



STARTING A FAMILY SUPPORT
GROUP:
A FAMILY TO FAMILY RESOURCE

*...because few things are stronger or more
supportive than family*

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STARTING A FAMILY SUPPORT GROUP: A FAMILY TO FAMILY RESOURCE

Families of children with special needs often want and need to connect with other families in similar situations for information, resources and support. Support groups can provide:

- Mutually needed information
- Emotional support
- A sense of community
- Understanding
- A place to laugh about the same things
- A place to talk about problems and help each other.

More and more families are meeting together in support groups across the state; however, many families are still seeking a group to join. This resource is a guide for anyone who is considering starting a group in his/her community. A great deal of information, helpful tips, and quotes from successful group leaders are included in this pamphlet. Our hope is that it will aid families in forming successful support groups.



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WHAT SUPPORT GROUPS CAN DO

Support groups are run by and for its members to provide support, information and resources. Not every group is a perfect fit for every individual, but once you find a group in which you feel comfortable, support groups can:

- Provide a safe, non-judgmental, and confidential outlet for sharing with peers who have gone through similar experiences.
- Enable individuals to recognize that they are not alone.
- Provide evidence that it is possible to feel better about dealing or coping with disabilities, and to develop positive attitudes about the future.
- Provide the opportunity for members to help each other through the sharing of knowledge and experiences.
- Provide ideas and avenues wherein members can begin to regain some control over their lives.
- Offer resources, speakers, information, and literature not readily available outside of the group.
- Provide the opportunity for the formation of new support relationships which may exist outside of the group framework.



ARE YOU SURE YOU WANT TO START A SUPPORT GROUP?

- **Are you personally ready to be a support group leader?**
 - You will be viewed as a role model by other parents joining the group. While you don't have to be an expert on disability issues, you should be prepared to network and develop a "nose" for resources in your community because people will be turning to you.
 - If you plan to be the facilitator, you will have to be prepared to defer to other group members; so if you have a strong need to share your own story/experiences, you may want to choose someone else to be the group facilitator.
- **Do you have time to devote to a group and its administration? Running a support group is a lot of work!**
 - Do you have 2-3 people who might be willing to help you? If not, consider asking professionals working with your child if they know other parents who might be interested.
 - Are you flexible enough to share control of the group with other parents?
- **Are you okay with receiving little or no personal recognition for your work?**
- **Is your family supportive of your plans?**
- **Are you flexible enough to let other members work through their own problems without giving advice/suggestions? If not, you can still start a group; just find someone else to be your facilitator!**

WHERE DO I BEGIN?

- **Decide who your target audience is.** Who can attend the meetings? (e.g., parents of children with autism versus parents of children with any disability)
- **Get an idea of how many people in your community and Cluster LPCC are interested in attending a support group.** Talk to other parents, professionals, First Steps providers, school personnel.
- **Check to see if another support group already exists in your community.**
 - Order ASK's support group directory which lists support groups across Indiana. Call 1-800-964-4746 or check "Resource Directory" on their website at <http://www.aboutspecialkids.org/>
 - Check community, neighborhood, or metropolitan sections of your newspaper for support group announcements
 - Check with First Steps providers, area preschools, and/or special education staff at local schools
- **If you find another group, talk to the leader.**
 - Does the group serve the same target audience (e.g., parents of children with Down syndrome)? What are its goals? If the existing group has the same target audience and goals, either band together or try to schedule meetings at different times; support groups should not compete!
 - If the group has a different target audience or different goals (e.g., the existing group is for parents of children with Down syndrome and you want to start a group for parents of children with autism or the existing group is mainly educational and you want to form a group with a social focus), ask the leader about useful tips for running a support group in your area.

- **Make a goal statement outlining the mission for your group.** Is your goal primarily educational or do you mainly want parents to meet and form friendships? This will influence which group format you choose. Let members express ideas about goals and be flexible—goals may change over time.
- **Decide what kind of group you want to have** (see page 3).
- **Determine frequency and location of meetings** (see page 3).
- **Decide how you will get the word out** (see page 5).
- **Choose a name for your group**—try to choose a name that explains what you do and where you do it (e.g., Bloomington Cerebral Palsy Support Group).
- **Set up phone numbers and contact names.**
- **If you want your group to have an educational component, begin to make a list of speakers, topics, consultants, etc.**
- **Think about issues like childcare and transportation.** Will you provide these? How can you utilize professionals and agencies/organizations in the community to help you? Consider asking parents about their needs before you decide.
- **Develop forms that you will need** (e.g., contact sheets, member profile cards to record caller data). See example forms at <http://www.mhselfhelp.org>.
- **Attend trainings** (e.g., ASK, INSOURCE, Family to Family), subscribe to newsletters, and familiarize yourself with resources. Learn about the Family Involvement Fund at <http://www.inf2f.org>.



