

Resources on Confidentiality for Self-Help/Mutual Aid Support Groups



Confidentiality is the anchor of mutual support.
By creating and maintaining trust we can share, support and heal more deeply.

This collection of resources is designed as a kit to help you and group members take steps to build clarity and commitment about confidentiality within your group.

Inside you will find:

- An introductory Fact Sheet (yellow)
- Planning Guides to help you build clarity and commitment in your group (green)
- Help Sheets for difficult challenges you may face (orange)
- Group Activity Sheets to help you talk about and practice tough situations (pink)
- Information about the Ontario Self-Help Network program and services (blue)



Resources on Confidentiality for Self-Help/Mutual Aid Support Groups

These resources were developed by the Ontario Self Help Network in collaboration with Martha Jack of the Women's Health Care Centre of the Peterborough Regional Health Centre/Four Counties Self Help Network. We drew on some resources from the Government of B.C.'s Self-Help Mutual Aid Facilitator Training. Drawings are by Leslie Fraser.

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Fact Sheet: Confidentiality in Self-Help Support Groups

Here is what some people have said about confidentiality in groups:

- “Generally speaking, confidentiality means never discussing, without direct consent, the circumstances of another group member.” (Self-Help Mutual Aid Facilitator Training, Ministry of Social Services, Government of B. C.)
- “What you see here, what you hear here, when you leave here, let it stay here!!” (Dreamcatchers peer support group pamphlet)

What is confidentiality?

Many of us have been told personal stories “in secret” by friends or family members. In a self-help group we hear personal information and stories from people who are “strangers” or people we don’t know well. Most self-help support groups ask participants to keep information and stories in confidence, or “in secret”.

Technically speaking, confidentiality means we do not share any information or stories with others. However, many groups decide that members may talk about what they heard or learned in the group, as long as no identifying information is shared. This means nothing about name, workplace, family members, address, etc. is shared.

It is very important that each group member respects general agreements about confidentiality and anonymity. Confidence is defined in the dictionary as “a state of trust”.

Why is confidentiality so important?

Personal sharing is important to self-help. An environment of trust and safety allows group members to share more deeply with others.

People must feel that information will be kept confidential before they can safely share their stories. Some groups describe confidentiality as the anchor of mutual aid.

Confidentiality is the anchor of mutual support. By creating and maintaining trust with each other, we can share, support and heal more deeply.

Two exceptions you should know about:

There are two exceptions where you must report information. You should make sure that group members understand these exceptions.

1. If you suspect that a child is or may be in need of protection.
2. If someone declares a plan to harm him/herself or another adult.

1. In a case of suspected child abuse or neglect:

The Child and Family Services Act states clearly that members of the public (including professionals who work with children) have an obligation to report promptly and directly to a children's aid society if they have reasonable grounds to suspect that a child is or may be in need of protection.

Action must be taken if "the person having charge of the child" is suspected of causing, or knowingly failing to protect the child from: physical, sexual or emotional abuse, neglect or risk of harm.

If you need to contact a children's aid society (sometimes called "family and children's services"), check your telephone directory for the closest office or call the police. For more information on this child protection law, call the Ontario government publications office at 1-800-668-9938 and ask for a copy of their pamphlet "Reporting Child Abuse and Neglect" (ISBN 0-7778-9391-6).

2. If a person plans to harm him/herself or another adult:

If a group member clearly states a plan to harm him/herself or another adult, it would be wise to quickly get confidential advice on how to help or intervene. For example, if you believe that someone is in danger right now, try to call a distress or help line. The counsellor on the phone can help you figure out the situation and decide on the best (if any) action you should take. A professional who provides support to your group could also help with this. Otherwise, call the police.

Besides the two exceptions outlined above, the only time you can change a commitment to confidentiality is if you ask and talk directly with the person concerned.

What does my group need to do about confidentiality?

Confidentiality is both a commitment and a skill. To gain people's commitment, discuss the specific needs of each group member. Then decide on shared rules for your group.

To be sure everyone is clear, (especially newcomers) you can:

- Read out a statement at the beginning of each meeting
- Ask people if they have questions or concerns about the group's current confidentiality agreements
- Give examples of a common situation where confidentiality needs to be practiced (e.g. meeting a group member at a public event)
- Use rituals which remind members about their commitment

To support group member's skills in practicing confidentiality you can:

- Talk about case studies or group members' experiences
- Try role playing difficult situations

The Ontario Self-Help Network has more resource materials to help you take action on the above suggestions. For more confidentiality resources, guidance or training, call 1-888-283-8806 or email oshnet@selfhelp.on.ca.

