About TBI Support Groups
April 2003

The responses below were provided via the Federal TBI Program's TBISERVE listserv participants, and those on the Brain Injury Association of America's StarWB Yahoo Group.

Original Question:
The Brain Injury Association of Virginia is interested to learn what techniques and strategies other states have found effective in sustaining support groups?

Brain Injury Association of Virginia

RESPONSES

From: AZ Governor's Council member

In response to your question about sustaining TBI support groups. As a facilitator and group leader in Arizona, some things that I found useful:

1. A trained facilitator and co facilitators who are able to lead focused group discussions has been beneficial to my group. A facilitator can insure that all participants are heard and encourages participation from members who have difficulty in communication. He/She can also lead the discussion within the time lines and structure of the group. Since many of our participants may have communication impairments, behavioral challenges or may be physically compromised, we are especially trained in providing sensitive redirection and cuing when necessary while honoring the special needs of each member. Using co facilitation also lessens the burden of coordination.

1. A monthly communication via direct mail, fax, e mail which provides the necessary details of the group as well as featured topics or guest speakers provides a consistent message each month.

2. Assist in directing the group in being self directed. At each meeting we ask for input and suggestions or recommendations to meet the needs of the members. As a facilitator, I will seek out experts in the field who can answer the difficult questions.

3. We have joint family and survivor meetings as well as individual family and survivor meetings. The special needs of each group are better served.

4. As the facilitator, I encourage interested parties to contact me to discuss the nature of the group and personally invite them to attend. Each new person is whole heartedly welcomed and attended to personally by group leaders. This lessens the fear of joining a group that is cohesive and "knows each other's stories".

5. When there is resistance to coming to the group, I discuss concerns personally with that member. I encourage them to share since they are also helping the other members of the group through their experiences. I try to reinforce how much everyone is needed and valued.

6. Refreshments provide an informal and comfortable environment.

7. A group member (volunteer) personally contacts each member on the list to remind them of the meeting. Those we have not seen in a while are contacted for a status update and to remind them that they are missed.

   I would be happy to discuss additional ideas as well. Thank you for giving me the opportunity to share.

From: Florida

Have them contact Brain Injury Association of Florida at 954.786.2400. One of the ways they have developed is through a monthly newsletter.

From: BIA of Georgia

We have been pretty successful here. We now have 32 successful groups in the state, including 3 that have started in the past 6 months.

The secret to success, very simply, is leadership. We have one group that is having trouble right now and the reason is that the founder/leader has health problems and cannot find anyone willing to take on the responsibility.

While most of our groups are led by a family member or caregiver, some (including some of the most successful) are led by individuals who are professionals in the field. In particular, one hospital in Atlanta and a rehab hospital in Augusta pay individuals on staff to coordinate the support group activities. This institutional support seems to lend a stability that we don't always see in some of the more rural groups where the leader is a caregiver.

Hope this helps.

From: Idaho

Our Support Group has been very successful. We meet once per month from 7-9 PM. From 7-8 we have a speaker. The topics that are most popular are usually related to long-term adjustment issues. This has served a dual purpose because family members who are paid by Medicaid can use this as their educational requirements. Then from 8-9 we have "Support Groups" for people with brain injury and for family members/significant others. Members either build on the topic of the evening or discuss what ever is on their minds. Both groups are facilitated by professionals, but we definitely use a Support vs. Therapy model. We have discovered over the years that it works well for a professional to organize the group because sometimes people with brain injury or family members become overwhelmed with their life situations and have difficulty with all the details associated with the group. We seek active participation from the members in terms of topics for speakers and social opportunities they would like. Three times a year we have parties, a picnic, a Holiday party, and a bowling/pizza party. I solicit local physicians for donations to cover the cost of the parties so they are free to all members. We typically have 40-50 people in attendance and at the Holiday party usually a 100. Good luck, it does take work!

From: Family Support Brain Injury Assoc. of New Jersey

We have 20 affiliated support groups around the state that are all run by professionals who volunteer their time. Some of the groups take place in facilities and

some take place in the community (one takes place in a park's activity center). All of the groups take place in the evening. We have a Family Support program that provides care coordination to individuals who need more one-on-one assistance accessing resources and services. Our Family Support Specialists act as the support group liaison for each group that is in the counties they serve. They go out to the groups twice a year, and bring our publications, discuss the services our association provides, and monitor how the group is doing. They also remain in contact with the leaders throughout the year, to answer questions they might have, help them find speakers, etc.

Once a year, we have a support group leader meeting that allows the leaders to meet with one another and get some training. We just started this two years ago, and the leaders seem to really appreciate it. We also evaluate the leaders and the group attendees once a year. Last year, we distributed evaluations at the meetings, but this year we mailed them out to each of the group's mailing lists. The support group leader evaluations help us to plan the annual meeting for leaders, and the evaluations of the attendees give us an idea of how the group is doing and what would make the groups better. We share the evaluations from each group with the leaders.

In order to help with attracting new people to the groups we post the support group info on our website, list it in our newsletter, put a listing in every info packet we send out, and give the info to our callers. We also recently made a flyer for each group and send it out to our mailing lists for individuals in their area if their attendance starts to drop. We are also making media lists for the groups so they know the local media contacts that can post info about their group.

We also provide the group leaders with monthly mailings that provide new info on resources and services that might be of interest to group attendees, and they share the info in these mailings with their group's every month.

We are also working on building a speaker's bureau for the groups, since many attendees expressed an interest in having speakers come out and discuss various topics through the evaluations we have done.

Sustaining support groups is an ongoing effort, and we find that the annual meeting, bi-annual visits, mailings, outreach efforts, and evaluations all help to keep the groups going.

From: North Dakota

North Dakota has some problems with retention, too. Fargo is really good at setting up a yearly schedule of speakers, so their turnout is really pretty good. The topics are based on assessed need of group members. They have a good turn out that is mainly self-driven.

Secondly, we are looking for resources for two families each with three young children. Anyone have any books, material, etc. to recommend for family to use with kids to help explain their mothers' brain injury and how she may have changed even though she looks the same? Kids range in age 3-12.

From: North Carolina?

[Lash and Associates Publishing has a few products that may be helpful for these two families:

1. When a Parent has a Brain Injury: Sons and Daughters Speak Out
2. ELVIN The Elephant Who Forgets

More information on these products is available at <http://www.lapublishing.com/BooksOnBrainInjury.htm#TBIchildren Books>.]

From: Pennsylvania Support Group

Our group has been together since 1989 and I have been xxxxx for the last 8 yrs. I have a open meeting every other month and some times break the group up into care givers and survivors. Plus I have speakers that the group wants to hear from. I found that most people just want information about where to go & who to see for there loved ones. We also have a picnic in Aug. which draws a lot of people. Hope this will help?

From: Brain Injury Association of Wyoming

In order to increase attendance we did the following things: In October we had zero attendees for the meeting. We sent a written notice to all of our mailing list each month for three months before we started to have a few people show up. Then we mailed notices and meeting schedules to organizations and medical programs/ facilities/doctors who work with brain injury survivors. We got several new referrals to the group. At the start of our first meeting with 5 or more people, we discussed what each person would like to get out of the group, and then I did research and provided written materials on those topics at the following group, at which we had a guest speaker. The guest speaker was very popular, and we still had a short time for informal discussion at the end of the meeting. This last month we again sent out written reminders and told people what the topic would be, who the guest speaker would be, and that we would provide refreshments. We had 20 people this month! We are now looking at whether to split the group into two; one for survivors and one for family members. :)