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Strengthening Organizations, Strengthening Communities

HOW TO START A SELF-HELP/ADVOCACY GROUP OF MENTAL HEALTH CONSUMERS

Where Do You Begin?

You begin at the beginning, with the desire to start a self-help/advocacy group of mental health consumers (mental patients, clients, or whatever term you prefer). Like all good things, a group can begin with one person with an idea. You don't even need to know what you'd like the group to accomplish; at this stage, you can concentrate on bringing people together--goals can wait. People have started self-help groups simply out of a wish to find other people who had similar experiences. Or they may be angry about the treatment they have received and want to try to change the system. Or they may be feeling isolated and want to meet people to share activities with--to go to the movies, or go out to dinner, or bowling. Or they may have heard about other self-help groups--such as Alcoholics Anonymous—and want to put the same energy to work for mental health.

Sometimes people are spurred to start groups after hearing a stirring speaker, such as nationally known consumer activist Marcia Lovejoy of Minneapolis, describe how she started a group and what can be gained from it. Or they may have read a publication of the mental patients' movement, such as *Voices from Minneapolis*, or *Positive Visibility*, published by Reclamation, Inc., in San Antonio, Texas, and this may have sparked their interest.

Once you've got the idea, it's important to find at least one or two other people who have the same idea, or whom you can sell on the idea of starting a group. It's very difficult to start something entirely by yourself; it's a good idea to have someone with whom to share the work and discuss your plans. Finding these other people may be as simple as asking a couple of your friends who have been through the same experiences you have if they want to start a self-help group.

If you don't know any people you can interest in the idea, you might try putting an ad in the newspaper. In fact, many newspapers have a free "bulletin board" column where you can list events; your meeting would qualify. Or you might ask local service providers if they'll put a notice up. Notices can also be posted, with permission, in unemployment offices, Laundromats, 7-11's--any place that people might see them. These notices only have to say that so-and-so at such-and-such a phone number is interested in starting a self-help group for present and former mental patients (or mental health consumers, etc.) and invite anyone who may be interested in such a group to call.

Another way to find interested people is to "network." Talk to everyone you know and get the news out by word of mouth; the grapevine often bears fruit.

One relatively easy way to identify interested people is to attend conferences where a lot of ex-patients are present, or go to speeches being given by ex-patient activists. You might ask the speaker if you can announce the formation of a self-help group before or after their presentation; they'll be delighted to agree. Then, with everyone's attention, you can ask

interested people to come up and give you their names and phone numbers after the meeting. Then you can contact them when you have set up a time and place for your first meeting.

Your First Meeting

Your first meeting can usually be arranged very easily, especially if it only involves the few individuals who are planning the group's development. You might ask for space at the local community mental health center to hold your first planning meeting. This also gives any clients at the center who want to become involved the opportunity to meet at a familiar place; you'll have the benefit of inertia in attracting participants.

There are some drawbacks to this plan, however. Often, community mental health centers (CMHC's) insist that a staff member be present at on-site meetings, which has obvious disadvantages. One, it is inappropriate--this is, after all, self-help. (There are exceptions to this; professionals may help start and facilitate a group. But their role should keep getting smaller and smaller; it usually should not continue past the start-up stage.)

Another obvious disadvantage of the presence of a staff member at the meeting is that many mental health consumers feel uncomfortable in the presence of staff. Third, staff members may forget their ex-officio status and try to run the meeting. But you may find--especially if you live in a rural area--that the local CMHC is the only space available. So use their facilities if you must, but view it as temporary and find other space as soon as you can. If you are meeting in the CMHC, make clear that the group is independent and that fees should not be charged and no names should be taken by staff. This is not a mental health center program. At the beginning, it's sometimes easier to meet at a local diner, where you can begin the early stages of planning a group over a cup of coffee and not have to worry about finding a meeting place. In fact, one group in Miami, Florida, started out meeting in diners, and they're still doing it. Sometimes, for the price of a cup of coffee or a bowl of soup, a restaurant will let you meet in a private back room.

Do Professionals Have a Place in Self-Help?

As mentioned above, professional involvement in self-help is tricky. Even the most progressive mental health professionals may hold attitudes and prejudices, albeit unconsciously, that may stand in the way when their clients try to develop a truly independent self-help group.

It can also be difficult for clients to deal with a professional in a consulting role. Generally, most programs encourage clients to be the recipients of services, instead of a co-producer of their own support systems. Indeed, many ex-patients believe that the only role of the professional mental health system in self-help should be as a funding source. As one mental health consumer put it, "If professionals are involved, then it's not self-help." But the professional who truly believes in self-help can be of considerable assistance in getting a group started.

For example, many consumers have never heard of the self-help movement. The professional can be a transmitter of knowledge, to get the word out that the self-help movement exists. Ideally, the professional's role should evolve from one of greater to lesser participation--ideally, to total disengagement. At the beginning, the professional can be a conduit of information. He or she can talk to clients about the movement, tell them about movement publications, and invite consultants from other groups to speak. If the clients show an interest, the professional can take the next step and become an initiator, perhaps calling the first meeting. Once a group has begun to meet, the professional's role should change from initiator to facilitator. It's important that the consumers take the leadership; the professional should encourage this. After the group has gained some momentum, the professional must take another step backwards and become a consultant, "on call" in case the group wants outside assistance. He or she may keep in touch, even attend occasional meetings, but must wait for an invitation before intervening in any way.

The First LARGE Meeting

Once you have been able to find one or two other individuals who are interested in starting a self-help group and willing to put in some effort to get it off the ground so that the entire burden does not rest on any one individual, the next step is to plan your first large public meeting. This does not mean a cast of thousands--we're talking about trying to attract at least another six or seven or ten or twenty people.

