

## Parent Support Group Action Pack



### Keeping your group going

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This guide is for information purposes only and is not intended to be a source of legal advice and must not be relied upon as such. Other organisations are listed for information purposes only and inclusion does not constitute endorsement by Contact.

## Introduction

When you first started your group, you put a great deal of thought into attracting members. You will have had a clear purpose and aims as to what you want to achieve with your group.

It is all too easy after a while to simply rely on the odd poster or word of mouth to keep your group alive and kicking. But you will need to adopt a concerted drive to keep your members and get new ones through the door.

Most local parent support groups worry at some stage about not having enough members. Common concerns are:

- the group is new and it is difficult to find people to join
- the group started off well but now numbers have dropped
- people come once or twice but don't come back
- there are several long-standing members but it seems impossible to attract new parents
- there are lots of members but hardly anyone comes to the meetings or offers to help
- how do you ensure people know about your group?
- having got new people along, how do you tempt them to come back?
- having got them back, how do you look after them so that they stay with the group?

Whatever the stage or size of your group there are some common steps you can take to tackle problems of low or inactive membership. There is usually more than one cause and so it is best to consider the various angles, such as:

- Is the group actually needed?
- If it is needed, how do you ensure people know about it?
- Having got new people along, how do you tempt them to come back?
- Having got them back, how do you look after them so that they stay with the group?

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### Is the group needed?

This may seem an odd question, particularly if your group is very well-established and everyone expects it to be there when needed. Long-standing members may value the friendship and help they have gained through the group and feel guilty at the prospect of not making it available to new parents.

However, parents groups do come and go: children grow up; members move on to other things or feel they no longer need the group.

Sometimes an established parents' group closes because its members lose interest and later a group of new parents decide to fill the gap. This is natural and very positive.

So, if your group has been around for a long time and is struggling with low numbers, get the active members together and discuss whether you wish the group to continue. It would also be helpful to acknowledge how much effort members can continue to offer to the group.

### **How well is the group functioning?**

Assuming that you wish to continue, it may be helpful for the active members to look at the group's overall functioning. For example, are you still carrying out your original aims and objectives or have these changed? We have produced a quiz to help groups evaluate their progress; you can find this at the back of this guide.

### **What do other members think?**

It would also be a good idea to write to all your members asking for their views on the value of the group. Their answers will be useful in thinking through how much work you need to put into recruiting new members. You could use the sample questionnaire at the back of this guide.

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## **Promoting your group**

You may have reached the point where you need a concerted publicity drive. It is worth revisiting the people who helped you publicise your group initially, and contacting them again to make sure your group is on their radar. People may have moved on and there may also be new organisations in your local area you can approach.

There are various methods you can use to tell parents about the support group. Choose the methods that work best for you. Try to get other parents involved in spreading the word.

### **Ask professionals to let parents know about you**

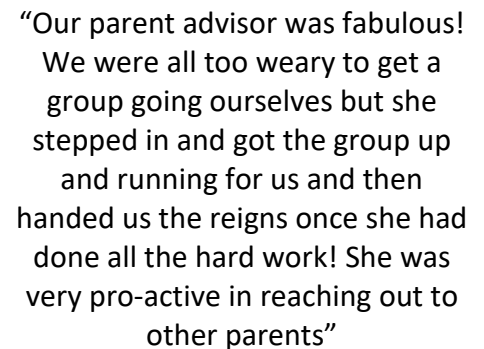
It is vital to build contacts with key friendly professionals who are likely to encourage other parents to make contact with your group. You can ask if they would be willing to hand out your literature to families accessing their services.

