

SUGGESTIONS FOR  
PARENT ADVOCACY ORGANIZATIONS

October 31, 1979

After almost 7 years of working as a parent advocate, I have decided to put on paper some of the things I have learned and encountered so that others may benefit from my experience.

About ten years ago, my son, 15 at the time, got into the illegal drug scene and became schizophrenic. Following that we went through the usual: Private Psychiatrist, private hospital, the usual therapy, medication. He lived at home, skilled nursing facility and the state hospital.

The usual treatment modalities have not been helpful for my son, in fact, I believe they have been harmful. Up to this time, the only improvement we have seen has been through the orthomolecular approach, especially diet. At the present time he is on a ward in Napa State hospital where this mode is used and we have seen a marked improvement. This is not to say that this is the answer or that this will work for everyone.

About 6 years ago, Eve Oliphant, president of "Parents of Adult Schizophrenics", called about 5 families to a meeting at her house. My wife, Fran, and I attended. We soon realized that the only way we could help our own family member and ourselves was through group action. We decided our purpose should be: better care and treatment for the Mentally Ill, mutual aid and support for the family members and to foster research. We are still very active members.

Several years later we organized "Association for the Mentally Ill at Napa State Hospital". I was first President, Fran was secretary. We are active members.

By 1977, there were 7 family groups in California, mostly in the San Francisco Bay area. We started holding meetings with the intention of starting a state organization. The first statewide conference was held in Fresno, California in November, 1978. At that time there were 15 family groups, 2 were state hospital organizations. I was elected president, my wife, Corresponding Secretary. There are now 25 member organizations, from San Diego to Eureka in the north.

During this time I have served 5 years on the County Mental Health Advisory Board, one year as Chairperson. I am now Regional Chairperson of the State Organization of Mental Health Advisory Boards.

From this experience I would like to pass on the following:

1. The first thing to realize is that the consumer played no part in setting up this bureaucracy that is called the mental health system. We have a system that is not responsive to our needs and we have to make changes. On the other hand, there are very powerful, vested interests that do not want changes and oppose our movement.
2. Most of the money spent on Mental Health is public money. Decisions as to how public money is spent are not based on need or common sense, political clout is the prime mover of political decisions. For this reason we must be strong and develop political clout.
3. We must learn where the power is, where the decisions are made and what influences these decisions. We must learn how to impact these decisions, become a power ourselves and use this power wisely.
4. We must develop within our organization the necessary expertise and resources and not depend too much on outside help. The larger and most viable groups tend to be those that have had to pull themselves up by their own boot straps.
5. Be careful about accepting outside money. Many times there are strings attached.
6. If the main thrust of the organization is to be advocacy, don't spread yourselves too thin. Serving on committees and boards is desirable if it doesn't take too much energy from the main purpose. The same is true of starting and operating residential care facilities or providing other services.

7. Don't get sucked in. The system often encourages and helps advocacy groups to start providing services. Quite often they see this as a way to divert your energies and/or put you in a provider category. A certain amount of credibility is lost if the decision makers see you as a provider. If it is decided that there is sufficient energy to provide a service, do not operate it under the parent organizations' name. Set up a separate corporation for this purpose.
8. Watch for predators. There are always people that want to use the power and influence of the group for their own special interests. This is not to say that we should never support others, just be wary.
9. Don't be too narrow in your aims and goals. If the thinking and thrust is too narrow, the group will attract only a small number of people, others will lose interest and be turned away.
10. Build the organization from the ground up, there must be a solid foundation to survive and grow.
11. Create a newsletter for communication and educational purposes. The success and survival often depends to a great extent on the quality of the newsletter.
12. Work closely with other advocacy groups but maintain our identity as a families organization. The fact that we are family members is what brought us together in the first place and this will help to hold us together. The mutual aid and support is very important, only a family member really understands the mutual problems.
13. Open an office as soon as possible. This helps to get people involved and share the work.
14. Be united and coordinate efforts. Resolve issues within the organization or organizations. Show the decision makers a united front. Remember, if different stands are taken on an issue by like organizations, you cancel out each other.
15. Support State and national organizations. This will help provide the strength and coordination needed. Bring all families under one roof.
16. Promote alternative treatment modalities. In a survey held in California among parent groups, the overwhelming number felt the commonly used therapies were not helpful, in fact, most felt they were harmful. There is very much interest in the orthomolecular treatment. Although this may not be the total answer, it has worked on some people and does offer some hope. Its use should be encouraged.
17. It is generally agreed, even among professionals that very little is known about mental illness. For this reason we have to push for more research. We have found that speakers on research and alternative treatment modalities have drawn the largest crowds at our local meetings.
18. Remember, the good and survival of the Organization must take precedence over individuals' wishes and goals. Without organization, none of us or the people we are trying to help have much hope.
19. Remember the basic formula to effect change; Be well organized, strong, knowledgeable, credible, highly visible, very vocal and very determined.

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