

♥ NHFV, Parents Supporting Parents

Organizing and Maintaining Support Groups



NH Family Voices

New Hampshire Family Voices (NHFV) provides information and support to families of children and youth with special health care needs (CYSHCN) and the professionals who serve them via: individualized assistance, training, focus groups, conferences, resource guides, newsletter, lending library, and website. NHFV provides and facilitates the voice of families through partnerships and collaboration.

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Organizing and Maintaining Support Groups

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Introduction

What are Parent Support Groups?

When a family faces a diagnosis of a chronic health condition, a developmental, physical or behavioral challenge, it may produce a sense of loss, fear, anger isolation, and/or frustration. These feelings may seem strange and frightening. Many stressors may appear in their lives. Stressors such as:

- ♦ Intellectual - having to master massive amounts of new and complex information;
- ♦ Practical - finding solutions for the day-to-day problems of arranging personal and family life around a child's condition or challenges;
- ♦ Interpersonal - new relationships and adapting as old ones are disrupted;
- ♦ Emotional - the war we rage inside ourselves over fear, frustration, doubt, love and truth.

These challenges also present parents with an opportunity to respond with solutions, assistance and interventions which will meet the needs of their child and family, the needs of other parents/families, and the needs of the community serving their families. One of the most effective responses in providing support and developing coping skills, has been the creation of parent support groups. Parents raising children with special challenges often have special concerns. A parent support group is generally a group of other parents who share this experience and meet on a regular basis. Parent groups can serve many purposes, but primarily they offer parents a means to meet other families with similar needs, share information, and personal experiences with the goal of supporting each other and their children.

How Can a Support Group be Helpful to Me?

An important function of nearly all parent groups is to introduce parents to others like themselves. When families with similar concerns meet, there is a sense of community, of understanding. You create a place where you can laugh about the same things, where you can discuss the same problems, where you can help each other. By creating a social network of friendships and activities, parents provide non-threatening, supportive settings where families relax and have fun and where their child's illness or disability is not perceived as a stigma.

Parent groups vary on the basis of what binds them together. There are groups of parents whose children all have the same chronic health, developmental, behavioral or physical disability. There are groups whose members all live in the same geographical area or who want to learn more about educating their children.

When choosing a group ask yourself, what kind of a "joiner" are you? Are you more comfortable with formal organizations, or do you prefer less structure?



Join a Group/Start a Group

When exploring parent groups, it is helpful to review your personal needs. Are you looking for moral support or advocacy training? Do you just want to get to know other families who have a child like yours? Are you looking for a play group for your child or interested in hearing speakers on topics relating to your child's well being and services that interest you? Statewide parent organizations will very often be able to assist you in finding a group or assist you in identifying resources in your area.

Many times there will be no local group available to meet your family's needs and you might be someone who has identified a need and is willing to begin a group. Support groups can be relaxed gatherings of parents and be held in someone's living room or organized outreach to a number of families. This handbook identifies a more structured approach to starting a group.

Before you put time and effort into creating a group, speak to people in your community about the need that might be going unmet. Speak to therapists, educators, physicians, people who come in contact with other families struggling with the same concerns or needs as you.

Do you know other families facing the same challenges? Talk to them and find out what they expect of a support group. Talk about possible ideas (e.g. monthly, evenings, daytime, useful resources, interest levels, etc.). Is someone willing to join you in this endeavor of starting a group? Consider contacting the organizers of other support groups and find out how they run their group.

Affiliated with an Existing Group or Organization

There are basically two ways for families to start a parent group. You can either affiliate with an existing organization or you can start a new group. After you have answered the questions above, look to see if your goals and needs match with an existing organization. For example, if your goal is to provide support for families having children with behavioral needs, you might want to affiliate with NAMI NH and draw upon their expertise. If you have identified your group's goals to provide mutual support by getting families to talk, then you might find it beneficial to affiliate with NH Parent-To-Parent or perhaps you are looking to increase your skills and knowledge in advocacy where an organization such as NH ABLE would be helpful.

If you find an organization whose goals and activities are similar to what you would like to do, contact them and ask about affiliating with them. Talk to them about assistance they can offer in setting up your group and letting other families know about it. Do they offer materials, speakers, or other forms of help? Will they expect specific things from your group?