If you are clear about who your group is aiming to reach, it may be clearer who your useful contacts will be. For instance:

- parents whose children are deaf or have impaired hearing: useful contacts – ENT specialists, audiologists, speech therapists, educational support services, peripatetic teachers, National Deaf Children’s Society
- parents whose children have a learning disability: useful contacts – child development team, portage workers, community paediatrician, educational psychologist, opportunity playgroup, national charities such as Mencap and other local charities
- parents whose children have specific, rare conditions: useful contacts – specialists with an interest in the condition, specialist centres or clinics, charities or groups who support rare conditions
- parents in your local area regardless of their disability: useful contacts – schools, GPs’ surgeries, local shop noticeboards, libraries, local family information services, and if you are in England, your local parent carer forum.

They could also include:

- community paediatricians and child development teams
- early years workers such as health visitors, portage workers, pre-school teachers who work with children at home
- Information, Advice and Support Service for SEND (formerly Parent Partnership Services)
- special schools and SENCOs in mainstream schools
- local voluntary organisations and carers’ centres. For example, Barnardos, Carers Trust, Mencap
- social workers and family support workers
- children’s therapy teams such as occupational therapy, physiotherapy and speech and language therapy
- support workers and social workers in Child and Adolescent Mental Health Services (CAMHS).



“Our parent advisor was fabulous! We were all too weary to get a group going ourselves but she stepped in and got the group up and running for us and then handed us the reigns once she had done all the hard work! She was very pro-active in reaching out to other parents”

Choose some key professionals and invite them to attend the group and send a letter of introduction and some leaflets to other professionals asking them to let parents know about the group. Add your groups’ details on Facebook and local community websites. For more information see our Group Action Pack guide on [Social Networking](#).

## Information stalls at events

You can ask to have a stall at events which parents with disabled children are likely to attend.

This might include:

- school parents' evenings or annual fêtes
- disability-specific events and conferences
- family fun days
- local shows
- supermarkets/shopping centres

## Publicity

Reach the wider community with a press release - local newspapers and radio are always on the lookout for local stories and are usually keen to support good causes. You may like to find out which reporters have an interest in health, social services or consumer issues and build up a relationship between them and your parents' group. Let them know about events that are coming up and invite them along.

For more information about publicity and the media see our guide to [How to spread the word about your group](#).

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## The work of the group

### Sharing the work of the group

In the most effective groups, members share responsibility for tasks and making the group attractive to members. All this requires is organization and thought. Not every parent will be a consistently active member. Some may be unwilling or unable to play an active role – they may simply lack the time or energy.

Sharing the workload means:

- less work for one or two people
- more ideas
- more skills for the group
- individual skills development and confidence building
- a greater range of activities can be taken on
- commitment
- response to change and growth in the group
- greater democracy
- wider publicity outside the group
- valuing mutual support and individual contributions.

Factors that might stop people from joining in are:

- lack of confidence
- lack of experience
- lack of time
- the formality of structures
- domination by one person
- lack of information on how to do the job
- cliques
- class or cultural barriers
- no one ever asks!

## **How to encourage people to share in the work**

The following checklist gives some ways in which people can be encouraged to feel that their contribution counts, however small it may be.

### **Sharing decisions**

- everyone helps decide on the group's activities
- members are consulted and their views are heard.

### **Sharing work**

- list tasks and share them out; these could range from putting up some posters or making the coffee to booking the room, arranging speakers, writing the newsletter
- a large group with a big job could form sub-groups to work together on specific tasks
- work in pairs; perhaps a new person with a long-standing member
- even fairly inactive or new members may be willing to deliver some leaflets or put up a poster or make the coffee and tea one night
- if you have a committee, encourage different people to take on the roles of chair and secretary. Perhaps split the secretary's job into two; one to take minutes and one to respond to letters
- a time limit on jobs can ensure they are rotated regularly and new people are involved.

### **Sharing information**

- keep a record of how jobs are done so they can be passed on
- show new people how to do things as early as possible
- make use of people's contacts; for example a new member may have a good relationship with a helpful social worker or know a reporter on the local paper.

### **Sharing skills**

- don't let older members dominate forever
- fundraise for and offer training if appropriate to your group, for example, listening skills if you specialise in befriending

- give everyone a chance to contribute any skills they have, such as book-keeping, writing, speaking, design, fundraising

### **Sharing practical solutions**

- members may need a lift to the meetings or help with babysitting so that they can attend.

