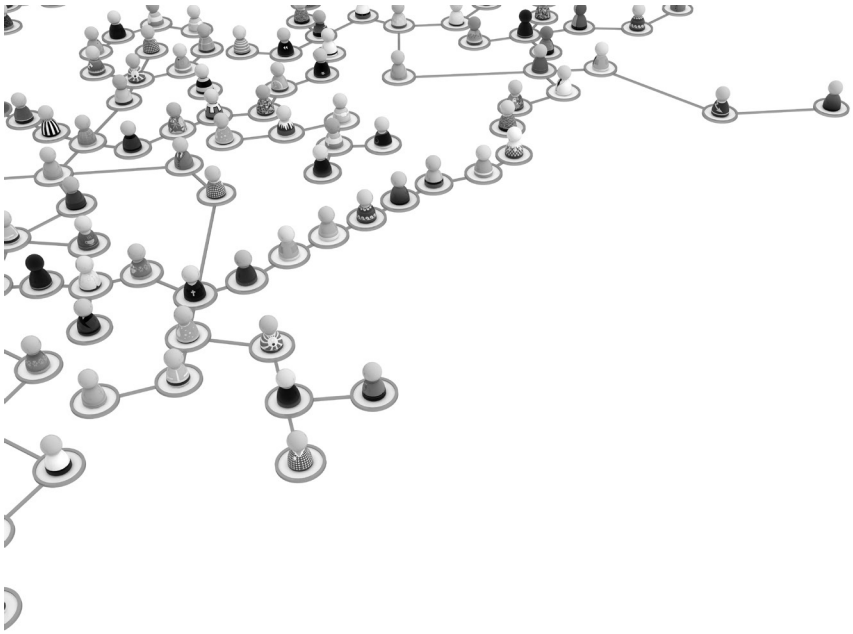
ACT's Autism Manual for B.C.

Living and Working with Children and Adults with ASD

Chapter 11:
ACT'S GUIDE TO CREATING A COMMUNITY GROUP

Contributed by Deborah Pugh, Executive Director, ACT– Autism Community Training



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The "Introduction to ACT's Autism Manual for B.C." provides valuable context to this chapter. Download at: www.actcommunity.ca/autism-manual.

Autism Information Database

"Like Google for Autism but Better!"

Throughout this chapter you will see AID links that connect to resources: www.actcommunity.ca/aid-search/

ACT's Autism Information Database (AID) has over 2000 autism-related information and community resources. It is easy to search using keywords and postal codes, which saves time in finding B.C. resources. There are links to excellent international websites on a wide range of topics relevant to children, youth and adults with ASD and their families, which community professionals may also find helpful. ACT's staff has reviewed each of the resources we have included — our focus is on providing practical, useful resources that empower families and communities. Do you have a community resource to recommend for the AID? Go to www.actcommunity.ca/submit-resource/

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11 ACT'S GUIDE TO BUILDING A COMMUNITY GROUP

Contributed by Deborah Pugh, Executive Director, ACT– Autism Community Training

In 1995, I started a group for parents of children with autism in North Vancouver. Those were very difficult years; my son was four and very challenging to parent. It was a time when autism was still rarely recognized, knowledge was sparse, and parents were starved of information and support – as was I.

Looking back over my four years as facilitator, I realize I learned more about parenting a child with autism from other parents in the group than from any other source. From other parents I learned that what I had seen as my failures were, in reality, a lack of knowledge. Together our group focused on learning about autism and strategies to help our children.

Once a month, we met to share our often bizarre experiences as we navigated our communities, trying to find "safe passage" for our children, who broke every social rule in the unwritten manual of community life. From streaking naked through parks, to pulling out the wiggly teeth of a classmate, to peeing in the demo toilet at the local hardware store, we shared it all, sometimes in tears, often crying with laughter. For me, meeting with the parents group was the opportunity to spend time with those who shared my very atypical experiences as a parent; I could no longer relate to parents whose greatest anxiety was whether their child would be allowed into the French immersion program. Most of us were struggling to help our children learn to talk.