Developing a Support Group

Joining Forces

Once you have identified the needs your group will address you need to assemble a team to help with setting it up and maintaining it. One person can do it all if they have the time and motivation, but being able to share the workload and responsibility will make the endeavor that much easier and more fun. So, how many people do you need to run a group? There is no minimum number but consider the steps identified in planning and how many it would take to share the load.

Identifying Skills and Assets

Once you have organized a team and you have a good sense of your goals for a support group, you can identify the skills your team members can contribute to a smooth running group. At the back of this booklet is a suggested Team Roles worksheet that you might find helpful in identifying support group needs and team member tasks.

Not only do your team members bring skills and talent to the group, they may also have tangible assets which they may be willing to use or share. For example they may have a computer, printer, fax, camera, or coffee urn.

Planning

Now that you have identified your collective core skills and assets you need to work out exactly what you are going to do. A good way of doing this is to have a 'brainstorming' meeting with your team. Get together and create an action plan. You may want to develop a mission statement and perhaps define group guidelines.

Think about the support you wish to provide and what you can realistically manage. To promote your group you may decide to produce a flyer or information sheet. Identify key places in your community to put flyers (library, school, churches, town hall). The Support and Services Worksheet can assist you with a list of options you can work through and consider. With this you can create your action plan.

If you decide to form a relationship with a statewide organization, that organization will let the group know what services it provides and what obligations it requires. It may expect a community group to do some or all of the activities below, so plan *who* and *how* the support group will work with the statewide organization.

- Keep it informed about group activities;
- Keep it informed of membership names and addresses, with regular updates of additions, deletions, and corrections;
- Notify it about changes in leadership;
- Participate in its surveys of needs of children/families;
- Be familiar enough with its goals and activities so group members can represent it locally.

Creating a Name/Logo

Your "brainstorming" meeting can also provide a great opportunity to discuss possible names for your group. Do you want a name that clearly identifies the group's purpose? Or do you want a name which will identify a specific diagnosis (i.e. Autism Support, Epilepsy Support). The name you choose for your group is very important because it will help create an "identity" for the group and invite others to join.



Designing a logo for your group is not essential, but as with the name it helps create a recognizable 'identity' for your group.

Privacy & Confidentiality

A support group provides a safe environment for members to share their experiences, hopes, fears and joys. Group members may share personal and intimate details during meetings or conversations. While planning your first meeting think of a privacy statement that will convey to all members the importance of maintaining confidentiality. Below is a sample Statement.

'Your privacy and confidentiality will be respected at all times. Information shared within the group meetings will remain confidential. Private contact information is collected for the purpose of distributing information only.'

Getting the Word Out

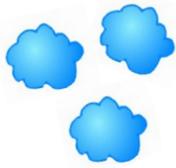
An essential key to making your group a success is marketing and promoting. Knowing where you can best reach your potential members, what kind of media they are most likely to access (i.e. newsletters, flyers, newspapers). What community organizations are likely to pass on information about your group? Is there someone within your school district who would be willing to help you?

Funding

Activities such as flyers, usually require financial backing. A new group may want to pool donations from members to sustain a small budget, or look for sponsorship from a local business, or organization in the community. The group may want to think of how they can get direct donations-in-kind such as a printer that will print flyers for free. Perhaps a support agency will mail the groups materials to families.

Don't overlook fundraising like having bake or yard sales, this can be an excellent means to publicity. A fundraising activity should be viewed as an opportunity to spread the word about the group and about the children's conditions and needs of children and families.

Groups have raised money to cover: printing and mailing costs, handbooks, resource guides, transportation assistance, and grants for personal equipment. The Supports and Services Worksheet will help guide your ambitions.



Ready To Get Started

You've investigated, discussed and planned, and set goals now its time to create the action plan.

Meeting Space

Think carefully about a meeting place. A sponsoring agency may supply a meeting room. Some groups, however prefer to meet in more neutral places, such as community centers, churches, libraries or private homes. Pick a setting that is within easy distance for most members and has adequate parking. Think about accessibility for someone attending in a wheelchair.