### **Going solo!**

Sometimes members of a support group may have a tendency to do everything themselves and appear reluctant to involve other people. This can be because they feel new people would not fit in to the existing group or they would have too much to learn to get up to speed, or on a basic human level, the members of the founding group feel that they 'own' the support group. This is a well-known phenomenon that happens with groups, and it is understandable. It is sometimes referred to as 'founder syndrome'.

A founder who is at the centre of all decision-making with little input from others, who may have few other interests or projects, devoting nearly all his/her time to the group and makes comments such as, "I don't know what would happen without me, I have been here for years". Founder syndrome can happen to extremely talented and dedicated individuals.

Sharing the workload avoids 'founder syndrome' and also prevents all the effort and work falling to one or two people.

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## **Relationships in the group**

A friendly, accepting atmosphere is vital to members' well-being. The group needs to be a haven for members, somewhere to escape to from their daily struggles and hassles. This can be best achieved by the following:

### **Remaining sensitive to members' emotional needs**

- listening to everyone's point of view
- allowing time to share feelings
- supporting members through crises
- not forming cliques.

### **Finding ways to relax**

- having interesting speakers
- going on group outings
- including families for special events

- giving yourselves treats.

You could also revisit the information on the emotional needs of the group in our guide to [Starting a parent support group](#).

## Managing conflict

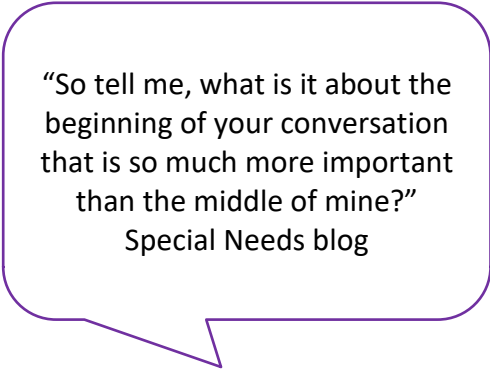
Whilst our desire to share our experiences ultimately brings us together, one of the most common causes of groups disbanding is because of unresolved conflict or when one person dominates. People come from different cultures and backgrounds and have different opinions and values. This, coupled with stressful and emotional situations in peoples' lives, can have a big impact on how parents interact with one another. Conflict can actually be an important step in building and maintaining relationships if addressed constructively. So what can cause conflict? (This list is non-exhaustive):

- personality clashes
- disagreements
- domination of one person (monopolising time and space)
- not being listened to
- disrespectful language being used
- people simply having a bad day
- lack of confidence.

Remember, it need not necessarily be the chairperson or group leader who has the skills to deal with conflict. There might be a member who has natural 'people' skills, is a good listener and diffuser of problems. As stated earlier, it is always a good idea to form some ground rules for your group and have them on display during each session.

## Resolving conflict

- Start a discussion between the parties concerned, and agree a time to try and resolve the problem through negotiation rather than arguing in the heat of the moment. Refer back to your ground rules as it is possible these have been broken.
- Ask for each person's view of the situation giving everyone equal time to speak without interruption, assuring them that you respect their opinion. Be sure to focus on how the conflict is affecting the group and leave personalities out of the discussion.
- You will need to agree to a mutual solution that everyone has had a fair input into and will find acceptable.



“So tell me, what is it about the beginning of your conversation that is so much more important than the middle of mine?”  
Special Needs blog



- If everyone is satisfied with the solution, then ask each person what they think would solve the problem. This could yield lots of ideas and suggestions.
- Hopefully the conflict has been resolved and a better understanding gained of the position of others. Failing this, a compromise will need to be negotiated that will satisfy everyone to some extent.