By 1996, I was overseeing the establishment of 30 parent groups across British Columbia, helping train and support dozens of facilitators, in my job with the Autism Society. While the information presented in this chapter draws on my experiences, I cannot claim to be the author in the true sense of the word. This chapter draws on the insights of many, both within the autism community and those who have researched and supported self-help groups. Special thanks are due to Cathey Camley, who contributed to an early draft.

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

Margaret Mead

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Autism Speaks Canada funded ACT to provide training for a dozen Parent Facilitators to come to Vancouver for training in June 2012, and to publish this guide. We are extremely grateful for ongoing support from Autism Speaks Canada that allows us to target underserved communities.

We support this information being used widely and adapted to differing circumstances. We would appreciate if ACT is acknowledged. Details are available in the front of this manual.

DEDICATION

This chapter is dedicated to the dozens of parent facilitators I have worked with over the past two decades. In particular, the twelve remarkable mothers who participated in the volunteer facilitator training that ACT organized in June 2012. They came from across rural B.C. and spent two days together, learning how to facilitate a community group and getting to know each other.

Watching how they enjoyed sharing their experiences as rural parents, committed to engaging their communities to better support all children with autism, was inspiring. Their progress since has reaffirmed my conviction that, even in the age of the Internet, coming together face-to-face to share common goals empowers community volunteers.

From top left: Sheila Seitcher (Harrison Hot Springs), Kristina Vanlierop (Langford), Kirstin Cain (Terrace), Maureen Sharp (Ft St John), Roberta Johnson (Quesnel). From middle left: Patricia Rousseau (Courtney), Ivy-Lynne Stein (Cranbrook), Kim Dragseth (Osoyoos). From bottom left: Ana Pakenham (Kimberly), Gretta Bakewell (Salmon Arm), Catrin Webb (Squamish), Hillary Lewis (Prince George)

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THE PURPOSE OF COMMUNITY GROUPS

Community groups focus on supporting their members through the sharing of experiences, knowledge, emotional support, information and practical ideas. In essence, they are sharing their common experience. This chapter is focused on the experiences of those trying to build understanding of autism[1], but the information is also broadly applicable to the special needs community, in particular those dealing with an invisible disability. Sharing the experience of any condition with peers strengthens all participants. No one is an expert but many have expertise.

Traditionally, most community groups within the autism world have been for parents, but that is changing as it is more widely recognized that all members of the family are affected and may benefit from discussions with their peers. Siblings, in particular, carry a burden that is little recognized.

Teens and adults with autism themselves are also finding getting together and sharing their experiences to be a great way of breaking through isolation and building a network of support. Increasingly, grandparents also are seeking out each other as they struggle to support their children and grandchildren affected by special needs. Fathers also have benefited from meeting as a group as they often share a common reality.

These informal groups are sometimes known as "support groups," "parent support groups," "peer support groups," "mutual self-help groups," "parent information groups," "parent-to-parent support," or "sibling support groups." For the purpose of this guide, we will refer to them as "community groups," as the tips and resources that we provide here are widely applicable and have benefited by decades of experiences from those who have discovered there is much to be gained from getting together to share experiences and find solutions to common concerns.

The key to the most dynamic community groups is that they are run by and for members of the group — this is the essence of peer support. "Helping professionals," like teachers or counsellors, may participate from time to time, but usually only at the request of group members. These are not therapy sessions, but it can be very therapeutic to build trusting relationships with others around a common experience that is very uncommon to most members of society. However, a community group is infinitely adaptable, as its objectives are set by its members.

1 Autism Spectrum Disorder will be referred to as autism in this chapter.

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There are extensive online resources that can help anyone contemplating setting up a community group. Four of the best are:

1. PeerNetBC (www.peernetbc.com).
2. Self Help Ontario (www.selfhelp.on.ca).
3. The Community Tool Box, part of the Work Group for Community Health and Development at the University of Kansas (www.communityhealth.ku.edu).
4. Siblings Support Groups require a special approach. The leading international specialist is Don Meyer, who has developed "Sibshops." To access excellent siblings resources online, see AID Resource www.actcommunity.ca/resource/1890/.