TYPES OF GROUPS

You've written a goal statement. Now you need to decide which group format will best accomplish what you want to do. Below are some common types of support group formats. Feel free to mix and match depending on your goals!

Peer Support Groups: These groups are led by parents of children with disabilities and are focused on providing emotional support to its members. They may or may not include an educational component.

Discussion Groups: These groups have an educational emphasis and are not necessarily focused on personal support. They may show videos, have speakers, or discussion topics for each meeting.

On-going Groups: Most parent-led support groups are on-going. These groups meet regularly throughout the year, have no set curriculum, and accept new members at any time. These groups are more flexible than time-limited groups in that they can alternate between just support and educational/support meetings and members can take a more active role in the direction of the group.

Professionally-Led Support Groups: These groups are led by professionals like a psychologist, social worker or counselor.

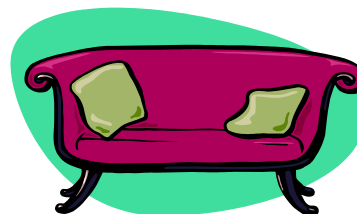
Time-limited Groups: These groups are often run by professionals and meet within a set time frame, have a definite curriculum, and are closed to new members after the initial meeting. These groups are very structured and always include an educational component to meetings. They have specific goals and a sense of urgency about group's tasks due to the limited time. They are often gateways to ongoing support groups.

LOCATION

- **Poll a few parents/professionals to get some ideas.**
- **Find a building that is accessible** and easy to reach by public transportation.
- **Decide on a central location.**
- **Try to find a neutral location** where everyone will be comfortable (e.g., Don't meet at a hospital; some parents might not feel comfortable there).
- **If you want to provide childcare,** try to find a place with an extra room for that purpose.
- **Try to get a long-term commitment** from the facility.

"Try to set the same location and same day of the month for one whole year. You can't bounce around dates or locations or people won't attend." —Support group leader

- **Possible locations:**
 - Churches
 - Elementary school gymnasiums
 - YMCA/YWCA clubs
 - Service clubs/organizations (e.g., Lions and Elks Clubs)
 - Colleges/Universities
 - Library community rooms
 - Social service organization conference rooms
 - Volunteer fire stations
 - City recreation centers
 - Private homes
- **Be sure to leave the room spotless!** Always be aware of your image in the community.



FUNDING



Your need for funding will depend on the size and scope of your group. Usually groups spend money on items such as printing newsletters, fliers, postage, hiring special speakers, renting facilities, and paying for childcare. Bigger groups may subsidize social events, group outings, etc.

Ways to Save:

- **Arrange to meet in a free space** (e.g., most of the suggestions made on the previous page would be rent-free).
- **Find free childcare** (e.g., spouses of group members, college student volunteers, high school service teams, 4H, girl scouts, church organizations).

"Support from our First Steps program is what got our group going. First Steps personnel even provided free childcare for our first few meetings!"—Support group leader

- **Network with hospitals, doctors' offices, your local school district or your local SPOE office to help with the cost of mailings/copies.**

"Don't incur a lot of out-of-pocket expense yourself; it can get very expensive if you make 25 page handout copies for 40 people to attend each month."—Support group leader

- **Ask for other donations** (e.g., ask grocery stores to donate food for meetings). Try hand-delivering a letter describing your organization and how the store's assistance will help you improve the community.

- **Apply for a small grant.** Some groups look for money from outside sources to sustain the group and allow it to grow. Applying for grants from outside organizations may sound daunting; here are some suggestions to get you started:

—All communities have a community foundation. These foundations can be great sources of grant money. They give mainly to nonprofit organizations but usually have some money earmarked for other groups that aren't nonprofit. Contact your local community foundation to ask about grant money (if you have trouble finding the foundation, contact your Chamber of Commerce).

"Many more doors open up if you become a nonprofit organization. Particularly if you are trying to start something more than just a monthly meeting, that is the way to go. It only costs \$10 to file."—Support group leader

—Check into the grant writing and fundraising trainings offered by the Indiana Youth Institute. Check out the grants writing section on their website (<http://www.iyi.org>).