Often just being given the opportunity to speak uninterrupted, and have someone listen to what the issues are and how they affect the other person, can be a major step towards the resolution of a conflict. People are often so caught up in how something affects them or their child that they do not consider the bigger picture or think about how the same issues may affect others in very different ways.

### **TOP TIPS**

- Managing conflict calmly is key to neutralising or resolving it
- Develop team 'ground rules' that commit to respecting the views of others
- listen to all sides of an argument
- encourage individuals to move from their fixed positions or interests
- Try to find solutions that incorporate any different viewpoints, if possible.
- Thank people for their contribution to the discussion.
- Ensure that any decisions are made collectively – by vote if necessary, and are recorded.
- Ensure you have a code of conduct so there are agreed processes for managing very difficult situations before they occur.
- help people focus on what is needed in order to move beyond the issue
- encourage the group to find a solution which is owned and acceptable to all parties
- write an agreement which everyone must stick to
- enable the support group to refocus their attention on the positive outcomes they are trying to achieve.

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## **Keeping your group interesting**

### **Invite a speaker**

Many groups like to invite guest speakers from time to time. They can:

- offer valuable information
- stimulate discussion
- bring in new ideas
- be encouraged to put other parents in touch with you
- maintain your contacts with other organisations.

## **Choosing a speaker**

You can overcome any worry about small turnouts for guest speakers if you check in advance that there is a genuine interest in the speaker and topic and you publicise the event adequately. You will also feel more comfortable if you warn the speaker beforehand that attendance at meetings can fluctuate!

Your members may be interested in a variety of speakers, including people:

- with specialised professional knowledge
- with experience of running a support group
- who are trying new approaches to supporting and informing parents
- who are involved in local campaigns of interest to your group
- who provide services in your area

Ask your members who they would like to come and speak at their group. Compile a list that can be added to for new members and new ideas and suggestions.

## **Practical details**

Don't forget to brief the speaker before the meeting with the details of the meeting time and place, what you want them to talk about and for how long and any expectations that the group might have of the session. They might also require travel expenses.

You will also need to publicise the meeting in advance and arrange the venue on the day, with seating arrangements, any audio-visual equipment and refreshments, if provided.

You may find it best to leave practical details to one or two members. Making arrangements for a meeting can be a good way of involving newer members, particularly if you prepare a checklist of what needs to be covered. Working alongside a more experienced member will help to share skills and responsibilities and develop confidence in new members.

## **Put on different activities**

Ask your group if they are interested in any particular activities, or learning about something new. Most local charities and services will be happy to come along and talk about what they do. Some may be funded by the local authority to provide sessions free to particular groups – for example relaxation techniques, healthy eating/cookery class, or hand massages. Have a trawl of businesses and charities in your local area to see what they offer. Also national charities may also have people who will come and talk to your group.

Here is an example of a local support group's programme:

## Salisbury Footsteps Group Programme

<b>January</b>	Talkabout
<b>February</b>	Speaker – Educational Psychologist on Assessments and EHC Plans
<b>March</b>	Talkabout
<b>April</b>	Easter Holiday event for all the family
<b>May</b>	Talkabout
<b>June</b>	Relaxation Techniques Family picnic (bring and share picnic, drinks provided)
<b>July</b>	Summer coffee morning – introduce a friend to Footsteps (bring summer food/fruit to share)
<b>August</b>	NO MEETING
<b>September</b>	Talkabout Evening Social at the Pelican Inn
<b>October</b>	Speaker – Sex education and growing up for the special needs child
<b>November</b>	Talkabout Group Information Stall at the CDC Open Day
<b>December</b>	Coffee morning Christmas Party for all the family

TALKABOUT mornings are for you to talk about your concerns and to share experiences with other group members.

Adapted from a Footsteps Programme with kind permission of the group.

## Being inclusive

There may be challenges in creating a group which is truly inclusive but being aware of the issues involved and being committed to including all parents is important.