Community Groups are Adaptable

Community groups can take many different forms and can develop in various directions. Keep in mind that there are no hard and fast rules. It is up to the members to decide what meets their needs. What follows are some guidelines based on the experience of many groups; you may find them useful as you consider taking the plunge!

Here are some areas that community groups focus on:

- **Support** – providing opportunities to reach out to each other through:
  - Sharing resources;
  - Talking through the problems they are facing or choices they have to make;
  - Listening and sharing strategies (but stopping short of telling others what to do).

- **Education** – giving members an opportunity to learn more about:
  - Autism (or any other condition) and how they can help all members of their family flourish;
  - Local information helpful for parenting an exceptional child, including services available from the Ministry of Children and Family Development, school district programs and policies;
  - Local service providers (i.e., a great swimming program or autism-friendly dentist).

- **Advocacy** – bringing members together to work on issues within their community:
  - Raising awareness of autism;
  - Promoting more opportunities for child care;
  - Working with local school districts to improve educational services or standards;
  - Improving vocational/educational opportunities for adults.

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ADVOCACY RESOURCES FROM ACT

ACT has developed a wide range of material to support parental advocacy, including:

1. Online Videos (previews available; see AID Resource www.actcommunity.ca/resource/2460/):
   - *Education, Integration, Inclusion: Key Information for Parents of Children with Special Needs* – Suzanne Jacobsen, R. Psych, & BCBA-D
   - *The Art of Advocacy – A Parent's Guide to Advocating for Their Child With Special Needs* – Clair Schuman

2. Chapters free online at ACT's Autism Manual for B.C. at www.actcommunity.ca/autism-manual-for-bc:
   - Chapter 7: "The B.C. Education System An Introduction for Parents of Students with ASD"
   - Chapter 8: "The Role of Parental Advocacy in Navigating the B.C. Educational System"

2. ACT's Autism Information Database (AID) www.actcommunity.ca/aid-search/ has numerous resources. Search "advocacy" in the keyword search.

Why Do Such Simple Activities Make a Difference?

Many participants in community groups are relieved to discover that they are not the only sibling, parent or grandparent to face a particular challenge, whether within their own family or at their child's school. Frequently, participating in a group provides insights into the impact that autism is having on one's own family.

The realization that the issues that arise within the family are part of autism, and not the result of maliciousness on the part of the affected individual, can promote a greater sense of empathy. This is particularly relevant for siblings who are often frustrated by the demands on parental resources of their brother or sister with special needs. This is exacerbated in autism, as the disability is invisible and is often accompanied by challenging behaviors in the home, at school and in the community.

At the very least, learning about the effect of a special need on a person's behaviour helps stop the cycle of self-blame and criticism that can permeate family life in the absence of understanding. Many report feeling empowered by building relationships with others who have followed a similar road. This feeling of shared experiences is often missing when they talk to peers (in the case of siblings or individuals with ASD) or to other parents or grandparents who do not live their reality.

For most participants, the educational and support functions of a community group are sufficient. For others, there is a natural progression to building a more formal organization, which seeks to engage in all aspects of commu-

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nity development including advocacy. (See "Formalizing Your Community Group – Setting up a Registered Not-for-Profit Society" on page 16).

WHAT COMMUNITY GROUPS CANNOT DO

A community group cannot solve all its members' problems, nor can it replace the services of specialists and other helping professionals. These are not therapy sessions; however, the process of sharing experiences, insights and knowledge can be very therapeutic, when the sensitivities of group members are respected.

STEPS FOR SETTING UP A COMMUNITY GROUP

Step 1: Exploring Existing Resources in your Community

The first step is to find out if there is already a local group in your community that meets your needs. In British Columbia, ACT provides a province-wide online listing of support groups across special needs.[2] The listing can give you an idea of what is happening in your region and may provide inspiration and mentors to help you get started.[3]

Step 2: Considering Your Own Resources

The big question is whether you have the time and energy to start a community group? It will take some work to get things organized at the outset. But if you can find a few others who share your vision and are willing to help, it is not a difficult task if taken step by step.

