Consumer/Survivor Self-Help Group

Development
Introduction

The Mental Health Consumers in Action Program (MHCIA) has been designed to develop and implement mechanisms and strategies that will enhance the leadership, capacity, and advocacy skills of consumer/survivors. The MHCIA Program is a joint initiative of the Self-Help Connection (SHC) and the National Network for Mental Health (NNMH).

The Self-Help Connection is a provincial non-profit organization that has promoted self-help/mutual aid development throughout Nova Scotia since 1987. Our purpose is: to enable Nova Scotians to improve control over their health by increasing their knowledge, skills and resources for individual and collective action.

The Self-Help Connection
63 King St.
Dartmouth, NS
B2Y 2R7
Tel (902) 466-2011
Fax (902) 466-3300

The National Network for Mental Health exists to advocate, educate, and provide expertise and resources, for the benefit of the Canadian consumer/survivor community.

The National Network for Mental Health
55 King St., Suite 303
St. Catharines, ON
L2R 3H5
Tel (905) 682-2423
Toll Free (888) 406-4663
Fax (905) 682-7469
The Mental Health Consumers In Action Program
63 King St.
Dartmouth, NS
B2Y 2R7
Tel (902) 466-6001
Fax (902) 466-3300

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Additional guides are available by contacting any of the above organizations.

This guide has been prepared by Francine Vezina, Coordinator for the MHCIA program.

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Step 1

Find Other Consumers/Survivors who Share your Interest

If you are interested in starting a consumer/survivor self-help group, find out who is doing it now or who has done it before. Call local or provincial Self-Help Clearinghouses, which maintain directories of self-help groups in their areas, (e.g., the Self-Help Connection in Nova Scotia) and also have information and resources for starting self-help groups. Ask for sample materials they have used, such as flyers, press releases, etc. Consider attending meetings of other self-help groups to get a feel for how they operate, then borrow what you consider their best techniques to use in your own group. They will be glad to share their knowledge.
Step 2

Think “Mutual-Aid” From the Start

Think of mutual-aid as a group effort from the start. Find other consumers/survivors who share your interest in starting (not simply joining) a self-help group. If several people are involved in the planning and early stages (refreshments, publicity, name tags, greeters, etc.), it is more likely that as the group continues, members will continue to share responsibility for the group. That’s what mutual aid is all about!

Once you build your team, encourage all members to share the responsibility of running the group. Having several members responsible for running the group can reduce the pressures that may fall on one person’s shoulders and prevent that member from becoming overworked. Having several leaders can also prevent the group from breaking up if a single leader decides to leave the group, gets sick, or moves away.

Step 3

Find a Suitable Meeting Place and Time

Try to find free meeting space, such as a local church, library, community centre, hospital or social service agency. Would evening or day meetings be better for members? Many people prefer week nights. It is also easier for people to remember the meeting time if it’s the same day of the week or month each time, like the first Monday of every month.

Step 4

Target Your Membership

When people first attend self-help groups, they are usually very needy and expectations can run high. New members often approach a group when they feel overwhelmed by their problems and are in urgent need of support. For this reason it is very important to make some decisions about membership when forming your group. For example: Who can attend meetings? Most consumer/survivor self-help groups have few requirements for
membership, but some thought should be given to who can join and who cannot. The reasons for refusing membership should be clear. Most groups, however, make it easy for people to join and leave groups. Do you want regular membership limited to those directly experiencing the problem? The most successful groups are the ones that deal with one issue, so make your issue clear! This will help potential or new members evaluate whether a particular group is right for them. It will also make it easier for groups to target new members. Do you want associate membership for spouses and family?

The first meeting is important. The core group will have to be ready with more than just a time and place. First impressions are important, so make sure you have someone to greet people as they come in. You want to make everyone feel welcome.

