



National Mental Health Consumers' Self-Help Clearinghouse



Knowledge is the key to open new doors

Technical Assistance Guide

Starting a Self-Help/Advocacy Group

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Funded in part by the Community Support Program of CMHS,
The Center for Mental Health Services

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Understanding the role of self-help/advocacy groups

Throughout the world, people calling themselves consumers, survivors, or ex-patients have used their own experiences with the mental health system to create a wide variety of self-help and advocacy groups, frequently called support groups, peer-run services, or alternative services. The consumer self-help movement grew out of the idea that individuals who have experienced similar problems, life situations, or crises can effectively provide support to one another.

People started the first mental health consumer groups in an effort to provide alternatives to what they saw as an oppressive and abusive mental health system. They also sought to join with others to fight the economic and social discrimination faced by individuals with psychiatric histories. These groups offered emotional support, friendship, individual advocacy, information about mental health issues and a way to improve the mental health system.

Self-help groups are peer-run, they are small and voluntary, and they accomplish their goals through mutual aid. Self-help groups offer the opportunity to bring both personal and social change, to assume personal responsibility for treatment, to recover and to be productive, and to find solutions with the help of others. Mental health consumers can offer each other support based on first-hand experiences with issues such as medication, over-medication, social security disability, housing, employment, human service agencies, neglect, and families and friends.

The effectiveness of self-help groups

These groups work because they are beneficial to all consumers involved. For years, consumers have known that the mutual-aid relationships formed within self-help groups enhance their personal wellbeing. Consumers have continually found the groups to help them better themselves in many areas of their lives:

- The act of joining together with others who have “walked in their shoes” enables individuals to recognize that they are not alone, that other people have had similar experiences and feelings.
- Individuals in the mental health system often do not have the support of family and friends. Self-help groups can provide the support that may be missing from these other systems.
- Self-help groups offer a safe place for self-disclosure.
- Self-help groups encourage personal responsibility and control over one’s own treatment. Because group members are actively helping others, they gain a sense of their own competence.
- In contrast to the professional/client relationships, members of self-help groups are equals.

After years of listening to consumers say how self-help groups have helped them, professionals have also recognized the effectiveness of self-help groups. In a landmark report on mental health issued by the Surgeon General, a section was devoted to self-help groups:

As the number and variety of self-help groups has grown, so too has social science research on their benefit. In general, participation in self-help groups has been found to lessen feelings of isolation, increase practical knowledge, and sustain coping efforts. Similarly, for people with schizophrenia or other mental illnesses, participation in self-help groups increases knowledge and enhances coping. Various orientations include replacing self-defeating thoughts and actions with wellness-promoting activities, improved vocational involvement, social support and shared problem solving. Such orientations are thought to contribute greatly to increased coping, empowerment, and realistic hope for the future (U.S. Surgeon General, 289).

Role of family and friends in a consumer-run self-help group

The idea behind a self-help group for consumers is that the consumers should make the rules. These groups provide a haven to which consumers may go to seek the support they are lacking in “the outside world.” Family and friends might want to help, but the support that comes from other consumers is the driving force behind the effectiveness of many self-help groups. As you are starting a group, you might consider including family members, but there are risks to that involvement. While there are family members and friends who are supportive and considerate, there are also members who feel that a consumer is a burden and who will not support him or her. This relationship between consumers and un-supportive family members or friends would not allow the self-help group to thrive. You can lead such friends and family members to groups that have been started by family members for family members. Your local chapter of the National Alliance for the Mentally Ill (NAMI) can help you locate such groups.

Role of professionals in a consumer-run self-help group

While the role of professionals in a self-help group is something that has been debated, many consumers feel that professionals have no place in such a group other than as a funding source. The professional who truly believes in consumer empowerment can be of considerable assistance in getting a group started. The professional’s role should evolve from one of greater to lesser importance – ideally to total disengagement. The professional could be “on call” in case the group wants outside assistance, but the professional should wait for an invitation to get involved.

Preliminary steps

Even before the meetings begin, starting a self-help group takes a lot of time and energy. A group can be started on the front steps of a church, in the back of a coffee shop, or in someone's living room. You don't need a license or permission to start a group; all you need is the desire and the initial idea. There are key elements that need to be addressed when it comes to the beginnings of any group:

Research

After you have made the decision to start a self-help/advocacy group for mental health consumers, your next step is to do your homework. Before you begin organizing your own group, find out what groups exist in your area. There may be a local consumer group that can meet your needs, and often, these groups love to help groups who are trying to get off the ground. There may be regional or national groups that you can affiliate with to gain expertise and resources. These groups can provide proven, workable models for the development of your own group. You can contact the Clearinghouse for groups in your area.