The most challenging period is the start-up phase, as all potential members of the group (whether parents, siblings or grandparents of a child with special needs) are probably dealing with many demands on their time. This also applies to groups of teens or adults with ASD who would like to start their own community group. It is best to start slowly, and keep your expectations realistic rather than exhaust oneself and risk burnout.

You may also want to seek funding for your efforts. See "Accessing Funding" for more information (page 12).

2 ACT's Information Database (AID) provides contact information on a range of support groups, including those focused on autism: www.actcommunity.ca/support-groups. Don't forget to add your group once you have it up and running!

3 The Family Support Institute is another great resource on what is happening in local communities across B.C. through their network of Resource Family Members – for more information see www.familysupportbc.com.

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Step 3: Building a Network – Getting Started

Once you have decided to take the plunge and set up a community group, focus on identifying a few like-minded peers or mentors who are interested in helping you brainstorm.

Identifying Key Collaborators

"I made an appointment with the local School District Special Needs Principal and sent her off an email. She sent it off to all of the support teachers in the district."

Roberta Johnson, Quesnel

- Write up a short description of what you have in mind. Send it by email to people you know, asking them to forward it to those who they think can advise on getting the group off the ground.
- Professionals involved in working with those with special needs can be a great resource in this process, including speech language pathologists, social workers, special educators and behavior consultants. They cannot give out confidential contact information about others, but they can forward an email to their contacts. This is particularly effective if the person forwarding your message can vouch for you as a reliable person who respects confidentiality.
- Contact ACT and ask whether there are active parents in your community that we can help you contact by forwarding your invitation. ACT can also send out a message to active adults with ASD and other family members.

Pulling Together a Steering Committee

When you receive a response, try to set up an opportunity to meet face-to-face or by telephone to discuss your ideas. Email is a useful tool but an in-person meeting is far more effective at this stage of collaboration. Not all of the people you will talk with will become active group members, but they may have great suggestions.

- Once you have two or three suitably active people on board, call a planning meeting and get everyone together. Ask them to consider being the group's steering committee. Having several people collaborating from the beginning will model for newcomers what your group is all about — not one person doing it all, but the active participation of all the members.
- Before you host your first meeting, you may wish to host several organizing meetings to explore ideas, identify your goals as a group, work out and assign tasks, and develop some basic meeting guidelines. Or you may want to jump into the deep end and call a meeting to see who is interested and build the group from there.

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- The issue of whether or not professionals should take a guiding role in leading or participating in the group may be raised and should be considered in advance.[4]

CHOOSING A NAME

It is helpful to choose a name for your group that reflects the purpose/function and possibly the location of the group. For example:

- "Happy Valley Autism Community Group"
- "Blue Creek Adults with Autism Meet-Up Group"
- "B.C. Adult Sibs Awareness Group"
- "Parents of Children with Autism Advocacy Alliance"
- "Special Needs Parents Community Group"

Step 4: Defining the Group's Membership

One of the key areas that will need to be defined is who is the group for? This is a tricky area as it is important that the group has a coherent focus, but if the group is too defined, it may be very small indeed!

Here are some questions to consider:

- Will this be restricted to those who are living the experience of family members or individuals on the autism spectrum? A group that includes everyone can also inhibit frank discussion. Siblings, in particular, appreciate a "siblings only" gathering where their needs can come front and centre and where their feelings can be expressed candidly.
- What about allowing community service providers to attend? Again, this may inhibit parents sharing their experiences with each other. Sometimes groups decide that certain sessions will be open to all—for example, when a speaker has been invited—while others are focused on group members only.
- Other groups may decide to focus on a particular therapy, language group or religious affiliation. It is legitimate to set up restrictive criteria as a group, but remember that you may be excluding great potential members if you are too exclusive.

"We have been quite specific with who we are willing to have at our support group. We have made it clear that this is for parents of children with ASD or that have been referred and are waiting for a diagnosis. We have many families in our group that do not disclose their child's diagnosis and we want to ensure that this group remains a safe place for everyone. Our policy is that I meet with a new parent prior to coming to a meeting and that they are emailed what our confidentiality agreement is prior to attending a meeting. This has been the clearest way and has worked very well for everyone."

