



Finding or Starting a Support Group

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When you receive the news that your child has an autism spectrum disorder, you may experience a range of feelings including confusion, fear, and loneliness. Even with spousal and/or family support, it may seem that no one understands what you are going through or that you have nowhere to turn for answers. You may begin to search for information on autism spectrum disorders. You may ask, "Where are the other parents like me and how do I find them?" It is hoped that this article will assist you in that quest.

Across the state of Indiana and the nation, parents, family members, and friends have come together to organize on behalf of persons who have been diagnosed with an autism spectrum disorder. Some groups are affiliated with other agencies; some are not. The groups are as diverse as are the needs of individuals with autism. If you are considering starting or joining a support group, please read on as we attempt to answer questions you might have. This article walks you through the process of joining or starting a support group.

Finding an Existing Group

Your first step is to research what might currently be available to you. The Indiana Resource Center for Autism has available a listing of parent support groups in the state of Indiana. Of the groups listed, most are focused on autism spectrum disorders. Those groups that have a broader focus on all disabilities still have a large portion of families who have children with an autism spectrum disorder. You may find this listing at <http://www.iidc.indiana.edu/index.php?pageId=546> or you may contact IRCA at 1-812-855-6508 or toll free at 1-800-825-4733 and request a copy be mailed to you. Every effort is made to keep the information, in this listing, current.

You will notice on the listing that some groups indicate that they are members of the Autism Society of America, or Autism Society of America, Indiana Chapter. Information about membership with ASI can be found at <http://www.inautism.org>. It is not necessary to be a member of the Autism Society of America in order to have a support group. Many groups are formed on their own, but may also be involved with the ASI on some level. Have more questions? Please contact us at one of the telephone numbers listed above and we will try to help.

There are so Many Groups-What's the Difference?

There are over 50 support groups listed on the IRCA website. You may wonder why there are so many and what each does. While we cannot detail each group here, you will notice that most have a phone number, e-mail address, and/or website for you to contact to obtain more information.

Groups may be organized based on a particular format. Some groups may "meet" entirely online at a set meeting time during which all members log-in to a specific website and share information via online chat. Other online groups may communicate via listservs, blogs, and e-mail at various times throughout the week, as each member's schedule permits. Other groups may meet face-to-face at a set time and place. Some groups may utilize both online and face-to-face venues for their meetings. A few of the groups have their own newsletters.

Groups may also be organized based on a particular focus. For instance, groups specifically for fathers, siblings, spouses, and grandparents of individuals on the autism spectrum are starting to garner more interest. These

groups tailor their information and support based on the needs of the target population which makes up the group members. Additionally, some groups may choose all disabilities as their focus, while others may narrow their focus to autism spectrum disorders, and still others may narrow their focus to Asperger's Syndrome.

Some groups may be formed to support parents with children of a particular age-group such as preschool, school-age, or adult. These groups may be affiliated with a particular school or service provider. This may be apparent by the name of the group; however, you may need to contact the group for details on their potential affiliations.

Each group should have a well-defined, specific purpose. Many are "peer" support groups led by parents of children with autism spectrum disorders or other disabilities and their purpose is to provide emotional support for the group members. This type of group may or may not have an educational or advocacy component. Education groups are also common, with an emphasis on providing information and resources, and not necessarily emotional support. Education groups present the latest information using video and/or special speakers, or by having members gather information and present their findings or experiences on specific topics. Some groups are task oriented and focused on fund raising or advocacy tasks, for example. Professionally led support groups are also available. These groups are led by professionals such as psychologists, social workers, counselors, or local school personnel.

Groups may also be ongoing or time-limited. Usually, parent-led groups are ongoing with regular monthly or bi-monthly meetings at a designated site. Time-limited groups are often run by a professional who presents a specific topic or curriculum. These groups will meet a specified number of times, and when finished, will open up to new members and repeat the topic or curriculum.

Once you find a group that you are considering joining contact the leader and ask questions. Don't be afraid to find out the group's format, focus, and purpose. Try to attend at least two meetings in order to determine whether or not this group is one in which you would feel comfortable.

If a group is not available in your area, or if you want a group with a different format, focus, or purpose, you may consider beginning a group of your own.