You should define a target audience. You might want to include family members or friends or you might want your group to remain made up solely of consumers; you might want a certain age group to attend; you might want people who are trying to survive in the workforce; you might want to include anybody and everybody who considers themselves to be a consumer. You should decide while you are planning your group. You can look to professional organizations to help you identify and reach your audience, and you can find others who share your interest to help you get started.

Enlist Help

Once you have determined the need for a group in your area, it is time to find people who will help you get the group off the ground. Starting a group on your own is very difficult, and it would make everything easier if you found a *core group* of people who share your interests. Once you have found two of three individuals who share your vision, you can begin planning your first large meeting. You might already have friends who are interested in starting a group. If not, you can advertise in your local newspaper. Often newspapers offer free space to list local events.

Another way to find people to help you is by posting flyers in local community centers, unemployment offices, doctor's offices, etc. These flyers have to say nothing more than that you are interested in starting a self-help group for present and former mental health consumers and should give some contact information.

A way to reach consumers immediately is by speaking in public. Attend conferences, speeches, or other presentations aimed at mental health consumers and advocates. Ask the speaker if you can announce the formation of a self-help group before or after the

presentation. Have interested people come up to you after the meeting and have them give you their names and phone numbers.

Develop a project plan

To develop a project plan, meet with your core group of people and brainstorm before you begin advertising your first meeting. Several questions should be addressed as you develop a project plan. You might begin by asking each member of the group to discuss his or her own goals for the group. You can then begin to address the following questions:

- What is the purpose of this group?
- Who are we trying to reach?
- How will we recruit participants?
- How will we work with other available services?
- Where will we meet?

The answers to these questions will make up your project plan. Have a member of the group type up a copy of the plan to refer to and share with the new group members. This plan will grow as your membership grows and people add ideas and expertise.

Find a place

Your meeting place should be neutral, comfortable, and accessible. Start with the Yellow Pages: places of worship, community centers, and schools often allow community groups to use their facilities. Ask your local Alcoholics Anonymous group where they hold their meetings. Contact the community relations or social services department of your area hospital. You can also contact the municipal buildings in your area such as City Hall chambers, firehouses, and town recreation centers.

While many of these buildings offer space to community groups free of charge, to develop a good relationship with your host organization, it is a good idea to pay rent. Even a little money collected by the group will help to establish your good name. One of the purposes of paying rent is to prove that you are both a reliable organization and that you will respect the space and your host's requests. To help you in securing a consistent time, always remember to leave the room cleaner than when you found it. Along with paying rent, this act of responsibility will help to earn respect and support from your host organization.

Once you know what buildings are available to your group, you can select one that best meets the needs of your particular group. Some things to consider:

- Accessibility to people with physical disabilities
- Central location, easy to find
- Close to public transportation
- Available parking

The meeting room itself should be well lit with comfortable chairs arranged in a circle or around a large table. The room should be easy to access with no cumbersome stairs or heavy doors, and be relatively private where you will not be disturbed. Choose a room that does not feel “institutional.” The room should be close to a restroom. If you anticipate smokers in your group, make sure smoking is permitted in or near the meeting room. The room should be large enough to accommodate your anticipated group size but small enough for members to easily converse. Also, select a room large enough to show a video or film, or to accommodate a guest speaker. A final important point to keep in mind when selecting a place is to find somewhere that you can meet on a regular basis. It is hard to have regular meetings when you can’t rely on a consistent schedule.

Setting a date and time

The next step is to set a date and time for your first real meeting. In addition to determining where your meeting should be held, decide when the group will meet, how often and for how long. You will need to select a meeting place well in advance (2 to 4 weeks) of your first meeting in order to give you and your core group of people time to publicize the meeting. You can advertise your self-help group in the same ways in which you advertised for your core group of people.

You may also want to consider your meeting place when selecting a time. Is the area unsafe in the evenings if you chose to have an evening meeting? How safe are the parking lot and the building itself? How late does public transportation run?