Try to get the group going right away. Some people will be meeting others for the first time. Others will be re-establishing contact with someone they may have talked to on the phone or met at a workshop. Each person will have to decide whether or not s/he wants to participate in the group, so it’s important to set the tone and establish some direction. Starting with a good foundation will serve the group well in the meetings to follow.

Define the Purpose of the Group

Deciding the purpose of the group is the first thing to do. What is the group for? What will it do? Who is likely to join? Are the goals clear? Get them down on paper for future reference. Is the main focus of the group emotional support, education, mutual support, policy and standards development, or advocacy? The following are some sample statements of purpose from various self-help groups:

- To mutually support, in confidence, the normal grief and unique needs of widowed persons.
- To work toward reducing the stigma of mental illness.

Publicize and Run Your First Public Meeting

Reaching potential members is never easy. Consider where potential members go. Would they be seen by particular doctors or agencies? Contacting consumer organizations, doctors, clergy or other professionals can be one approach to try. Posting flyers in post offices, community centres, hospitals, libraries is another. Free announcements in the community calendar sections of local newspapers, radio and cable T.V. can also be helpful.
• To provide a safe place for discussing and listening with the emphasis on the well being of the members.
• To actively seek new sources and information on treatment, research, coping skills, etc.
• To provide emotional support and practical help in dealing with a problem common to all members.

Your group may choose from these statements or develop your own statements of purpose.

**Step 7**

**Decide on a Meeting Format**

Most self-help groups should go slowly at first before developing a permanent structure. Groups should create their own structure to meet the needs of members. What amount or combination of discussion time, education, business, program planning, socializing, etc. suits your group best? What guidelines might you use to assure that discussions are nonjudgmental, confidential and informative? Groups also need to decide if they will take on a formal structure such as a 12 step program, or a less formal structure that is good for meeting emotional and personal needs. The follow sections describe some key decisions your group will need to make about the way their group will run.

**What Will the Format and Content of Meetings Include?**

The following are common activities for many self-help group meetings and can be used to guide your meetings.

• Greeting of new members
• Formal opening of meeting
• Introduction of members
• Discussion, education, and information sharing
• Business section
• Formal closing

After you're underway, consider using resource people (consumer/survivor leaders, health professionals, pharmacists, etc.) as speakers, advisers, consultants to your group, and as sources of continued referrals. Consultation can focus on a variety of issues, such as, helping with group organization, finding information, and skill building. Making these contacts is also a good way to educate the community about your group and what it does.

**What is the Purpose of the group?**

It is a good idea to state the purpose of the group at each meeting as a reminder to returning members and to orient newcomers. It will remind members why they are there and what it is they hope to accomplish. Sample statements of purpose are outlined in Step 6.

**What About Confidentiality?**

It is important to state and clarify the guidelines around confidentiality often. This will help to create a place where members feel safe and comfortable sharing feelings and experiences. Some groups have members sign a confidentiality agreement (see Appendix C for a sample
confidentiality form). This is a good way to show members how important confidentiality is to the group. It also protects members in the event that confidentiality is broken, that is, everyone is clear that it will result in being asked to leave the group. Also keep in mind that respect and attentiveness for each member's needs and opinions is important. Ensure that all members receive equal, uninterrupted, air time to share their concerns, feelings, strengths and wisdom.

What Guidelines Will the Group Follow?
Establishing guidelines is a good way to help groups function well. For example, establish rules around talking, air time, group responsibilities, or how you want to interact as a group. Below is a list of sample guidelines you may use or adapt for your group.

- We listen, explore options, and express our feelings. We do not prescribe, diagnose, judge, or give advice... we suggest.

- We know what we share is confidential and that we have the right to remain anonymous if we choose.

- We each share the responsibility for making the group work.

- We each have the opportunity for equal air time or the right to remain silent.

- Avoid interrupting. If we do break in, return the conversation to the person who was speaking.

- We have the right to take part in any discussion or not. It is important that we actively listen when someone is talking and avoid having side conversations.