—Explore the following websites for more information about grant writing:

—<http://www.guidestar.org>

—<http://www.npguides.org>

—<http://www.inrn.org>

—<http://www.foundationcenter.org>

—<http://www.publicwelfare.org>

—<http://www.not-for-profit.org>



PUBLICITY



Now that you have laid the groundwork for your support group, you need to get the word out to your target audience. After all, the most beautifully-planned support group won't get off the ground if people don't attend! Here are some tips:

- **Make a list (name, address, phone number, email address) of people/ organizations that you want to contact about your group**, such as: public library, community center, bulletin boards, pediatricians' offices, hospitals (pediatric units, NICUs), grocery stores, children's therapy clinics, special education departments, bagel shops, birth centers, etc.
- **Deliver fliers to these people/ organizations in person.** If you can't go in person, do a mailing and then follow-up with a phone call. Fliers should be eye-catching and brief—just date, location, time, and a brief description of the group. Tear-off tabs along the bottom of the flier are helpful. Note: You will need to send fliers often; this is not just a one-time task!
- **Most newspapers have a free "Calendar of Events" listing.** In addition, figure out who writes the human interest stories for your newspaper and contact that person regarding a press release for your group. Maybe s/he will write an article too!
- **Most radio stations and local cable channels do public service announcements (PSAs).** Look for high school radio and TV programs and community interview shows.
- **Try www.congress.org.** Click on "Media Guide" at the very bottom, and then enter your zip code. All the media sources (newspaper, TV, radio) in that area will come up. Then you can click on up to five and email a press release.

- **Make sure that the phone number you put on the fliers and in the press releases is working!** Unanswered phone lines or unreturned phone calls/emails will hurt your chances.
- **Register your group with About Special Kids (ASK).** They have a support group directory for the state that they often use to refer callers to local groups.
- **Consider creating a brochure** for new or potential members.
- **Consider creating rolodex cards or business cards** to give to professionals/ referral sources.

"I printed my own business cards and refer people to them when they want phone numbers and information when I am out and about, at conferences, trainings, grocery stores, therapy, etc."—Support group leader
- **Consider creating a webpage for your group.** Some groups even decide to primarily "meet" online using a listserv. This appeals to some parents and not to others. At the least, the web provides another source of publicity and can answer basic questions about the group. To see an example of an Indiana support group webpage, visit www.fuseinc.org.

"The web has been a big part of our success. Express Page offers free, easy-to-use space. Or, for wider options, execute a Google (<http://www.google.com>) search for other free hosts."—Support group leader



SUPPORT GROUP STAFF

"To get started it only takes one with a lot of energy."—Support group board member

Don't hesitate to start small. If you can find one other person to co-chair the group, that will give you backup and support and someone to fill in if you have to be absent. If you need to, however, you can start a group all by yourself. You can always expand and grow as it is comfortable to do so. The information below is designed to give you an idea of the organization and time it takes to run a large support group over a period of time.

In general, for a group to run smoothly, there are three main areas that need to be covered. Ideally, for a bigger group, three different parents might take on these areas:

Administrator: Handle all nonmember contacts, keep books/records, contact speakers, arrange meeting schedules, prepare news releases and announcements and keep track of funds.

Facilitator: Greet members as they arrive, introduce them to other members, model acceptable group behaviors, establish ground rules and agenda for meeting, defer to other members, make sensitive and well-timed remarks to draw members out and be alert to each member's involvement or lack thereof.

Manager: Keep records of date/time/attendance at meetings, keep profile cards on each member, telephone new and prospective members when appropriate, help facilitators set up meeting room and refreshments, attend each meeting and aid in group networking.

Don't forget your most important resource—your members! Getting members involved (bringing refreshments, choosing a book to discuss, etc.) will increase their commitment.

TIME MANAGEMENT



- Consider having planned times for talking with folks ("office hours").
- Get an answering machine and screen calls.
- Since there are questions you'll hear frequently, have your answers for those questions prepared ahead of time. Build a facts notebook (more efficient than reformulating your answer each time). Or post this information on your webpage.
- Share the load—if you've been doing this by yourself, try to identify 1-2 other group members who might be willing to share leadership with you; delegate things like meeting planning, refreshments, putting together the newsletter, etc.

ROLE OF THE PROFESSIONAL

Some people don't think professionals have a role in support groups. However, in California, 1/3 of support groups are started with the help of professionals. Although the professional's role should evolve from one of greater to lesser importance (ideally to total disengagement), professionals can be helpful in the following ways. They can:

- Help you facilitate a group.
- Act as consultants.
- Be "on call" in case group needs outside assistance (e.g., may be able to assist you with members who need to be referred).
- Develop resource materials for groups.
- Provide support material.
- Refer their clients to groups.
- Inform or educate colleagues about usefulness of groups.

IT'S MEETING TIME!