How to facilitate a large meeting

By the time you have scheduled your first meeting, make sure that you and your core group of people have reached a consensus on the general ideas and purpose of the meeting. One of the members of the core group of people should stand at the door and “meet and greet” newcomers. Once everyone has arrived, the group members should begin by stating the group’s possible purposes and goals. Everyone at the meeting should receive a copy of the project plan so that everyone knows what will be happening. Explain that the group is designed to meet the needs of its members so their input will determine the goals as well.

At the start of the meeting, brainstorming can begin. Use a blackboard or easel to write down what members hope to gain from the group. At future meetings the group can develop an “action plan” to work on achieving these goals.

Leading the discussion

After allowing time for comments and feedback, ask group members if they would like to share some information about themselves. Your core group may want to begin this process in order to make newcomers comfortable and encourage them to share their own experiences. Encourage new members to share, but don’t pressure them. Make sure that all members have an opportunity to speak if they wish.

The opening speaker should talk longer than other speakers, and will set the standard of how the speeches should go for the rest of the meeting. When the floor is opened to other participants, remind everyone to let the person talk. There should be no interrupting, there should be no comments, and there should be no advice given unless asked for. Let people finish their thoughts so that everyone has a chance to speak their mind without interruption.

Planning ahead

Try to stick to your original agenda but be flexible and allow members to speak freely. Discuss future meetings. Who will decide on an agenda? How will the meetings be run? Establish ground rules and let new group members know that they are welcome in the planning process. Discuss the agenda for the next meeting and divide tasks, such as bringing in refreshments, among willing members.

Before the meeting is over, pass around a contact sheet to obtain names and numbers of new group members. Make sure that group members have the name and number of a contact person. Establish when and where your group will meet in the future. Discuss the availability of group members to determine how often the group should meet. During your first group meeting, try not to get bogged down with organizational details, these can be addressed in future meetings. Thank everyone for coming and invite them to stay for refreshments.

Ideas for further meetings

If you plan on bringing new ideas and perspectives to the meetings, adding variety is an excellent means to do so. Variety will simply alter the routine – instead of having a string of meetings that seem to be the same.

There are many ways to add to your group's dynamics. A speaker can come to talk about topics both related and unrelated to those which you have been covered in your group meetings; organizing a Speaker's Bureau will make the task of finding speakers a lot easier. Speakers do not have to cost money; local organizations, stores, or community centers might have suggestions as to finding a speaker, or they themselves might have someone who would come and speak to your group. Further ideas and explanations can be found in the Clearinghouse's Technical Assistance Guide, *Organizing and Operating a Speakers' Bureau*.

Authors or poets are also good speakers, and they might present a more unconventional talk. Authors might read from their books, and poets could hold a poetry session where members of your group could also share things that they themselves have written. These speakers might present a different perspective on the consumer movement.

Having a session on advocacy would be a constructive way to hold a meeting, and the Clearinghouse offers a *Freedom Self-Advocacy Curriculum* that can be taught over three meetings. The result of leading a workshop would be a better understanding of how consumers can advocate for themselves. This skill is imperative in our society and learning this skill in a self-help/advocacy group is a perfect way to spend a meeting. After learning these skills, your group can hold a letter-writing meeting which will allow group members to use their self-advocacy skills. Call the Clearinghouse for more information on how you can present the *Freedom Curriculum*.

A movie/video night would be a way to incorporate ideas talked about in previous meetings, or a way to construct other topics for future meetings. Looking at the way other members in society look at the consumer movement would be a great way to start a dialog. Watching the movie (or part of it) at the beginning of the meeting could lead to a good discussion.

A few final words

As your self-help group grows, you can gain influence by networking with other groups. The Clearinghouse can put you in touch with other local groups, as well as statewide consumer networks and national organizing efforts.

Starting a self-help advocacy group for mental health consumers is not an easy process, but it can be a rewarding one. The information on these pages is meant to serve as a starting point. Keep in mind that once the group is off the ground, the responsibility to keep the group going does not lie solely with one person – every member of the group must take responsibility for the progress of the group. Don't be discouraged if your first attempt at starting a group is unsuccessful.

If you cannot find enough interest in your area to develop a group, go back to your original research. Seek out other groups in the area that you can join or seek advice from. The individuals that showed interest in the group might want to join you in another type of project.

Consider an online support group. The Internet is a great resource for information on consumer issues. It also allows you to meet consumers from all over the world. The bottom line is stay involved. Remember that consumer involvement ensures that consumers will continue to have a voice in mental health policy. Don't let someone speak for you!

Reference

U.S Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.