Catrin Webb - Squamish

4 To see a detailed discussion about the role of professionals in groups based on peer support, see www.peernetbc.com/peer-and-professional-roles-in-peer-support.

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- Do you wish to make your group one that has members from across special needs? This means you will have a bigger pool of people to draw from and that will be a strength. However, in a generic group it will sometimes be challenging to keep everyone engaged, as experiences can be very different. In small communities, a group that includes all special needs will probably be necessary, but all members will have to work harder to make it relevant for all members.

Step 5: Deciding on a Meeting Format

There are many different ways of running a community group:

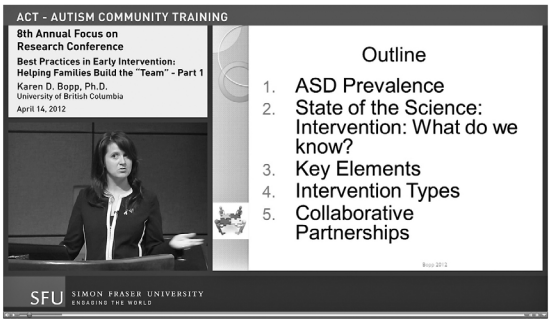
- One way that can be highly successful is to alternate between meetings that focus on sharing information within the group with more formal presentations. This is particularly appealing to participants who are motivated by finding out more information that can help improve their parenting skills, for example. Groups that focus on education can also address the concerns of many potential participants that the community group's purpose is purely emotional support. Some participants may shy away from the word "support" as they assume that this will entail dealing with self-pity.

- Other groups start each meeting with 30 minutes for updates and information sharing and then have a presentation. Some use a format where everyone in the group participates in this round table; others leave it up to individuals to decide whether to provide an update.

- Above all, be warm and welcoming to newcomers. Do your best to avoid the pitfall of any group of members being seen as a clique. Be as open as possible and extend invitations for others to join in and help. (See "At the First Meeting" on page 13.)

"Above all, be warm and welcoming to newcomers. Do your best to avoid the pitfall of any group of members being seen as a clique. Be as open as possible and extend invitations for others to join in and help."

ACCESSING ACT TRAINING IN YOUR COMMUNITY



ACT is happy to offer community groups access to our online videos free of charge, as our way of helping to support build community support. Watching the videos together on a large screen is a great way to generate discussion and ideas.

ACT online videos feature excellent speakers presenting important and often very practical information that applies across special needs and across provincial jurisdictions. For details, see AID Resource www.actcommunity.ca/resource/2460/. Contact info@actcommunity.ca to gain access.

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Step 6: Deciding on Group Guidelines

To increase the potential for success, community groups often use guidelines for their meetings to set expectations well in advance. With your steering committee, decide how the initial meetings will be run. No matter how informal your group, meeting guidelines will make meetings more effective and discourage difficult behaviour. To ensure that all members are familiar with the guidelines, you may wish to have handouts available for your members, or post them at the meeting or, if you have one, on your website. The group can, of course, decide to change their guidelines.

There are several different formats for sharing meetings that work well depending on the culture and needs of your group. The excerpt below provides an excellent overview of reasonable expectations that fit the needs of most groups.[5]

SUGGESTED GUIDELINES FOR GROUP MEETINGS

We start and end our meetings on time.
We try to arrive on time, because people arriving late can sometimes be disruptive. We also need to respectful of people's time and end the meeting on schedule.

We keep confidential all personal information shared in the group.
What we share about our personal lives and experiences is to be kept absolutely confidential by all members. "What is said in the group stays in the group."

No interrupting or side conversations.
It is important that we actively listen when someone is talking and avoid interruptions or side conversations.

We don't give advice.
We do not prescribe, diagnose, judge, or give advice. Rather, we respect each member's right to reach and make their own personal decisions. We listen, speak as to what has worked for us in similar circumstances, and help members to recognize and explore their options.

We share what helps us.
While we present the problems we face, we all make a special effort to always share our successes, coping skills, insights, strengths, and hopes — no matter how small.

We don't monopolize the group's time.
We don't talk for excessively long periods of time or talk too frequently. We are respectful of the need for all members to participate.