Congratulations! You've planned well and you've publicized your meeting. Now the day has arrived. Here are some things to remember:

- **Bring these materials:** refreshments, name tags, paper, pens, printed information about the group and other community resources, agenda for this meeting and future meetings (if speakers/topics are planned)
- **Have plenty of seating;** arrange in a circular arrangement.
- **Decorate** the room
- **Try to know who is coming.** Review member profile cards (you will have filled these out when you talked to prospective members on the phone)
- **Greet each participant.**
- **Always have people sign in with their address and phone number** (may want to create a form or keep a spiral notebook just for this purpose)—this keeps your mailing list up-to-date.
- **Go around and check in with everyone.** You may want to ask them to say something good that has happened since the last meeting (to combat the negativity that sometimes comes out in support settings) and to list specific questions they want answered during the meeting (this provides an agenda).
- **If your group has an educational component, introduce speaker.** Speakers can be drawn from universities, local hospitals, city/government agencies, etc.
- **Plan a time for people to socialize before or after the meeting;** keep your meetings short—2 hours or less.

- **Some suggested ground rules for your group**

- Everyone agrees that all information disclosed in the group is private and totally confidential. If a group member shares group experiences with outside individuals, this can have a negative effect on the group's relationship with the community and the willingness of other group members to share.

- Everyone will have a chance to speak but will not be under obligation to do so.

- All expressions of feelings are allowed with the exception of physical violence.

- No side conversation will be conducted during meeting.

- **Possible Discussion Topics:**

- Medicaid waivers

- Parent/professional relationships

- Upcoming trainings/conferences

- F2F learning opportunities: www.inf2f.org

- Approaches to behavioral issues

- How a child's disability affects relationships with spouse, siblings, etc.

- Educating the community

- **Phrases that Encourage People to Open Up:**

- "We know this is difficult for you."

- "It's all right to cry."

- "This is scary isn't it?"

- "It doesn't seem fair does it?"

- "You must feel like you are going crazy."

- "This seems painful to you."

- **Phrases that Discourage People from Opening Up:**

- "We know how you feel."

- "It's God's will"/"It's all for the best."

- "If you think you have it bad you should hear about..."

- "Can you sum it up? We're running out of time."

POTENTIAL PROBLEMS



"Don't give up if you only have a few people for starters, maybe even for the first few years. I think the biggest thing is being able to keep people interested." — Support group board member

- **Too few people:** This may make those who do attend feel more obligated to talk even when they are reluctant. **Solution:** Consider the time/location of the meeting—are they factors? Are you pursuing all avenues of publicity? Do you need to make reminder phone calls/postcards?

"I schedule six months in advance then I do reminders 1-2 weeks prior to EACH meeting." — Support group leader

- **Dominating member:** Does one member take up too much time, ask too many questions, and dominate the discussion? **Solution:** Reviewing the ground rules before every meeting and setting a clear agenda may be helpful.

"I ask them to see me or another person after the group for really individual questions; I spend one hour after each meeting doing personal questions." — Support group leader

- **Imposing member:** Does one member feel his/her coping skills, religious outlook, or general solutions are absolutely correct and better than anyone else's? **Solution:** Try saying, "Well, it sounds like you found something that works for you. Now, what are some things that worked for the rest of you?"

"Many of these parents are dealing with major trauma, seizures, g-tubes, surgeries. My daughter has Asperger's syndrome—the things I worry about, like whether my daughter will have friends at school this year, seem frivolous in comparison." —Parent

- **Inadequate member:** Does one member feel that his/her experience is negligible in comparison to the experiences of other members? This can result in reluctance to share self-perceived insignificant stories at future meetings and may lead to this person dropping out of the group. **Solution:** Repeatedly tell members, starting with the first phone call, that every person's stories of pain or joy are unique and valid.
- **Dependent group:** Does the whole group display low energy and low levels of participation? If this doesn't change, the group may evolve into just a social group. **Solution:** Instill a sense of ownership in each member by delegating tasks (e.g., ask one member to bring snacks to the next meeting, ask another member to find a book for discussion).
- **Social group:** Does the group always start late because people are visiting and do breaks **always** go long? If this happens, look at the progress of participants—some may no longer need to be there and the group may have lost its effectiveness. This type of group also risks alienating new members by making them feel excluded. **Solution:** Reestablish control of the group; cut social time short and schedule a speaker for the next meeting. Shake up the group and see who protests. Consider starting an alumni group for those who may be ready to move on.