Starting a Support Group

Preparing Yourself

When deciding to create a support group, there are few questions that need to be asked and only you can answer them. Questions such as, "Am I ready to be a support group leader?" and "Do I have the time to be a support group leader?" need to be addressed. You need to fully prepare yourself for the demanding and time-consuming task of assuming the role of a support group leader. You may benefit from setting some rules for yourself from the beginning. For instance, if other parents see you as an "expert" you may become overwhelmed with calls and requests for advice. By thinking about the role you wish to assume before the group even forms, you will be less likely to find yourself in an unsatisfactory situation later. You may wish to establish personal boundaries and limitations early and be prepared to tell each potential group member that you don't have the answers, but you want to work together with them to find the answers.

You also need to keep in mind that during the forming stages of your group, you will be setting the stage for your future role. You need to determine if you want to be a facilitator or if you want to be "in charge" of each meeting. You will also need to decide if you feel you will be able and willing to allow others to share in group responsibilities and duties. Lastly, you will need to realize that while you may be contributing a lot of time and effort to the group, you may receive little recognition for your contributions.

There are also personal concerns to be addressed before beginning a support group. Is your significant other supportive of you undertaking the additional responsibilities of a group leader? Are other members of your family

supportive of your decision to start a support group? These are discussions you need to have before you begin making concrete plans to form a group. Once begun, groups sometimes have a way of taking on a life of their own! It is best to have a core group of two or three people who can help and support in the early stages of your group as well as on an ongoing basis.

The Practical Aspect

When you approach others with your idea about starting a group, they will have questions. Some of the questions you should be prepared to answer are, "When and where will you meet?", "How often will you meet?", "Is there going to be child care available?", and "Will you have refreshments?"

A meeting place is the first essential. Churches and public libraries are common places to hold meetings and are usually available at no cost to the group. City or county buildings, the YMCA/YWCA, service clubs, and other organizations in your area might also have meeting rooms that they would allow you to use free of charge. The ideal meeting location should be easy for people to find, centrally located, and offer free parking.

Keep in mind that the first meeting place doesn't have to be where your group will always meet. Once begun, the group might want to consider a location more conducive to your group's size, a place with room for child care, or just a more convenient location. The point of the initial meeting is to get people together and share ideas relevant to your group. Try to remain flexible as group members may have resources and ideas that may alter your initial plans. Additionally, stay open to opportunities and don't take it personally if changes are suggested. However, once your group is established, you should attempt to keep the meeting place consistent as frequent relocating could cause confusion and discourage people from attending.

Finding Others

What audience have you decided on for the group? If you wish to target parents of preschoolers, you might contact First Steps, local pediatrician offices, the preschool coordinator in the local public schools or other agencies that work with this population. Contacting schools will be the best place to start for connecting with families that have school-age children. Parents and families of adult children might be more difficult to find. If there is a Center for Independent Living that serves your county, that office might be a good starting place as well as the local Area Agency on Aging, the local Arc, or other service providers for adults with disabilities. Additionally, individuals at all of the above-mentioned agencies may be able to advise you of other possibilities for getting the information about your group to the families who may benefit from it.

As you begin contacting various agencies and organizations, keep in mind the confidentiality aspect under which they are bound. They will not be able to give you information about other children or parents. They may however, based on the internal policies of each organization, post flyers and notices of meetings in common areas. It is also possible that individuals working with families, who may benefit from this type of support, will pass the information on to them.

The IRCA maintains a listing of parents all over Indiana who wish to network with other parents. Either Brian Ketzner (bketzner@indiana.edu) or Marci Wheeler (mwheeler@indiana.edu) at IRCA may be contacted to get information on those families who wish to network.

Ready to go Public?

Keep in mind that you don't need to contact every potential group member initially. You may wish to start with a few key people and then expand to the general public. However, if you prefer to target as many individuals as possible initially, you may wish to begin by posting a flyer at various places in your community.

Most laundromats have message boards as do other local businesses and agencies.

You may also try contacting local churches or other places of common gatherings such as private clubs to find potential group members. For instance, service organizations such as Tri Kappa or Delta Theta Tau, the Elks Club, the Shriner's Club, the Exchange Club, and others might help to advertise or support your group. Make a list and check off people you have contacted so you won't duplicate calls or leave anyone out. Use the internet for further ideas and/or to obtain e-mail addresses of other organizations that may be able to help spread the word about your group.

If you want more publicity, the newspaper might be your next step. However, keep in mind that newspaper ads can be expensive. Consider contacting your local newspaper to inquire if the paper has a column dedicated to community announcements that may provide an avenue for free publicity about your group. You may even want to ask the columnist to do a story about your group!

You might consider advertizing on Facebook or starting a web page, listserv or blog to post information about your group. More and more families continue to connect and get information about resources in cyberspace.