It's a good idea to find a neutral and comfortable meeting place in the community for this meeting. You may find that your local library, church or school already offers meeting places to other self-help groups, and wouldn't mind adding yours to the list. Ask your local chapter of Alcoholics Anonymous where their groups meet; the same churches or other public meeting places will probably be willing to offer your group the same hospitality. Some places may charge a fee. If you can't afford this, you can usually--especially with churches--work out an arrangement where your group would do some in-kind service--painting a wall, raking the yard, etc.--to compensate for your use of the building. Other good possibilities are organizations like the Kiwanis and Lions and Veterans of Foreign Wars; these groups will sometimes offer meeting places at very low cost, if not absolutely free. Also try municipal buildings, such as City Hall chambers, fire-houses and town recreation centers--any places that the town officials may make available to their citizens.

You can always meet in each other's homes. This is fairly easy in the early stage, but if you want to publicize your group, it becomes more complicated. Some members may not wish to have their names and addresses included in an announcement of a self-help meeting for mental health consumers.

A Nice Place

Your meeting place should not be too drafty and cavernous--after all, you're not hosting the Miss America pageant or a political convention. Since you'll only have ten or twenty people, you don't want a hall that seats two or three hundred; you'll just rattle around in it. You want a relatively small, comfortable, private room where people aren't going to be constantly walking through. It would be great to find a room without an institutional atmosphere, although that may be difficult if you're choosing among classrooms, firehouses and municipal meeting rooms. However, a lot of churches have small, cozy rooms that they make available. Note: Avoid meeting in bars. Some people who might want to join your group may have a drinking problem, and you don't want them to feel excluded.

Planning the First Meeting

After you've found a meeting place, your small organizing committee of one or two people should plan your initial group meeting. This is the meeting that will set the tone for at least the next few meetings. What you're trying to do is spark the group's growth so that you're able to accomplish some of the goals you had in mind when you had the idea of starting a self-help group in the first place.

At this initial meeting, start opening the planning process up to the new participants. It's all too easy to get into a situation where the two or three people who have been involved from the beginning have some strong ideas about the group's goals, and consider the first meeting a forum for announcing their goals to the larger group. This is a serious pitfall. Since the hope is to involve as many people in the work as possible--since this is what gives the group its strength ("in numbers")--going in with your agenda carved in stone can only discourage the new arrivals. Therefore, although it's fine for the planning committee to have some clear ideas about its goals, it's important to solicit from the people who are newly involved what their own goals are and how they think the group should function. This will give these people a sense of ownership, of belonging to the group.

Brainstorming

You might bring in a blackboard or an easel with a large newsprint pad. After some orientation by the planning committee, ask each of the attendees to give at least one goal, one activity, one "thing" they would like to get out of the group, and list these on the board. Usually, during this "brainstorming" session you should not make any criticism or eliminate anybody's suggestions.

After everyone has had a chance to have his or her goals listed, you can narrow them down to the ones that a majority of the people involved agree upon. Keep in mind that the more realistic these goals are, the better your chance of realizing them. You'll find that most people have pretty much the same ideas as you do about the purpose of a self-help group. But be open to other ideas; don't be critical just because they're different from yours. The group should be a "group effort." If some goals seem very unrealistic, or the only group members in favor of them are the people who suggested them, some time might be spent in discussing how you can reach an agreement on the one or two goals everyone may have in common.

Sharing

During this first meeting, it's important to establish that the group is open to everyone's participation, and that the work must be shared. Although two or three individuals have done the lion's share of the work of getting the group going until now, a lot of these tasks now need to be divided among the whole group. Don't be disappointed if at first it seems to be the same two or three people who are doing all the work. It takes a while for people to decide that anything is worth investing much time or energy in. It may be two or three meetings before you're able to get people to handle some of the tasks that your planning committee has been taking care of.

Even from the beginning, it's good to list tasks as they relate to the goals the group has discussed. Demonstrate that there is a connection between tasks and achieving goals, and that everyone should pitch in, even if it's about something as simple as refreshments for the next meeting.

There's always a lot of work to be done in a group; the more that work is shared, the more people feel a sense of participation. But again, don't be disappointed if it takes a while for this to happen. It also may take a while to get people to focus on specific issues. In fact, they may not even get to this in the initial meeting. But it's your job as facilitator to try to keep the meeting running smoothly. From the beginning, establish some ground rules on how to keep the discussion moving. Some groups find it easier to use already established ground rules of other self-help groups; ask other local organizations about how they handle meetings. But you do have an important role in keeping the flow going and making sure everybody has a chance to speak--that no one dominates the meeting.

Agenda

Before the first meeting, plan to divide the time equally between business--when you are explaining the group and establishing ground rules as well as discussing possible goals and assigning tasks--and pleasure, a time for socializing. An hour and a half seems to be about the most that people want to participate in a formal group structure. So allocate 45 minutes or so to business and use the rest of the time for socializing. It's a good idea to have refreshments--at least some cookies and coffee or fruit juice--since eating always makes people feel more comfortable.

Some groups plan the business part with formal agendas and Robert's Rules of Order; the second part may just be free time for people to discuss anything they want, or it may be an organized group discussion of a particular topic, book, movie, etc.

Plan the Next Meeting

Don't forget to get everybody's name and phone number, and establish when your regular meeting time and place will be. Most groups find a weekly meeting is about the most they can

handle; some groups meet every other week. If you do meet every other week, make it at regular intervals, such as the first and third Wednesday of the month, or the second and fourth Thursday. This way, it's a regular time and people can plan for it.

Good luck with your group!

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