sustain a group working toward our goals? Or will consumers and families prefer to join an existing organization?*

Are there enough people to share the work? (Organizations in which the founder is the president, the treasurer, and the working membership director are doomed to failure.)

A: Starting and maintaining a NAMI working affiliate takes a commitment. Among the tasks you will likely encounter are: organizing, recruiting members, collecting dues, paying bills, finding meeting space, calling people to attend meetings, writing and publishing a newsletter, recruiting and maintaining volunteers and lots more.

There are already more than 1,000 existing NAMI affiliates throughout the country; but perhaps there is not one right where you live. You have two options:

1. You could start your own group.
2. You could start your own support group, but make it part of an existing nearby NAMI affiliate or the state NAMI organization

The Bottom Line: Be clear about your reasons for starting an affiliate group. The most productive approach in developing a new group (or even a support group affiliated with a nearby NAMI group) will be one in which leadership and tasks are shared with others who feel the same needs.

Step III. GETTING STARTED

From the beginning, you have two choices. You may chose to become 1) a support group affiliated with your state organization or a local affiliate, or 2) a NAMI Affiliated Affiliate. In order to be granted affiliation status for your Affiliate, you will need at least FIVE NAMI-dues paying members. Five to ten people with enthusiasm and ideas can accomplish much more than 20 people who have neither. Chances are you already know several peers, whether they are consumers, family members, or friends. Tell them about your ideas and invite them to come to the initial organizational meeting.

The best way to find members beyond your immediate circle is to reach individuals on a personal level.

Contact NAMI Center for Leadership Development at 703-524-7600 ext. 7913 and/or your state organization at _____ to learn about other local NAMI affiliate groups in your state. NAMI has a state organization and numerous local chapters in each of the 50 states, the District of Columbia, and Puerto Rico. Center for Leadership Development (at the National office) and your State NAMI Organization are here to assist you.

There are three ways that most affiliates or support groups get started:

- 1) Support and information to the attendees of a community meeting
- 2) Through association with a local affiliate or the state organization
- 3) As a continuation from the graduates from a NAMI education course held in your community or targeted to a particular interest group

Your State Organization and the Center for Leadership Development representative will guide and assist you through the steps you will want to take to get your Affiliate in action. Some of these may include:

- Contacting service providers (community support programs, mental health centers, hospitals) and asking for their support. Because of confidentiality, they cannot release any names to you. However, they can give your name and phone number to consumers or families connected to their organization.
- You may want to prepare a brief letter addressed to other families and ask providers to circulate it.
- You may wish to put a notice in libraries, grocery stores, church letters or church bulletin boards, etc. You can also put notices in the neighborhood section of the local newspaper. Self-help clearinghouses, when available, are excellent sources for contacts as well.
- If there is a support or education group at your local clinic or hospital, the leader may be willing to refer people to your consumer/

advocacy group. You may be invited to speak with the group, and sometimes the whole group may choose to become a NAMI affiliate.

For assistance in furthering your organizational structure once you have found a small nucleus of interested people (five is the minimum) contact NAMI Center for Leadership Development or your state organization.

Your First Planned Meeting

- 1. Contact your state office for guidance, coaching, and support in planning your first meeting.**
- 2. Try to find a neutral place to meet**, such as a library, bank or town hall. Many people feel reluctant to go to a mental health center or hospital. Whatever place you choose needs to have a private meeting room.

Sometimes meeting places are offered by mental health agencies or other types of organizations. While it may prove very helpful to accept these offers (e.g., free meeting space, a moderator, and help with resources such as copiers, paper, telephone, etc.), it is also good to be cautious and limit the time spent there. There may be strings attached or the sponsoring organization may have trouble letting go and cause the NAMI group to be absorbed by another organization. (This has been a problem for some NAMI groups.)

- 3. It's good to have light refreshments** such as cookies and coffee to make people feel comfortable, but don't let elaborate food arrangements take away from the business at hand.
- 4. Have a greeter at the door** and someone to facilitate the meeting.
- 5. When the meeting begins, have people introduce themselves.** Ask people to briefly say why they are interested in the group or to identify major concerns. Don't let anyone get involved in lengthy descriptions of personal problems.
- 6. Pass around an attendance sheet** to get the name, address, email address, and phone number of everyone who attends. You may also want to ask whether the person is a consumer, family member, or professional (or all three). Give a copy of the list to everyone who attends and encourage people to call each other for support between meetings if permission has been granted by the participants.

7. **You may want to have a speaker or show a video as a way to focus the discussion**, but be sure the program is brief enough to allow time for everyone in the group to speak. A leader from a neighboring affiliate or your state NAMI leadership would be an ideal speaker.
8. **If it seems that there are enough common interests and concerns to get a group started, get organized immediately!** Decide whether the group will initially become a support group, or whether it will get involved in other activities. Set a date, time and place for the next meeting, and decide who will publicize the meeting. You may also pass a hat to cover expenses such as postage, copying, refreshments, etc.
9. **Leaders or volunteers to take on small tasks.** If the group is small, give each person a specific task to accomplish before the next meeting. Such tasks include hanging posters, making phone calls, typing and copying the attendance list, finding information resources, etc. This delegation has two benefits: The leader (or leaders) don't become overwhelmed, and individual members feel needed.

SUBSEQUENT PLANNING MEETINGS

In your next several planning meetings you should attend to a variety of tasks that will get your organization under way. The order in which you do them may vary according to your needs and the availability of assisting persons. Consult with your NAMI state office or national Center for Leadership Development representatives for assistance in planning next-steps.

- **Plan an initial general meeting for families, consumers, and other interested people in the community.** One of the best ways to do this is to sponsor an educational meeting with a special program and speakers. (More details are provided in the next section.)
- **Apply for affiliation with NAMI and your state organization.** *(This is a vital step. You must contact NAMI national State Relation or your state organization for the applications and information on this process).*
- **Prepare an inexpensive brochure or flyer for wide circulation.** *(Contact your state organization or NAMI national Center for Leadership Development for samples.)* You may not use the name NAMI until you are officially affiliated or unless you are operating under your State's charter or under another affiliate's membership.

- **Begin writing a simple newsletter to keep your members informed.** *(Contact your state organization or NAMI national Center for Leadership Development for samples)* This can be an important function that will help bond your members together and is a convenient way to remind them of meetings or other opportunities to work toward your goals. Sending the newsletter to decision makers such as mental health administrators, doctors, legislators, agencies, and educators serves to inform them of your existence and to suggest what services should be available. You might also ask them to contribute articles on research developments, medications, group tips, health care, local services available, etc. Send copies to your state organization, NAMI national Center for Leadership Development, and, if you wish, other NAMI affiliates.
- **Once you have a minimum of FIVE individuals who will join NAMI,** you can enter the next steps for being granted affiliation status as a NAMI affiliate. Upon request, you will be sent affiliation applications and guidelines for applying for affiliation status.