WHEN TO REFER A MEMBER

- If a member breaks down at the same point in their story over the period of many meetings
- If a member declines to share his/her story after several meetings
- If anxieties and fears increase over time.
- If new phobias are acquired which interfere with daily activities
- If s/he makes consistent references over several months to loss of sleep, appetite, unclear thinking, and low self-esteem
- If s/he speaks of suicide, jokingly or otherwise
- If persons or places associated with occurrence of child's disability are avoided
- If s/he increases his/her use of alcohol, drugs, or self-destructive habits
- If certain topics cause panic or anxiety attacks
- Hallucinations or delusions
- If s/he exhibits acute grief reactions which increase over time
- If s/he is subject to sudden rages at other members
- If s/he displays great amounts of guilt or anger

Create a list of emergency phone numbers and professional contacts in your area that you can provide for members who might want to seek professional assistance. For example:

The Indiana Department of Health offers a Family Helpline (1-800-433-0746).

1-800-784-2433 is a national suicide hotline. To get a list of phone numbers in your city/county, visit their website at <http://www.suicidehotlines.com>

Indiana Coalition Against Domestic Violence:
1-800-332-7385

ESTABLISHING GROUP CONNECTIONS



"Like parents letting go of our grown children, we should trust our support groups to grow, change, and branch into ever expanding (or shrinking) new forms."
(Gill, N.S., 1994)

One of the signs of a successful group is more dependency on each other and less on the facilitator and staff. The goal of a good support group is to create and nurture friendships that will continue after the last meeting. As group connections strengthen, members feel more invested in the group as well—the group is theirs.

How can you nurture these group connections?

- Make meaningful introductions; mention things members have in common (e.g., similar jobs, children the same age, same home states).
- Start a listener group composed of members or previous members who are ready to become phone listeners for new members.
- Have listener meetings to share feelings/thoughts about phone calls.
- Distribute names and numbers of current group members (with permission).
- Occasional group activities (e.g., bake sale, picnics, booth at health fairs).
- Add social activities. It is a great way for families to spend time together outside of the formal meeting times. Vary activities and make them accessible to everyone.
- Suggest that members get together before or after the group as part of the meeting.
- If appropriate, establish a buddy system where new members are matched with established members.
- Establish an alumni association.
- Establish a monthly or quarterly newsletter.

RESOURCES

National Dissemination Center for Children with Disabilities

P.O. Box 1492
Washington, D.C. 20013
1-800-695-0285

<http://www.nichcy.org>

This is a great webpage; look at general disability resources or search for Indiana and get an extensive listing of IN resources, support groups, and disability organizations.

About Special Kids (ASK)

1-800-964-4746

<http://www.aboutspecialkids.org/>

ASK provides parent support, parent training opportunities, a series of informative brochures, and an Indiana support group directory. (see page 5)

Exceptional Parent Magazine

<http://www.eparent.com>

This magazine is a good resource for families and publishes an annual resource guide. Visit their website to order a free guide.

Parent to Parent Handbook (2001). Santelli, B., Stewart, F.S., Poyadue, J.L.Y. Paul H. Brookes Publishing Company, Baltimore.

You're On Your Way!



Hopefully by now you have a better feel for what it takes to start a support group. This pamphlet was designed to be practical and to provide as many concrete suggestions as possible. Hopefully you are also feeling excited about the possibilities. There is nothing more satisfying than creating new family and community connections. Support networks can improve and change life experiences. Please don't hesitate to call upon Family to Family if we can assist with your efforts in your community. Good luck!

About Family to Family

- This brochure was written and printed by the Family to Family Initiative.
- Family to Family offers information, resources, and connections for families nurturing children with special needs. We have a staff, spread across the state, of experienced parents of children with special needs. We also coordinate Parent Mentors across the state. Parent Mentors are trained volunteers who give peer support to another parent whose child is currently in the First Steps system. If you are interested in speaking with a Parent Mentor in your community or would like to find out more about volunteering, please call us at 1-800-964-4746 or email us at familynetw@aboutspecialkids.org
- Additionally, Family to Family assists families to connect with other families on-line. The Indiana F2F Parents listserv is for all families of children with disabilities or special needs. Use this group to exchange information and resources with one another. Please share information which will build the knowledge base and leadership skills of other Indiana families. Common topics include transition, IEPs, and questions about types of therapies/diets/surgeries. To join the Family to Family listserv, send an email to: INF@Fparents-subscribe@yahoogroups.com
- To find out more, visit our website at: <http://www.aboutspecialkids.org/>
- First Steps families who want to connect with other families may email familynetw@aboutspecialkids.org or call 1-800-964-4746.

FAMILY TO FAMILY
Connecting Families in Community