Some groups provide babysitting or a supervised activity for children in another part of the building during the meeting. (Your meeting space would need to accommodate this.) Consider utilizing organizations such as the Girl Scouts or 4H'ers to assist with children's activities. They are very often looking for community services.

Think about comfort when picking a meeting space. Try to provide a pleasant atmosphere. If there will be refreshments at the meeting, will there be equipment and utilities to support this?

Meeting Schedule/Calendar

Once you get established you may want to plan your meeting schedule for several months in advance, or set up a regular date and time for meetings. Publish the meeting dates well in advance so parents can plan ahead. When advertising your meetings remember to include necessary details such as date, start time, duration of meetings, contact person, location, directions and best car parking/transportation options. Having a designated contact person for meeting inquires who is easily contactable by email/or phone makes your group more accessible to potential new members.

Meeting Agenda/First Meeting

You can create a planned agenda for your meetings or keep them completely casual. What format is used should be decided by the group leaders taking into consideration the needs of group members.

An example of a planned meeting agenda follows:

- ♦ **Welcome** - group leader starts the meeting by introducing him/herself and welcoming everyone to the meeting. Introduce planning team.
- ♦ **About the Group** - It's a good idea to briefly go over how the group was formed and its purpose. You may want to outline what will usually happen at, and after meetings (i.e. socializing, speakers etc.) If you have created a mission statement this would also be the time to present it to the group.
- ♦ **Privacy and confidentiality** - You will want to bring this up periodically to reassure new members and as a reminder to others.

Meeting Agenda/First Meeting..... continued from 9

- ♦ **Agenda** - Go through the items on your agenda. Don't rush, but keep the meeting moving.
- ♦ **Topic of Interest/Speaker** - If you have a set topic for discussion inform the group what it is and whether it will be an informal discussion or information sharing (i.e. presentation or resource exchange)
- ♦ **Guest Speaker** - If you have a guest speaker introduce them in a warm friendly manner outlining their area of expertise and the topic of their talk. Always allow time for questions after a talk.
- ♦ **Next Meeting** - Ask for suggestions for topics group members would like to discuss or learn about. Encourage feedback on the current (and previous) meeting. Remind the group when and where the next meeting will be held.
- ♦ **Socializing** - Allow time for socializing and discussion. It's important for members to be able to talk to one another. It is also important not to let this aspect 'take over' the meeting, if other items are on the agenda.

Here are some suggestions to help your first meeting be successful.



- * Get there early and be sure everything is set up as you want it.
- * Be sure to put signs on the door, if needed, directing people to the meeting room.
- * Have a guest list for people to sign as they arrive. It is always helpful to have a mailing list of potential members. You may want to add one or two identifiers to the list, such as age of child, school child attends, disability of child, or whatever information may be useful in selecting future activities. You may want to assure guests that this is confidential and for informational purposes only, not for volunteering to do anything.
- * Provide name tags. Guest may not know each other. There are many ways to personalize name tags. Guest could be asked to include information about their child or occupation. For example, "Terry Jones, Jim's mom".
- * For your first meeting you may want to take a few minutes to have each person introduce themselves, tell something about their child, and what supports they need.
- * End on time, staying respectful of peoples time and commitments.
- * Having some resources to share could benefit those attending the meeting. You might like to consider getting newsletters, information brochures, or resource lists to share.

Social Functions

Support group meetings and support group social functions are two different things. Support groups benefit from providing separate social functions that allow members the opportunity to interact in a more relaxed atmosphere. Some support groups have a potluck every couple of months and bring their children with them. It is important to clearly identify which type of meeting or function you are holding. A social function can be disappointing to a member who is expecting a more structured meeting.

Maintaining A Support Group

Record Keeping

What is the current or potential size of your group? How formal or informal is your approach to running the group? Here are some suggested types of records to keep and why:

- ♦ Member contact information - important for maintaining contact and dissemination of information. Respect the fact that some support group members may not want to give contact information, explaining why you are keeping it will help families feel more open.
- ♦ Media contact information - it can be helpful when promoting your group to media sources to have contact information for the specific person with whom you've worked.
- ♦ Meeting minutes and/or agendas - this can be a brief outline of the topics discussed and the results of the discussion, or more formal meeting minutes if preferred.
- ♦ Promotional Materials - flyers, newsletters, copies of these types of materials are good to keep on file. These can be very helpful to new members joining the organizing team in familiarizing themselves with the group's history.
- ♦ Funds - you will need to keep accurate records of any funds you receive and spend.
- ♦ Correspondence - keep a copy of all incoming and outgoing correspondence and e-mails, i.e. request for information, sponsorship agreements, thank-you letters etc.