This factsheet was published by the Self Help Resource Centre, a United Way Member Agency.

Planning Guide: Deciding on a Confidentiality Agreement

Basically, the word “confidentiality” will mean whatever your group decides it should mean for you. Confidentiality means different things to different people. That’s why it is very important to talk about confidentiality as a whole group and be clear about what you have agreed to. It is also very important to make sure that new members know the rules of your group and agree to them.

Peoples’ ideas about what it means to keep confidence about what happens and what is said in the group can and will be different. Some people will think that NOTHING about the group should be shared.....as if it is a secret society. Others will think that simply protecting the names of people who are there means that the group is confidential. A good confidentiality agreement probably lies somewhere in between these two viewpoints. Set aside at least one whole meeting to talk about confidentiality. You will need to come back to this subject every once in awhile as things come up, or go over it with new members.

Here’s how to walk your group through a discussion about what confidentiality will mean to everyone in the group:

Step 1.

Go around the group, asking each person to say what protecting their confidentiality would mean to them. Write all this on a flip chart.

Step 2.

Once everything is written, go back and encourage people to talk about what each statement means. This is where you will all begin to see how different people see confidentiality differently.

Step 3.

Take each statement one by one, and begin to “flesh out” an agreement for each issue with a 1 or 2 sentence explanation for each. For example:

We agree to keep private the identity of people in this group. We will not give each others names, addresses or phone numbers to anyone, and will protect any other identifying information as well. We will respect members’ requests to not be greeted at chance meetings in public places.

What this agreement means:

- a) That your membership lists are never shared
- b) That any one member will not give any other member’s information to anyone for any reason
- c) That members will not tell other people’s stories outside of the group with information that might identify the other person. This could be information about where they work, what school their children go to, what church they attend, information about their partner, etc.

- d) That if one member meets another person at the mall, at a party, through work, etc, that they will not let anyone know that they know each other from the group.

Step 4.

Work out agreements to address each of the statements on the flipchart in the same way. Make sure that everyone has an understanding about exactly what you are agreeing to. Write down each agreement.

Step 5.

Once you have gone through all the things that group members identified as important to them, look over the list for things that are said more than once, or things that might not be clear.

Step 6.

Make sure the group has agreement about all the statements.

Step 7.

Talk about what will happen if group members break the rules. This will take extra time, but is a very important step. Make a statement about this and include it as part of the agreement.

Step 8.

Decide about whether or not the group wants to have a formal letter that all group members must sign, agreeing to respect the confidentiality agreements you have made.

Step 9.

Talk about what is NOT part of the confidentiality agreement. For example:

- a) It's OK to share the handouts from the group or any learning you get from here.
- b) If you have feelings left over from the group, and you need to talk to someone about them, its OK to talk about your feelings, or what the discussion brought up for you. It's NOT OK to share any information about who the person is whose story triggered these feelings.
- c) It's OK to let others know you belong to this group, if you feel comfortable about that.
- d) People will report suspected child abuse or neglect and any declaration of an intent to harm self or others (for example a spouse or partner). For more details on these exceptions, see the Fact Sheet on Confidentiality in Self-Help Support Groups. For free copies of the pamphlet "Reporting Child Abuse and Neglect" (ISBN 0-7778-9391-6) call the Ontario government publications office at 1-800-668-9938.

You can contact OSHNET at 1-888-283-8806 or oshnet@selfhelp.on.ca to request sample copies of confidentiality agreements from other groups.
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Planning Guide: Ways to Help Group Members Stay Committed to Confidentiality

It is a good idea to remind group members of your agreements. This helps to maintain trust and safety in the group.

Here are some ways to help group members remember:

1. Some groups have a written confidentiality agreement which each member signs when they join the group. If your group does this, have each member review it once a year. Have the group look at it together once a year as well so you can make any needed changes.

2. Write the confidentiality agreement on a piece of flip chart paper and put it up at every meeting. This is a good reminder for every one and it gives the facilitator something to support them in a conflict.

3. Read out the agreement at the beginning of every meeting. This way you'll never miss making sure that new people know what's been agreed to. Hearing it every meeting also helps people to be clear about what they do and do not want to share with others in the group.

4. Have something that you do every meeting (either at the beginning or end) to help everyone remember to respect confidentiality.

Here's one example:

THE WELL OF CONFIDENTIALITY (This works with groups of 18 or less.)

- Have everyone stand in a circle with their **right hand** extended toward the middle, thumbs out, fingers clenched in a fist.
- Each person holds the thumb of the person on their right in their closed fist. In a large group, people will have to stand sideways to be able to reach everyone.
- Everyone's right hands will make a circle on the middle of the group. This is "the well of confidentiality".
- Tell members that this "well" is a place where everyone's stories go for safe keeping and that this encourages the group's commitment to confidentiality.

Help Sheet: What If Someone Violates the Group's Confidentiality Agreement?

It is not necessarily your fault if someone breaks confidentiality. However, this is a time for you to practice good leadership skills. It is also an opportunity to help the whole group go over their agreements.

As we have already said, it is **very important** to have as part of your confidentiality agreement something that says what will happen if someone breaks the rules.

A breach in confidentiality is serious because:

- It takes away the person's right to the privacy that was agreed to
- It gives group members a message that the group may not be a safe place in which to learn and to share experiences and information
- It breaks the circle of group trust and loyalty
- It could make for an unsafe or unstable situation for the group member whose confidentiality was taken away (for example, someone living with domestic violence, or someone whose job may be threatened if her boss gets information about her)

You can facilitate dealing with a breach by doing 3 things:

1. Help the person whose confidentiality was violated by:

- Finding out what happened by meeting with this person alone
- Finding out what this means for the person
- Taking steps to address any safety issues that are a result of the breach
- Helping the group member to confront the person who violated the agreement, if appropriate

2. Make it clear to the person who violated the agreement that this is serious by:

- Finding out what happened by meeting with this person alone
- Reminding them that they were part of a group agreements to honour confidentiality and that breaking that trust is serious
- Letting them know what the consequences of their actions are and enforcing those consequences
- If appropriate, helping them to meet with the person whose confidentiality was breached

3. Help the group as a whole to deal with what has happened by:

- Raising this difficult subject at a meeting of the whole group
- Helping the group to talk about what has happened
- Modeling good behavior by being respectful of everyone
- Supporting the group to enforce the consequences that they have agreed on about how to handle a breach
- Helping the group to see what they have learned from this
- Helping the group to make changes to the agreement, if needed.

Help Sheet: Caring for yourself under pressure

When keeping confidentiality is tough

Practicing confidentiality is not always easy. Sometimes, we may feel pressure to share another person's story. This pressure may come up if we have a strong emotional response to another person's story or situation and we feel the "need to talk" for our own personal support. Pressure could also come if a person who is outside the group questions us.

In these situations, it can be helpful to think of confidentiality as a boundary. When you are feeling pressure to cross that boundary, try to take a moment to:

- Look at the boundary;
- Look at what is pressuring you; and
- Problem-solve a way to address the pressure without crossing the boundary.

Here are some ways to deal with these different situations.

If you are emotionally distressed and "need to talk":

Sometimes we are "triggered" by someone else's story. It can be very important to think or talk through what your emotional responses are. Without breaking confidence, can you think of a way to look after your own needs?

Here are some ideas:

- Write in a personal journal.
- Find someone you can trust to talk with, someone who will give you the attention you need. Share general information about what has upset you. Focus on your own emotions and experiences without sharing any identifying information about the group member's situation.
- Go to someone who is professionally bound to keep confidence, such as a social worker, health professional or minister.
- If possible, speak with the person who shared their story with the group. Maybe it will help to talk with him/her. Maybe they will give you permission to speak to share the story with your partner, sister, or a friend.

If someone is questioning you in an invasive way:

Some people are more questioning than others. You may be talking with a friend and they may start asking questions and before you know it you are at that boundary – the confidentiality boundary. If you feel at all uncomfortable, take a moment to “check in” with yourself. What is the boundary? Where is the pressure coming from? How can you keep your commitment to confidentiality?

Here are some ideas for tough situations:

- Tell the person “I cannot share that information because it is confidential”. Remember, the more you practice telling friends and family that what goes on in your group is confidential, the easier it will be.
- If you can, avoid the question and change the subject.
- Ask the person: “why are you asking that question?” Answering a question with a question can change the conversation from the content into a conversation about process. It may then be easier to explain that you are committed to keeping information confidential.

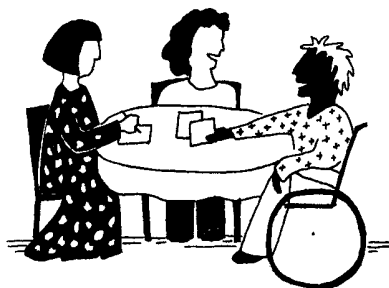
Protecting identity means different things in different places and situations. If you need to talk to someone outside the group, take time to think through how you can protect the confidentiality boundary that you have agreed to.

Group Activity Sheets

These group activity sheets describe different ways that your group can explore real situations.

This is a chance to work with problems before they come up. The activities will help build clarity and confidence among group members.

Role plays can be fun and flexible.



The role of the facilitator(s):

- Review steps for the chosen activity
- Photocopy necessary materials ahead of time
- Introduce the activity
- Using a flipchart, review and list general confidentiality guidelines and skills (e.g. active listening, assertiveness, asking questions).
- Begin the activity
- Before wrapping up, get people's feedback on the activity – what did they learn? What would they change?

Group Activity: Discussing Case Study Situations

Members of your group will be better prepared to protect confidentiality if you consider possible situations ahead of time. Below is an agenda to help your group facilitate a discussion of case study situations.

Allocate at least an hour of your group meeting time for this exercise. Use the case studies attached, or write up some of your own. Prepare a copy of all the case studies for each member/participant.

STEP 1 – Small Group Discussions

Divide into small groups of 2-4 people. Give one case study to each group for consideration. Ask the groups to review their case study situation and discuss the related questions. Give them 15 minutes to do this.

STEP 2 – Report Back to the Group

After the small groups have tackled their case study, come back together as a large group. Ask each small group to report on the situations they considered: what were the key problems, decisions and actions they discussed? (This may take 15-25 minutes).

STEP 3 – Wrap-up and Debrief

Once all the situations have been reviewed, spend the rest of your time (20-30 minutes) “debriefing” the exercise. You can use the following questions to guide your discussion:

- How did this activity make you feel?
- What did it make you think about?
- Will this discussion change your personal commitment to confidentiality?
- Do members want to make any changes to how the group introduces and encourages confidentiality?

Scenario #1

Nicholas has come to an anxiety group several times. At the last meeting he shared, for the first and only time with anyone, how deeply stressed and upset he was by his son's acting out behaviour.

After the meeting he began to worry that he had said too much. Then about a week later a casual friend approaches him at the grocery store and says, "I hear you are really struggling with problems with your son, is there anything I can do?"

How do you expect Nicholas might be feeling now?

Is there anything you can think he might want to say to the group?

What action do you think the group should take?

Scenario #2

Niles is a recent member of a gay and lesbian support group. He has not yet made the decision to “come out” and has not told the members of the group. Another member of the group, James, meets him at a café with some other men and openly discusses their support group.

How can Niles handle the situation?

How can James respond?

How could this situation have been avoided?

Scenario #3

Marianne is a group member who has breached the confidentiality of the group. She gossiped about some of the issues that other members had raised at the last meeting. This is the second known occasion on which she has done this. The first time it was brought to Marianne's attention that the expectation of the group was that everything discussed at the group remain within those four walls. Marianne had apologized at that time.

What do you think the group should do now?

Scenario #4

Agatha belongs to a parents' support group and mentions at one of the meetings that she is concerned for the safety of a two year old in her apartment building. She often hears the parents screaming and yelling as well as crashing and banging. The parents often have late night parties and Agatha believes they abuse alcohol and drugs. Other tenants have seen the two year old alone in the halls.

How do you think the group should handle this information?

Do the members of the group have a responsibility in this matter?

Who would you talk to about what Agatha said?

Scenario #5

Debbie has recently had a prolonged and serious illness, which required debilitating surgery. She will be at the hospital for a long time. Debbie decided to join a support group in the hospital for patients with long term and serious illness. One day, she was in the hospital gift shop when she overheard one of the facilitators of the group, discussing her situation in detail with a nurse. No name was mentioned, however, due to the unusual and complicated nature of her illness, it was obvious they were discussing Debbie's case.

What can Debbie say to the facilitator privately about what she overheard?

How might Debbie bring the situation to the group meeting for discussion and reflection?

What can the group do to rebuild trust/safety?

Scenario #6

Antoinetta lives in a small town and belongs to a breast cancer support group. She has had a bad experience with a local physician who did not clearly explain the treatment choices available to her and was unsupportive of her decisions. Antoinetta is fearful that her fellow group members might have a similar experience at this doctor's clinic. She herself, was able to find helpful information from other sources i.e. the Internet, Breast Cancer Foundation etc.

What are the potential impacts if Antoinetta reveals the physician's name to the group, realizing that most people will know the physician?

How might she describe her experience and support others to have a better experience without mentioning the physician's name?

Group Activity: Using Role Play to Explore Tough Situations

In tough situations, it takes thought and practice to keep confidentiality. Sometimes there is no clear "right way" to do this. Using role plays to explore tough situations and experiment with different ways of reacting can be a fun and helpful exercise for your group. The description below can help you set up a role play and then practice a technique called "stop theatre" to explore options in a given situation.

Allocate one to two hours of your group meeting time for this exercise.

STEP 1 - Choose The Context

Choose a support group similar to your own as the context for your role play scene. If participants are from different kinds of groups, choose a different group context for each scene.

STEP 2 - Create The Scene

Have volunteers choose a scene and act it out using improvisation. You can choose a scene based on the experience of a participant, or select from the scenes below:

Over lunch:

- You are at lunch with an old friend.
- You tell her/him how much better you are feeling and how a big part of your improved outlook is the result of the support group you recently joined.
- Your friend is interested and asks questions to learn more; the questions become more detailed.
- The questions include: Who goes to the group? What kinds of situations are they dealing with? Where does the group meet and when?
- You feel uncertain about sharing some of these details, but you don't want to be rude to your friend.

At the drop-in:

- You are hanging out at a drop-in the day after your group meeting.
- Only 4 people are at the drop-in, two of them are other members of your support group.
- Leslie is an old-time member and people in the drop-in know that he/she attends the support group. Leslie is talking casually about the general issues covered at the meeting yesterday, engaging both you and the other group member in the discussion.
- Although you are also open about your membership in the group, the third member is new and does not seem comfortable talking about group matters in a larger social environment. This becomes increasingly apparent to you. Eventually, that member leaves the room to "go to the washroom."

At a meeting:

- You and another group member are meeting with a social worker at the local community centre to request space for an educational forum on a topic related to your group's concerns. You had set up the meeting because you teach community work at the local college and some of your students had completed practice placements with this social worker.
- The other group member reveals to the social worker that you are both members of a self-help support group sponsoring the event. This is not information that you want known within the broader community.
- The social worker keeps a professional face but you are uncomfortable about where this information may end up.

STEP 3 - Replay The Scene, Stop Theatre Style

Once the volunteer "actors" have completed acting the scene once, begin again from the beginning. This time, ask group members in the audience to think of an opportunity where they could STOP and CHANGE the scene.

- At that point in the dialogue, any member of the audience can clap their hands and yell "stop".
- He/she will then replace the self-help group member in the scene and try out a different dialogue, to create a more positive outcome.
- Allow the new stop theatre "actor" to try out one or two different angles, then go back to the beginning and replay the scene again with the original "actors". This time another audience member may want to yell stop and try acting out on a different point.

Remember: There are no best answers. The purpose of this exercise is to explore as many different options as possible.

STEP 4 – Wrap-up

Once your group has run out of new ideas, give the "actors" a round of applause.

Now, spend some time discussing the results of the stop theatre experiments. How did the different approaches influence what happened?

ONTARIO SELF-HELP NETWORK

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The Ontario Self-Help Network (OSHNET)

OSHNET is a program of the Self Help Resource Centre, funded by the Public Health Branch of the Ministry of Health and Long Term Care. OSHNET was established in 1992 in order to link self-help/mutual aid groups and organizations across the province. OSHNET's goals are:

- to enhance existing self-help/mutual aid activity
- to encourage and support the development of new self-help initiatives
- to provide networking opportunities for self-help/mutual aid groups and organizations and to facilitate local education and skill development opportunities for individuals and professionals interested in self-help/mutual aid.

Contact - Gillian Kranias, OSHNET Coordinator oshnet@selfhelp.on.ca

OSHNET - What We Can Offer You

◆ Referrals

In cooperation with 15 affiliate centers across Ontario, OSHNET refers mutual aid seekers and professionals to a diverse range of self-help groups and organizations. Issues addressed by self-help initiatives include: abuse, addictions, bereavement, body image, cancer, caregiving, disabilities, employment, heart health, parenting, sexual orientation, HIV/AIDS, men's health, mental health, physical health, relationships, seniors' health, women's health, and more.

◆ Networking

OSHNET coordinates networking among its affiliates across the province. We also support networking among self-help organizations, self-help groups, health-related non-profit organizations and professional health intermediaries from a range of sectors and communities.

◆ Training

OSHNET offers a variety of workshops on understanding and enhancing self-help initiatives. Workshops for health intermediaries include: Understanding Self-Help, Developing Self-Help Leadership, Transitioning from Professionally-led to Member-led Groups, Evaluating Self-Help and Working with the Hard Parts (Communication and Conflict). Workshops for self-help volunteers include: How to Start a Group, Enhancing Shared Leadership, Communications and Listening Skills, Working With the Hard Parts (Communication and Conflict) and Evaluating Self-Help. New workshops are developed on an as needed basis.

◆ Consultation

We provide consultations to non-profit organizations and professional health intermediaries working with self-help strategies and initiatives. OSHNET and its affiliates across the province provide consultations to self-help volunteers who want to initiate or enhance their own self-help group.

◆ Information Resources

OSHNET publishes and distributes a range of resources on self-help. These include: how-to workbooks and factsheets, a 200 page Resource Kit on Making Self-Help/Mutual Aid Work, and summaries of self-help research. For education and awareness purposes, we maintain web pages at www.selfhelp.on.ca, publish a bi-annual newsletter and sponsor Self-Help Awareness Week each fall.

ABOUT SELF-HELP/MUTUAL AID

Definition of Self-Help/Mutual Aid

Self-Help/Mutual Aid is a process of sharing common experience, situations or problems. Self-help is participatory in nature and involves getting help, giving help and learning to help yourself as well as sharing knowledge and experience. There is no charge to participate, although a nominal donation to cover expenses is sometimes requested. Self-help initiatives are run by and for participants, meet on an ongoing basis, and are voluntary in nature. The primary focus of self-help is emotional support, practical support and information exchange.

Types of Self-Help/Mutual Aid Initiatives

- ◆ **Self-Help Groups** may be traditional face-to-face groups (open or closed to new members), transitioning groups (moving from a professionally-led support group model to a self-help model) as well as internet/on-line groups
- ◆ **Self-Help Networks** are groups of self-help groups networking around common issues i.e. breast cancer
- ◆ **Self-Help Organizations** are those that have a significant proportion of their services dedicated to self-help initiatives
- ◆ **Self-Help Centres** (or Clearinghouses in the US) are responsible for maintaining contact information for self-help initiatives in a given location (i.e. city, county or province). These centres may also provide assistance and training in the development of new self-help initiatives.

Does Self-Help Help?

Self-help initiatives are now being recognized as viable, effective methods supplementing and extending the present health and mental health care system. Research conservatively estimates that 2.1 million Canadians are currently using self-help groups, making self-help an “emerging social movement” (Borkman 1990; Katz 1981). In Canada, federal and provincial governments and agencies have shown a growing interest in and support for self-help initiatives as part of health promotion work.

Self-Help and Health Promotion

“Informal networks are recognized as a fundamental resource in the promotion of health. There is strong evidence that people who have strong social support are healthier than those who do not.”

- *Achieving Health for All, Health Canada, 1988*

“The self-help movement is an astonishing development that is sweeping the country. It is both the newest therapy and the oldest - human beings gathered around the campfire to comfort and sustain one another. Self-help groups are a brilliant response to the high cost of health services and the increasing alienation many people feel towards institutions and health care professionals.

A warning must be sounded early in this whirlwind movement; self-help does not equate with free-help. Administrative costs must be met and professional resources made available as required. With such backup, the self-help movement offers a level of familial support and empowering insight that is the best, brightest hope the community can offer to the troubled, the sorely wounded and the lost.”

- *June Callwood*