Refer to Self-Help a "How to Manual", available through the Self-Help Connection, 63 King St., Dartmouth, NS, B2Y 2R7, Tel (902) 466-2011 for more detailed information about self-help group meetings.

Step 8

Develop Shared Leadership

The role of leaders in self-help groups is to assist group members to find out what they want to do and then to help them do it. One person does not have the responsibility to take a leadership role in all areas.

Consumer/survivor self-help group leaders often become overworked and overburdened with the responsibilities involved in running the group. This often happens when one or two people are responsible for all aspects of running the group, and as a direct result of putting aside too many of their own needs to keep others and the group going. Another risk, when a group depends on one person to keep that group running, is that groups often stop meeting when that one leader gets sick or decides to leave the group.
The best way to avoid leader burnout is to develop shared leadership. Consumer/survivor self-help group members should share leadership responsibilities. Develop leadership skills in your group by encouraging everyone in the group to be involved from day one. The group can discuss how and in what way various members can contribute, what skills, knowledge, and resources are needed to do a job, what kinds of contributions will help the group, and what the group can do to improve the ability of its members to contribute.

Some people think leaders are born, not made. But leadership is a composite of learnable skills that all individuals in the group can learn, either by doing or learning to do.

Section #2 Consumer/Survivor Leadership contains more detailed information on leadership.

If you would like more information about leadership, "Self-Help a How to Manual" and "Tips for Self-Help Groups leaders" are two manuals available through the Self-Help Connection, 63 King St., Dartmouth, NS, B2Y 2R7, Tel (902) 466-2011. These manuals provide more detailed information about self-help group leadership.

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Step 9

Encourage Members to Attend Meetings on a Regular Basis

Most self-help groups go through stages when they lose momentum, that is, slow down or discontinue. Groups may become discouraged when participation drops, problems develop, or when the business items of the meetings conflict with the support/sharing elements. People may want change and variety. As the group changes or gets larger, members may go off in different directions or the group may become more complex. Members can develop different plans; some may become more task oriented, others may want more sharing and support from the group.

The following are suggestions for motivating members to continue to attend meetings or to become more active in sharing leadership activities:

- Try to share the workload. People may be willing but not confident enough. Ask people to do specific things. For instance, can someone in the group draw? Ask her or him to draw a picture for your newsletter or a poster. Is someone a good listener? Ask him or her to be a contact person for the group. Various leadership styles may be needed for various groups.

- Create a warm, comfortable, informal atmosphere at an accessible meeting place and time.

- Provide interesting activities and involve the members
in selecting the activities they want (i.e. make use of videos).

- Share ideas and responsibility.
- Try to conduct the business of the group outside of the support group meeting (e.g. money, etc.).
- Set up a welcome committee to greet members at the door.
- Introduce new members at each meeting.
- Use name tags if the group is not an anonymous group. Make it clear if anonymity is preferred.
- Keep an attendance book along with a members list with contact addresses and phone numbers - if members agree.
- Serve a simple lunch and/or refreshments.
- Encourage interaction among members at group meetings and outside the group. This could include planning social events.
- Stay in touch with members through a phone committee so they are aware of activities and have the opportunity to talk to someone.
- Have fun and introduce humour when appropriate.

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**Step 10**

**Develop Agendas**

Once the group has had a chance to develop the format and purpose of the group, members can plan programs and activities for future meetings. Appendix B contains sample agendas for your first two self-help group meetings. These agendas are provided as guides and can assist your group in getting off the ground. When your group is well underway, as a group decide what form future meetings will take and develop your own agendas.

Section #3 *Consumer/Survivor Participation* provides more information about preparing for and running meetings and information on covering the agenda.
Appendix A

Additional Resources


Appendix B

Sample Agendas

Agenda Meeting 1

Length of Meeting: 2 hours

Purpose of Meeting: To define the purpose of the group. What is the group for? What will it do? Who is likely to join the group? Is the main focus (education, support, social, or advocacy)?