If you are trying to make a parent support group as inclusive as possible, it is important that this message is conveyed through the group's publicity. If you use photos on group leaflets or posters, make sure they reflect ethnic diversity, otherwise some parents may assume the group is not for them. Similarly, if you are keen that fathers come along, include pictures of dads in flyers. You can also arrange meetings at times and with activities planned that are more attractive to fathers.

Depending on the diversity of your local area, you might also want to produce some publicity in community languages, or publicise the group through organisations who support specific communities.

Try to make events and meetings accessible to as many people as possible:

- consider having events at different times of the day, including evenings and weekends so more parents can attend
- choose dates that do not clash with religious festivals and holidays
- make arrangements for people with special dietary requirements, including religious ones
- choose venues that are as culturally neutral as possible
- if running an all day event be aware some members may need to worship at different times of the day and a separate room or area may be required for this.

## Targeting 'hard-to-reach' groups

At some stage you will want to review your membership to find out if there are particular groups of parent carers you have not yet reached.

These might include:

- parents from minority ethnic groups, including parent carers who do not speak or read English
- parents of children with very complex needs, who might find it difficult to leave the house
- parents who live in geographically isolated areas
- parents whose children are 'under the radar' because their children are in mainstream settings
- parents who move round a lot and/or are in temporary accommodation
- parents with low levels of literacy and/or learning disabilities
- families from the armed forces
- teenage mothers
- parents with mental health problems or fathers
- single parents
- parents who work
- disabled parents.

Families from hard-to-reach groups often have the most trouble accessing services, so your group could really help them.

Rather than expecting parents from different communities to come to you, you might want to try to meet with them in settings where they already meet. They are more likely to agree to meet with you if you are introduced to them by someone they trust. Try to make links with organisations in your area who work with a particular community. Your local voluntary action groups should be able to help you with this. You can find their details at [www.navca.org.uk](http://www.navca.org.uk)

Alternatively, many communities have leaders or elders who are trusted by members of the community or speak on their behalf. Try to meet them and ask for their help in making contact with families who have disabled children.

### **Useful resources**

Further information about religious festivals and holidays and calendars of religious festivals can be found at:

[www.interfaith.org.uk](http://www.interfaith.org.uk)

You can check school holidays for your areas on your local authority website.

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## **Checking on progress**

Support groups have lives of their own. Like individuals they progress from infancy through adolescence to maturity; they grow at different rates, and can go backwards as well as forwards. Attendance can fluctuate. Groups come and they go.

The stages in group development have been described as: forming; storming; norming; performing. You might find this a helpful way of looking at your group.

### **Forming**

At the beginning of a group's life, people can feel anxious or shy or unwilling to commit themselves. It is therefore very important to be friendly and welcoming to everyone; to be supportive and encourage people to contribute at the level that feels right for them.

### **Storming**

As people become more confident they may start to disagree about how the group should be run. This is a sign that people are beginning to care about the group. It is very important to listen to everyone's views and to share decision making as much as possible

### **Norming**

Members will now begin to trust each other more and to feel a sense of belonging to the group. This is a good time to encourage members to develop new skills and perhaps to try a new venture.

### **Performing**

At this stage everyone feels responsible for the group and members are able to listen to each other, express their opinions freely and share responsibility for the group working well.

## What makes a healthy group?

Planning on areas to address from the start ensures the success of your group; and getting into the habit of regularly taking stock and reviewing the health of your group will help you spot problem areas quickly.

To help you concentrate the planning of some of your key areas when setting up a new group, or to take stock and review the state of your groups' current activities, we have produced a 'health checklist'. This checklist is a basic tool to help you ask some of the questions you need to and make a record of areas for development or improvement.

### How to use the checklist

The checklist can help give you an idea of development around areas of setting up and running your support group, whether you are a 'coffee and chat' group or running a short breaks scheme. The categories are:

- Networking
- State of Play
- Management and Planning
- Governance

Categories within our checklist are divided with statements to help you best reflect the position of your group. The columns listed in the tables enable you to identify the progress needed to meet your targets. The options for each column are:

- ✓ To do – target to be considered
- ✓ Making progress/ongoing – work on the target has started
- ✓ Fully met – you have achieved your aim and have the correct guidelines, activities and policies in place
- ✓ Not needed for now – self-explanatory!