If you are going to make a flyer to post or write an announcement for the newspaper, certain things need to be included. Here are some ideas:

- Explain the goal of the group. State this in your flyer or announcement. If the format, focus, or purpose is still open for discussion, let your readers know that this is an information gathering group, or a group to explore possibilities and ideas.
- Identify who might be interested in the group. Provide a description of potential members; "parents of children with autism" or "if you have a loved one with autism" or "if you have a preschooler with autism." If you want to open your group up to include all disabilities, be sure this is clear to your readers. You don't want to imply one thing and then have people attend your first meeting and find that they were not the intended audience.
- Include the meeting place and time. Be sure to indicate the time zone as Indiana observes several different time zones across the state. Provide the full address of the meeting location. A sketch or map might be necessary or helpful.
- Specify if children are welcome at the meeting or if child care will be available. Note: if children are coming, do reservations need to be confirmed in advance?
- Provide a phone number or e-mail address for people to obtain further information. Make sure that you will be available to respond to these inquires. It may be helpful to establish a separate e-mail address that is specifically used for group purposes.

That's all you need to get started! Are you ready for the initial meeting?

The First Meeting

Your first meeting probably won't go as smoothly as you would like it to, so anticipate this and relax and do your best. Here are some ideas that may help you facilitate the initial meeting.

Create a sign-in sheet and have people sign in as they arrive. Be sure to include a space for people to enter their phone numbers and e-mail addresses so that you will be able to contact them. You could also provide name tags; however, be aware that some people may not feel comfortable using them. If at all possible, someone should be available to greet people at the door.

Refreshments are a good way to get people mingling; they also give people who arrive early something to do while they wait. Keep the refreshments simple. Cookies or chips and coffee or bottled water are fine. After the first meeting, group members may decide to take turns bringing refreshments, or you could take donations and have someone be responsible for bringing them to each meeting. Ideally, you may find a local business willing to donate refreshments or funds with which you may purchase refreshments for your group.

Have an agenda to hand out. An agenda gives people an idea of what is going to happen during the meeting. If you have a guest speaker, his or her name should appear on the agenda. The main agenda item should be setting a mission for the group. It is good to brainstorm ideas pertaining to the group's mission, focus, and format, but keep it simple at first. You might want to write down what other support groups have done as a guide. You may also wish to discuss a name for the group if you haven't already chosen one. Try to select a name that conveys what your group is about.

The format for the first meeting should be simple, but organized. Consider having someone from a similar group speak briefly about their experiences. Agenda items might include finding out what others need or want from the group experience. You may want to have a form ready for people to fill out and turn in so that the responses may be reviewed later.

The formal part of the meeting should last about an hour, but no more than an hour and a half. After this time, let people know that they can mingle for another thirty minutes or so, but it should not be an unending evening. Remind everyone that there will be more meetings and everything can't be done at once. Setting time limits will help you organize as well as set group member's expectations.

You are on Your Way

Please contact the IRCA to have your support group posted on the web site and listed on materials that are distributed to parents and professionals in your area. We want to help families find you and your group! IRCA staff is very supportive of parent groups across the state. Being on the IRCA list of parent groups will also keep you better connected to information distributed by IRCA that may be valuable to you and your group members.

Congratulations! You have started a new community resource. You should be proud of this accomplishment! At this point, it is normal to feel anxious about the creation of your group. Try to recognize signs that indicate you are feeling overwhelmed. If you begin to feel stress, remember to allow yourself to delegate to others. Try to remain flexible to suggestions and offers of help from other group members. Also, try to stay organized by keeping all of your group materials separate from other household and/or community resource materials.

Remember that new endeavors such as the creation and maintenance of your group will provide opportunities for both growth and change for you and your group members. Do your best to help the group stay focused on the established goals and mission. The key is cooperation, not competition. The challenges of having a child with a disability are many, but there are many joys as well. Sharing the ups and downs with others going through similar situations may provide you and your group members with the support you need during challenging times, and an opportunity to share all of the wonderful things about your children!

Resources

Parent Support Groups in Indiana

<http://www.iidc.indiana.edu/index.php?pageId=546>

Starting a Family Support Group: A Family to Family Resource

http://www.inf2f.org/documents/F2FsupportgroupampamphletRevised09_000.pdf

Statewide Parent to Parent Network

<http://www.aboutspecialkids.org/Directory.aspx?keyword=%22family%20support%22>

Wheeler, M., & Ross, J. (2009). Finding or starting a support group. Bloomington IN: Indiana Resource Center for Autism.

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