Importance of Feedback

Groups are made up of members who have distinct ideas of what's interesting, needed, and convenient. Find opportunities for discussions with members about how their needs are being met or if the group needs to go in another direction. Keeping communications open, eliciting new ideas and participation will help keep your group fresh and alive. See the suggested feedback form.

Conflict Resolution

Groups need to be aware that conflicts may arise from time to time. As new members join with new ideas other members may not be willing to change their focus. Changing membership can create new goals or priorities for the group and unintentionally cause tension.

Openness, understanding and the ability to clarify will help defuse such conflicts before they arise. Each member needs to feel they are a useful part of the group and to be able to adjust to alternatives without giving up their personal needs. Open dialogue with all members will keep conflicts to a minimum.



Ongoing commitment

Families join parent groups to end the sense of isolation their unique situation can create. The nature of support groups is they have the potential to die away. When you have successfully created your support group with meetings and functions occurring on a regular basis, you may be tempted to sit back and relax. Continued success of the group will still require effort and commitment.

Recognize that parent's change as their child and their condition changes. Parents may find they have different needs as they grow in their ability to cope and as they encounter new concerns. They may leave to seek different forms of involvement and support. Groups who are aware and acknowledge such changes have a better chance of surviving.

Don't confuse effectiveness with number of participants. With continuing outreach to new families the substance of the support group will survive. Maintain your media contacts, stay in touch with your network of organizations and community ties. Most importantly be aware of your own and team members needs and limitations. The more outlets for action a group provides, the more members will feel useful and have a sense of ownership and vested interest in the group's continuance.

Support and Motivation

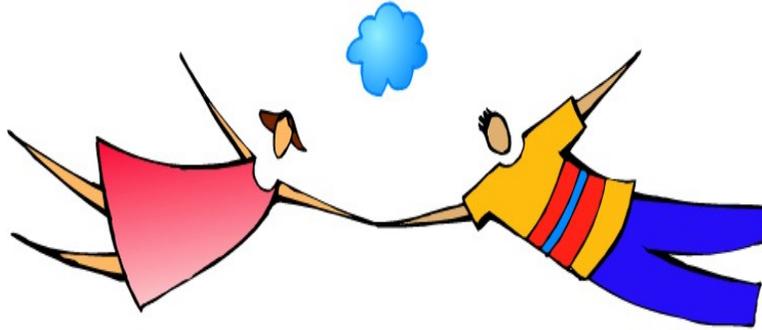
Support groups are obviously about supporting the members, but focusing on this aspect can make it easy to forget that the organizers also need support. Having a team of people sharing the responsibilities can be a source of mutual support. Connections with state organizations, other parent leaders and community initiatives will help expand the network for personal support and growth. Many statewide organizations offer training opportunities that can be both supportive in nature as well as sources for new information to bring back to the group.

Connections with other support group leaders can be a viable support and source of motivation. When things don't go well or as planned, having someone to talk with through a rough time and to creatively seek solutions will be invaluable.

Cultural Awareness

Honoring the cultures of families maintains a safe, supportive environment where parents feel welcome. There may be families in your community who are not fluent in English, who have children with special needs that may be interested in a support group. Look to community organizations that work with diverse families and talk to them about ways you can reach out and include their families in your support group. Look for state organizations that can assist with resources such as translated materials, interpreters and technical assistance in supporting families from diverse backgrounds.

Worksheets





Worksheet for Team Roles

Name _____ Phone _____

Address _____ Cell: _____

_____ Email: _____

- ◆ Consider the following areas of responsibility and tasks. Check off areas you would like to participate in and areas where you may have some experience or skill.