In each column, tick the option that matches the accompanying statement. There is also room for you to make notes.

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Networking	To do	Making Progress/ ongoing	Fully Met	Not needed for now
Members participate and know of local and regional networks to share ideas and to know what is going on within the community				
We publicise our group in a myriad of ways (examples): <ul style="list-style-type: none"> <li>• posters</li> <li>• newsletters</li> <li>• using the media effectively</li> </ul>				
We make links with professionals who can support our group through: <ul style="list-style-type: none"> <li>• speaking out for our group</li> <li>• sharing of information</li> <li>• working in partnership for the common good of the service provision</li> </ul>				
We work with other organisations and support groups to develop new ideas and ensure needs are being addressed and to: <ul style="list-style-type: none"> <li>• avoid duplication of services</li> <li>• reach new members</li> </ul>				
Notes				

Management and Planning		To do	Making Progress/ ongoing	Fully Met	Not needed for now
1	The constitution is reviewed regularly to identify changing needs				
2	We react to the needs of the community				
3	The group regularly seeks feedback on the quality the groups' services and activities from: <ul style="list-style-type: none"> <li>• members/users</li> <li>• volunteers</li> </ul>				
4	We keep records of all our money and a statement is produced every year				
5	We monitor our strengths and weaknesses to effectively plan for our future aims				
6	We know where to identify grants locally and nationally				
7	We keep records to assist us in making grant applications				
8	We plan activities clearly and well in advance Notes				



Governance		Not Met	Making Progress/ ongoing	Fully Met	Not needed for now
1	Resources and policies are in place: <ul style="list-style-type: none"> <li>• to meet health and safety standards</li> <li>• to safeguard working with children and vulnerable adults</li> <li>• for appropriate insurance cover i.e public liability;</li> <li>• equal opportunities</li> <li>• confidentiality</li> <li>• volunteer policy</li> </ul>				
2	Training is offered to volunteers if appropriate to their role: <ul style="list-style-type: none"> <li>• induction</li> <li>• clear role description</li> <li>• child safety</li> <li>• first aid</li> </ul>				
3	Training opportunities are sourced for parents: <ul style="list-style-type: none"> <li>• from local charities and the local authority for parent empowerment</li> <li>• from condition specific charities</li> </ul>				
4	Resources are showcased to share at each meeting				
5	Volunteering opportunities are widely publicised Notes				

## The Contact parent support group quiz

This quiz should be completed as a group exercise as this will aid discussion about the group's progress. Your group may like to distribute a copy to each member to complete, but it is best filled in and discussed in one session while ideas are fresh.

Read the three statements in each area and tick the one that you think best matches your group. Then simply add up your scores at the end. You must answer all the questions.

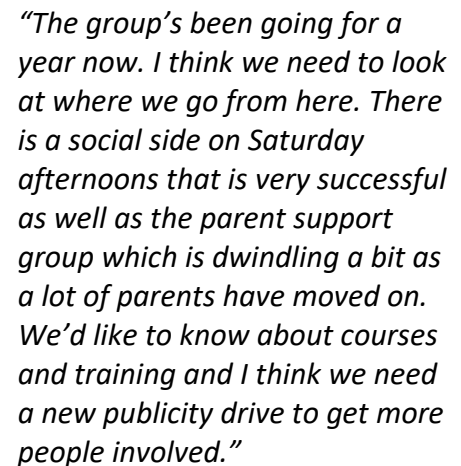
Then see how your answers compare! If individual members have different answers to some of the questions try to use this as an opportunity to open up a discussion about the group and a chance to resolve some differences. Or your responses could remain anonymous and you could also add your own questions or modify the ones suggested.