We have the right not to speak.
In our group discussions, each person has the right to pass on any question that he or she prefers not to answer.

We treat each other with respect.
We respect the basic human dignity of each and every member.

5 This is an excerpt from www.communityhealth.ku.edu.

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Step 7: Finding a Time and Place to Meet

Ideally the group should meet somewhere central to cut down on traveling time for group members. Often libraries and community centres will provide you with free meeting space as a community service.[6] Child Development Centres are often very welcoming. Sometimes the decision is made to host meetings in a member's home, but this can be stressful for the host. Ideally, a neutral venue that does not require a pre-meeting cleanup is best in the long run. Decent lighting, comfortable chairs and access to a kitchen or a local coffee shop are all advantages!

Try to get a sense from your steering committee if day or evening meetings would be better for your members. Most prefer weeknight meetings when childcare is easier to arrange. It is also easier for people to remember the meeting time if it is fixed, like the second Thursday of each month. Groups often do not meet during summer or in December. Sometimes they organize a summer barbeque for the whole family or a Christmas potluck instead. In the beginning, try not to be too ambitious. You do not want to wear out the energies of the group or yourself.

AT THE FIRST MEETING

It is a good idea to have each steering committee member take on a specific responsibility for the first meeting:

1. Someone responsible for arriving half an hour early to make sure the room is unlocked, and to make coffee/tea and set out goodies. The food should not be elaborate as this soon becomes a burden, but nothing breaks the ice like food! Some groups have an informal half hour to make coffee together and prepare the room before the main meeting starts. This is a great opportunity for new members to come early and meet people informally before the meeting begins.
2. Another person can take on the task of greeting people at the door, handing out name tags and gathering contact information from newcomers — if they are relaxed about sharing this. Sometimes it is best to wait until the end of the meeting to collect this information. Putting at the top of the page that the information is confidential and voluntary will reassure group members who have concerns about privacy.
3. One individual should take on the role of facilitating the meeting. They introduce the guest speaker if one has been arranged, introduce the steering committee members, and facilitate the evening's discussion.
4. Consider whether you want to start with an "ice breaker." This could be as simple as asking members to pair up and interview each other for five minutes so that they can introduce each other to the group. This is sometimes easier than a parent speaking about their own circumstances and tends to keep it briefer, too! www.icebreakers.ws/ has a collection of icebreakers that can be adapted to suit circumstances.

6 See page 12 for more information on funding.

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ACCESSING FUNDING

Most community groups do not charge membership fees, but there are expenses. Asking for a small donation or voluntary drop-in fee is acceptable and should be discretely handled. This will likely cover the costs of meetings.

Sometimes, service organizations such as the Rotary Club, Soroptimists, Lion's Club, the Legion, and other local organizations will provide a small amount of funds to purchase refreshments for meetings and pay for speaker fees. You may be invited to make a presentation to the organization about your group and their needs. It is best to begin by approaching the organization with a brief telephone call or letter of inquiry about the possibility of their organization sponsoring some aspect of your group.

Planning a fundraising event can tax a new group's energy if the event is onerous to execute. It is often best left until the group is more established and there are an ample number of volunteers who are willing to take on the work. However, fundraising events have the benefit of raising awareness about your group and their issues in the community. They can also help to establish greater bonds amongst group members as they work on the common goal of advancing the group's profile and funds.

An excellent avenue for funding in B.C. is through BC Children's Hospital Foundation, it offers small grants to assist grassroots community groups. BCCHF defines these groups as "families of children with a physical or mental disability/disorder who offer direct parent-to-parent support." They provide:

- Comfort funds for groups that hold regular support group meetings. These funds provide the little extras that make meetings more comfortable such as refreshments.
- Extended funds for established groups who maintain any structured form of ongoing communication such as newsletters, regular mailings or speakers.
- Special funding for a one-time event or project.