Materials: Flip chart, note pad or blackboard, markers, paper, pens

Activities:

1. Greetings and Introductions. Everyone should have an opportunity to introduce his/herself to the group and maybe state their reason for joining the group. This is especially appropriate for new groups forming or when new members are joining the group. It may take several meetings before some people feel comfortable enough to participate and share openly.

2. Formal Opening of Meeting. At the agreed upon time, the meeting should be called to order by the chairperson or facilitator for that meeting.

3. Define the purposes of the group. What is the group for? What will it do? Who is the group for? Have everyone in the group suggest ideas for purposes of the group. Write all ideas down on the flipchart/blackboard and then discuss and clarify, as a group, what the purposes will be. Make sure they are clear and write them down for future reference.

4. Decide on a name for the group. The name of the group will provide an identity and uniqueness to the group. Encourage everyone to suggest a name. Write down all the suggestions on the flipchart/blackboard and then discuss and agree on the best choice for your group.
5. **Closing.** It is important to indicate that the meeting is formally closed. Finish the meeting on time and decide on (or remind) members of the time and place of the next meeting. Refreshments may be provided after the meetings to provide an informal atmosphere for members to socialize.

**Agenda Meeting 2**

**Length of Meeting:** 2 hours

**Purpose of Meeting:** To decide on a meeting format for the group. What choice or combination of discussion time, education, business meeting, program planning, socializing, etc. suits you best?

**Materials:** Flip chart or blackboard, markers, paper, pens

**Activities:**

1. **Greetings and Introductions.** Everyone should have an opportunity to introduce his/herself to the group and maybe state their reason for joining the group. This is good for new groups forming or when new members are joining the group. It may take several meetings before some people feel comfortable enough to participate and share openly.

2. **Formal Opening of Meeting.** At the agreed upon time, the meeting should be called to order by the chairperson or facilitator for that meeting.

3. **Decide on a Format for the Meetings.** Sample activities for self-help group meetings include: greeting new members, formal opening of meeting, introduction of new members, discussion, sharing, business section, feedback, formal closing. Your group can discuss what sections or combination of sections suits you best.

4. **Develop Group Guidelines.** As a group, decide what guidelines might you use to assure that discussions are non-judgemental, confidential, and informative? Sample guidelines include:
   - We listen, explore options, and express our feelings. We do not prescribe, diagnose, judge, or give advice... we suggest.

   - We know what we share is confidential and that we have the right to remain anonymous if we choose.
   - We each share the responsibility for making the group work.
   - We each have the opportunity for equal air time or the right to remain silent.
   - We have the right to ask questions and the right to refuse to answer.
   - We encourage members to share their strengths, skills, insights, successes, and hopes.

5. **Closing.** It is important to indicate that the meeting is formally closed. Finish the meeting on time and decide on (or remind) members of the time and place of the next meeting. Snacks may be provided after the meetings to provide an informal atmosphere for members to socialize.
Appendix C

Sample Confidentiality Agreement

Confidentiality is the ability to keep secret what someone has told you or shown you. Self-help group members should have guidelines around confidentiality and should confirm both verbally and in writing that they will commit to the confidentiality guidelines. This will protect all members. Below is an example of confidentiality guidelines and an agreement that may be used and followed by group members.

Guidelines

1. Do not discuss with other persons (such as family, friends, neighbors, etc.) any information obtained in conversation with the group and/or its members.

2. Do not discuss with other people (such as family, friends, neighbors, etc.) any information that is told to you in confidence by group members.

3. Confidentiality extends not only for the duration of the time you are in the group, but also continues indefinitely once your membership with the group has ended.

Name:

Address:

During my membership with the [group name], I may learn personal and confidential information about individuals who call or are involved with this group.

Whether information is available to me through the group or accidentally, I agree to maintain confidentiality and not reveal information to any person in the group or outside the group.

I understand that breaking this agreement could result in the termination of my membership with the [group name].

Signature of Member:

Date:

Signature of Witness:

Date: