

SUGGESTIONS FOR FORMING AN ORGANIZATION  
FOR FAMILIES OF THE MENTALLY DISABLED

*We sent out this  
material in jacket -  
not always the same  
articles - whatever  
was current  
+ info on Ca org.  
and NAM?*

STARTING THE GROUP

1. One concerned parent can start a group. However, two or more families, who have a similar problem, can meet for mutual support and reinforcement, and take action to begin the group.
2. Decide on the time and place to hold the first meeting and publicize it as widely as possible.
3. Write an article announcing the formation of the group, giving the time and place of the meeting and the telephone number of the person to call for further information. Personally take the article to the local daily and weekly newspapers, so any questions the newspaper may have can be answered.
4. Place ads in the Personal column of the want ad sections of the local newspapers and posted notices on the bulletin boards of mental health centers, hospitals, etc., giving information on the formation of the group, time and place of first meeting, and telephone number of person to call for further information. (Example: "Advocacy group forming for parents of adult mentally ill. Phone number. -- Don't agonize--Organize!")
5. The person taking the telephone calls from interested parents should be prepared to devote a goodly amount of time talking to those who respond to the notices. For many it will be the first time they have spoken to anyone with similar problems and all that has been bottled up will come spilling out. It is important to have someone who is a good listener and who really understands.
6. To those who call, you should explain that the group you are forming is similar to other groups throughout your state and many other states which are successful in offering personal support to families. Have them give you their names, addresses and telephone numbers.
7. The first meeting should be informal, spent in getting acquainted with one another. Elect a leader-coordinator and decide how often you will meet.

MEETINGS

1. Establish a general monthly meeting date and place. General meetings can consist of business of the group and an educational program. Topics which can be presented include: information dealing with mental health services, research, treatment methods, rehabilitation, legislation, etc.
2. Some groups designate one meeting a month for a drop in "Share your Woe" night, usually for new parents to get acquainted with other understanding parents who provide mental support.
3. One meeting a month can be an open advisory board meeting where the business and direction of the group can be discussed.

## PERSONAL SUPPORT SYSTEM

1. As soon as the group is formed, establish a personal support system to families during times of crisis. Telephone numbers of those they can call during crisis periods should be provided to members of the group. Those answering such calls should have information available on where services may be obtained to pass on to the callers. They should be good listeners! People just want to talk to someone.
2. Any information is confidential! People are more honest, open and realistic in talking to other members of their group because whatever they say is not being recorded in medical records and it is not a threatening contact.
3. Keep a file of members having a crisis or problem. Follow up with calls until the problem is resolved. It means a lot to know someone is concerned about them.
4. Keep a file of information as to where services can be obtained.
5. Go to your local Mental Health and Welfare Department and obtain a list of the Chief and all the different department heads. Obtain names and telephone numbers of Health and Welfare people at the county level to call in crisis situations.

## NEWSLETTER

1. After the group is organized, send out a monthly newsletter with a schedule of monthly meetings, information about guest speakers, and informative articles on mental health.
2. Other items for the newsletter are legislation, meetings of other organizations and of related types of interest, and suggestions for speakers such as mental health officials, psychiatrists, etc.
3. Send monthly newsletter to elected legislative representatives, mental health providers, public and private, county, state and federal.
4. Send newsletter to anyone who expresses interest -- need not be a member of the group.

## PUBLIC RELATIONS

1. Obtain a list of names and addresses of your elected representatives: county, state, and federal.
2. Write letters of your concerns to elected officials. Always send copies of the letters and all publications to officials of opposite parties and to Health and Welfare Department -- they like to check up on each other. Sign your name and identify yourself as a member of your organization. When they do something in the mental health field that you approve of, write them a thank-you letter.

3. Keep a continuing contact with your local newspapers. They are helpful in running notices of your meetings and occasional news stories about your group.
4. Have information about your group available at all local mental health agencies, mental health hospitals, board and care homes, etc. in order to reach parents of new patients. Send speakers to P.T.A. meetings, churches, and fraternal, civic, and business organizations to educate the public and to make them aware of your group, and to work for acceptance and to mitigate discriminatory attitudes and social practices against mental patients in housing, employment and personal interaction.
5. Attend your local Mental Health Advisory Board meetings regularly, let them be aware that you are watching their actions. Try to get a member of your group on the Mental Health Advisory Board.
6. Attend County Board of Supervisors meetings, especially on items concerning mental health issues; make yourself known to them.
7. Attend public hearings at your state capitol, speak and be heard. Always mention that you are a member of your organization -- it will become a familiar name to your elected representatives in short time. Be informed. Don't give out false information or stories you can't substantiate -- be prepared with specifics. Learn well the state and federal laws covering mental health and don't back down.
8. Be active, join your local Mental Health Association, go to meetings and functions where you feel you can or may make contacts or learn something. Members of family organizations also serve on various committees in the mental health system of their counties, such as: the Mental Health Advisory Board, Board of Directors of a non-profit residential care facility, citizens advisory boards in community mental health centers, and many county-wide task forces.

#### MAINTAINING THE PARENTS GROUP

Maintain a well-organized group. It is helpful to establish goals and bylaws.

It is desirable to establish an office as a center of your counseling activities, record keeping, lists of membership, walk-in contacts, mail, mental health education library, referral information on agencies and social services and their functions and addresses and contact persons. An office is a central point where agencies and other organizations can contact your group.

Start a clipping file on mental health stories from newspapers, magazines, and journals and reproduce them for distribution to your members or print in your newsletter.

Have letterhead stationery made to add weight and authenticity to letters your group may want to send to agencies, elected representatives, etc.

Financial support comes from membership donations and other sources such as donations from organizations and friends and other money-raising activities. Raise funds to support your organization through various fund-raisers, i.e., educational movies, luncheons, parties, flea markets, rummage sales, and appeals to civic and fraternal organizations and businesses.

Be supportive of one another. Have your differences of opinion in private, never in public.

Do not limit your group to the support of only one specific type of mental health treatment. Be open. Seek out and actively support treatments, programs, and individuals acting to improve mental health care and treatment. Also support and foster the exploration of research into new methods of mental health care and treatment.

*A parent who survives the trauma of having a mentally ill son or daughter "wears many hats." Some of the roles you may need to fill in looking after the interests of your son or daughter are: attorney, accountant, secretary, therapist, nurse, doctor, and social worker. To do this it is necessary to be knowledgeable in the areas of mental health laws, patient rights, medical treatments -- mental and physical, drugs, social services, and the judicial system. Hopefully, the group you form will help you to become more knowledgeable in these areas by the sharing of information, and the investigation of areas where knowledge is not available in the group.*

*There is so much to do and learn -- constant education for yourselves and the public on the treatment of patients at different levels of their illness.*

Edited by  
Marie Hibler  
May 4, 1978