Applications can be downloaded from: www.bcchildrens.ca/YourVisit/Familyservices/Family+Support+Group+Funding.htm

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Step 8: Getting the Word Out

Once you are clear on what you want to do, it is time to let potential members know about your new community group. Thanks to technology and social media this is becoming easier all the time:

- Someone in your group may be able to set up a simple Facebook page or a website that can have the basic information posted.
- An email message with the crucial information can be sent out with a request to forward to interested individuals. Make sure you have another pair of eyes check to see whether it is clear before it goes out. It should contain, in brief:
  - The name of the group
  - The purpose
  - Where you are meeting
  - Who is invited
  - Who can be contacted for more information either by telephone or email. If you are providing a telephone number, you should state what time will be convenient to take calls.
- A small poster or flyer with the key information can also be a great tool to post on notice boards at:
  - Schools
  - Community Centres
  - Child Development Centres
  - Community Living Agencies
  - Doctor's offices
- Professionals to target with your flyers (so they can give them out in their offices) include:
  - Social workers
  - Pre-school, Childcare and School Staff
  - Community Health Nurses, GP's and Pediatricians
  - Speech Pathologists; Behavior Consultants & Occupational Therapists
  - Community Living Agencies & Child Development Centres
- In B.C., you can list your group on the ACT site. We are always happy to help people get a group started and we can connect you to local resources and help you publicize your ideas. Outside of B.C. there are many similar organizations, including local autism societies.

"We were lucky to have a special needs social worker who saw a parent support group as essential and who was willing to help us find connections in the community. We did not do advertising the first few months except through word of mouth and the social worker sent out to all of her mailing list that we were starting a group. The Child Development Centre was helpful and willing to help us begin the group. We currently have approximately 50 families on our mailing list."

Patricia Rousseau - Courtney

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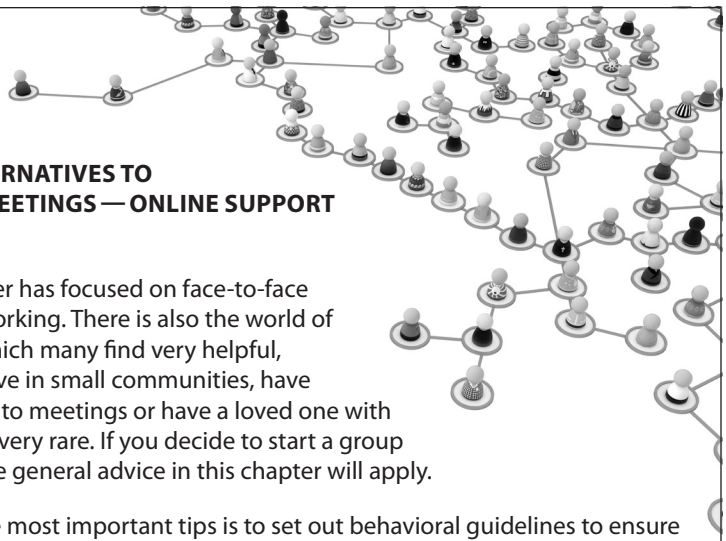
"We have a closed/private Facebook group that has been a great place to share information, keep in touch and send out group meeting reminders to parents."

Catrin Webb, Squamish



EXPLORING ALTERNATIVES TO FACE-TO-FACE MEETINGS — ONLINE SUPPORT & NETWORKING

Most of this chapter has focused on face-to-face support and networking. There is also the world of online support, which many find very helpful, especially if they live in small communities, have difficulties getting to meetings or have a loved one with a condition that is very rare. If you decide to start a group online, many of the general advice in this chapter will apply.

Perhaps one of the most important tips is to set out behavioral guidelines to ensure that all participants will feel respected. In written communication, it can be difficult to understand if people are joking, being ironic, or are simply passionate about their beliefs.

The following free resources may be useful. Most will require some comfort with computer technology and, of course, a reliable Internet connection.

- Facebook (www.facebook.com) is a popular social networking tool that many people use already. This can be a good way to maintain communications, but check the privacy guidelines.
- Skype (www.skype.com) is an online video or audio conferencing system. Meeting in real-time online can be challenging, but also rewarding.

There are many more online resources available that can host online conversations. The important thing is that the online space is accessible to your membership (both financially and technologically) and that you understand the privacy options of that specific online space.