Leadership	Administration	Marketing	Support
<input type="checkbox"/> Facilitate / run support group meetings <input type="checkbox"/> Assist facilitating support group <input type="checkbox"/> Find speakers for meetings <input type="checkbox"/> Seek out activity ideas <input type="checkbox"/> Liaison with state organization	<input type="checkbox"/> Find meeting space <input type="checkbox"/> Maintain mailing list <input type="checkbox"/> Schedule meetings <input type="checkbox"/> Phone inquires <input type="checkbox"/> Email inquires	<input type="checkbox"/> Graphic/desktop publishing (flyers etc.) <input type="checkbox"/> Writing - such as articles, newspaper notices <input type="checkbox"/> Willing to help get the word out that the support group exists.	<input type="checkbox"/> Phone time with parents <input type="checkbox"/> Face-to-Face, one on one with parents

Other suggestions, comments, information?



Supports and Services Worksheet

Group Name _____

Leader _____

- ♦ Consider using this form to get team members suggestions and preferences. It will also assist the team in making decisions and prioritizing activities.

Support	Print Resources	Online Resources	Projected Expenses
<input type="checkbox"/> Support meetings <ul style="list-style-type: none"> <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Bi-monthly <input type="checkbox"/> Social Functions <ul style="list-style-type: none"> <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Bi-monthly <input type="checkbox"/> Guest Speakers <input type="checkbox"/> Handouts <input type="checkbox"/> Presentation <input type="checkbox"/> Phone/Inquiry Line <input type="checkbox"/> Other suggestions:	<input type="checkbox"/> Group Info Sheet <input type="checkbox"/> Contact Cards <input type="checkbox"/> Flyer <input type="checkbox"/> Poster <input type="checkbox"/> Newsletter <ul style="list-style-type: none"> <input type="checkbox"/> Monthly <input type="checkbox"/> Bi-Monthly <input type="checkbox"/> Quarterly <input type="checkbox"/> Other suggestions:	<input type="checkbox"/> Web page (one page only) <input type="checkbox"/> Website (multiple pages) <input type="checkbox"/> Bulletin Board <input type="checkbox"/> List-serv <input type="checkbox"/> Other suggestions:	Support Meetings: _____ Social Functions: _____ Phone: _____ Print Resources: _____ Web Activities: _____ Other: _____

Other suggestions, comments, information?



Action Plan Worksheet

Group Name _____

Leader _____

★ Activity or Goal:

Action Required:

Person Responsible:

Resources Needed:

Date for Completion:

Outcomes:

Lessons Learned:

★ Activity or Goal:

Action Required:

Person Responsible:

Resources Needed:

Date for Completion:

Outcomes:

Lessons Learned:

★ Activity or Goal:

Action Required:

Person Responsible:

Resources Needed:

Date for Completion:

Outcomes:

Lessons Learned:

Feedback Form

Group Name _____

Your Name (optional) _____

* How long have you been attending the support group meetings?

* Do you feel the support group provides a safe environment to talk about your child & concerns?

* Are the topics offered at meetings helpful?

* Are you satisfied with the frequency of meetings?

* Is the meeting location and facilities suitable?

* Are you comfortable with the group leaders/facilitators?

* Do you enjoy the guest speakers (if provided)?

* Have you provided support to others as well as received support?

* Do you have any suggestions to improve group meetings?

* Would you like to participate or contribute to the running of the group in any way?

* Do you have any additional suggestions or comments?

On Line Resources

★ Forums/Listserv

- **Google** [http:// groups.google.com](http://groups.google.com)
- **Yahoo** <http://groups.yahoo.com>
- **MSN** <http://groups.msn.com>

★ Blog Providers

- **Blogger** <https://www.blogger.com>
- **Blogger Team** <http://www.bloggerteam.com/login.php>
- **Word Press** <http://wordpress.com>

★ Free web services

- **Geocities** <http://geocities.yahoo.com>
- **Tripod** <http://www.tripod.lycos.com>
- **Angelfire** <http://angelfire.lycos.com>
- **50 Megs** <http://www.50megs.com>

★ Free Business Cards

- **Vistaprint** <http://www.vistaprint.com>
- **DCP** <http://www.dcp-print.com>



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