Some people will be active participants: posing and answering questions, encouraging others to share their stories, and actively contributing to the creation of a safe and welcoming environment. Some may wish to browse, listen and take their time before engaging with an online community. All can be respected members.

Some simple community guidelines: be kind, share stuff, say thank you.

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Step 9: Ongoing Group Leadership

Community groups are typically led by one or more of their own members who take on the responsibility of leadership for a designated period of time—usually a year. Many find the idea of leadership intimidating at first and find it reassuring to share the leadership with another person who acts as a co-chair. It may be that your group is better run through a small committee with each person taking a turn leading the meetings.

One of your group may have had experience through their professional life in facilitating meetings and can help train other members to share this responsibility. Ideally, all members are the source of support and expertise through their shared experiences, not the facilitator.

As the founder or facilitator of a new group, members will naturally look to you for answers and guidance. Be careful not to become "the expert." Redirect questions put to you to the group. Work to pull together the collective wisdom that can be found in mutual-help groups when members share their experiences, resources and insights. It is a great feeling to see members helping one another through the group you have helped to start.

MANAGING DIFFICULT BEHAVIOUR

It is rare, but if a member of the group is disruptive, the best way to deal with the matter is to remind the group as a whole about the agreed-upon code of behavior. Don't single out any one person. Should the problem behaviour persist, have a private conversation with the person after the meeting. Point out how they can contribute and share in a manner that is within the boundaries set out by the group. It may be that they are unaware that their behaviour is making it difficult for others to participate. They may be in crisis and desperate. You can offer to help them find the right kind of support they need. For example, refer them to ACT to see if there is a family counselor or psychologist available in their community.

A NOTE ON KEEPING IT POSITIVE

Because raising a child with a disability is so challenging, it is common to find the group focusing on only the negative aspects of their experiences. Too much negativity can turn people off and may mean a drop in membership as people leave the meeting feeling worse than when they came! It is perfectly fine to discuss the downside of experiences, as long as the group can refocus from the negative to positive.

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Step 10: Moving On

Community groups come together to meet needs at a particular stage in the members' lives. Many last for a few years and then close, and a new one will begin, set up by a new and energetic group. However, as people retire from the group, they can still serve as a resource to newer members, if they are encouraged to do so. Group veterans also remain in touch with each other informally and often maintain relationships that last a lifetime.

Other community groups provide the impetus for the development of a different kind of organization, one that is more formal and can seek funding to provide a range of services to the community (see below).

It is important to remember that your group needs to be flexible and adaptable to meet its members' changing needs. Build review and change into the way you run the group, as well as making special efforts to check on how you're doing by surveying the membership.

FORMALIZING YOUR COMMUNITY GROUP – SETTING UP A REGISTERED NOT-FOR-PROFIT SOCIETY

This chapter has focused on informal community-based organizations, but often many of these informal groups have provided the genesis of formal organizations that have tackled a myriad of issues. In the area of autism, developmental disabilities and mental health, the generally invisible nature of these conditions has often forced onto the shoulders of parents the obligation to found organizations in order to provide services.

To develop an infrastructure within which programs can be delivered, an organization requires funding. To apply for significant levels of funding, it is usually necessary to become established as a government-registered not-for-profit.

Registered Society
A registered not-for-profit society is a formal organization that meets government criteria. In British Columbia this process is governed under the *Societies Act*, which requires that a society must have at least five people who become the society's first board of directors and who are elected by the group's members. The society must register with the Registrar of Companies and file a Constitution and Bylaws that set out the purpose and governing rules of the organization. To find out more about becoming a registered society, go to the Ministry of Finance Corporate and Personal Property registries website: www.bcregistryservices.gov.bc.ca/bcreg/corppg/societies/index.page?.

The benefits of becoming a registered society are that members of the group can rely on an established mission or purpose statement and set of rules by which the group is operated. The disadvantages of registering as a society is that it can be difficult at the outset to find five people to serve on a board of directors who all agree on a common purpose. Often groups start informally and after gelling as an organization, start the process of registering as a society. This is particularly important if the intention of the group is to raise money for the work they are involved in, as most donors will not give significant sums of money to an informal organization.

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