### Aims and objectives

- A We all agree on our aims
  - B Some of us agree on our aims
  - C We haven't a clue what our aims are
- 
- A We carry out our aims
  - B We sometimes get side-tracked from our aims
  - C We do whatever we feel like at the time
- 
- A Our publicity accurately reflects our aims
  - B We are not publicising our group well enough
  - C What publicity?

### Comfort and convenience

- A The room in which we meet is right for our needs
  - B Some people dislike things about the room
  - C Everyone dislikes the meeting room
- 
- A The time of day we meet suits most people
  - B We lose some members because of the time we meet
  - C Hardly anyone can come at the time we have chosen
- 
- A We are all pretty happy with the location
  - B Some people are put off by the location
  - C We know the location is not suitable



*"The group's been going for a year now. I think we need to look at where we go from here. There is a social side on Saturday afternoons that is very successful as well as the parent support group which is dwindling a bit as a lot of parents have moved on. We'd like to know about courses and training and I think we need a new publicity drive to get more people involved."*

## Views on meetings

- A We all enjoy the meetings and learn something
  - B Some of us do not enjoy some of the meetings
  - C Most of us feel the meetings are a let down
- 
- A We can all grumble or laugh and not feel silly
  - B Some of us feel awkward sharing our real feelings
  - C Everyone feels awkward about sharing their feelings
- 
- A We all get on well and listen to each other
  - B Some people are rather annoying
  - C We are not close to each other and our emotional needs are not being met

## Sharing

- A We all decide what to do
  - B Some people decide what to do and tell the rest
  - C One person decides
- 
- A We list the jobs and share them out
  - B The same few people do all the work
  - C One person does all the work
- 
- A Everyone has a chance to use their skills
  - B A few people use their skills
  - C Hardly anyone uses their skills
- 
- A We have a great variety of skills and knowledge in our group
  - B Some of us would like to learn more skills
  - C We badly need help with fundraising, publicity, etc
- 
- A We all welcome new members
  - B Some make the effort to welcome new people
  - C No one is responsible for looking after new members
- 
- A We all seem to share the leadership around
  - B Leadership is delegated to a few people
  - C We have had the same leader since we started
- 
- A We have a good selection of resources
  - B We have the odd magazine
  - C We have no resources whatsoever

## Membership

- A We have a comfortable flow of new members
  - B We have a trickle of new members
  - C We are desperate for new members
- 
- A We are happy that people are hearing about our group
  - B We wish we could get more publicity for our group
  - C No one seems to know that we exist

## Networking

- A We engage with other support groups and organisations in our area
  - B We are selective as to who we deal with
  - C We doubt anyone really knows we are here
- 
- A We are happy with our relationship with professional workers
  - B We would like more/less contact with professionals
  - C We want to change our relationship with professional workers
- 
- A Professionals tell people about our group
  - B Some professional workers sometimes advertise our group
  - C Professionals are not involved

## Scoring

A = 3, B = 2, C = 1

### A score of 55–60

You have a very happy group whose members feel a high level of satisfaction. This is a good time to take on new challenges if members all feel like doing so.

### A score of 35–54

Your group is ticking along and satisfying some of its members but most would like it to improve in various areas. Have a look at your B and C answers and see if you can pinpoint any areas where you could focus your efforts as a group.

### A score of 26–34

Your members seem to be quite dissatisfied about several aspects of the group. You might find it helpful to identify which areas are causing problems and then talk them through with a Contact development worker or with a worker from a local self-help support team.

### A score of 20–25

If you are a very new group everyone may still need time to settle down and decide the group's direction and get to know each other. If you are an older group then such a high level of dissatisfaction calls for a thorough review of your aims and objectives.

## Sample Questionnaire

### \*\*\*\* Parents' Support Group

The \*\*\*\* Parents' Support Group is planning future activities and, to help us, we are asking members for your views on the group as it is now and how it could develop. Please spare a few moments to fill in this questionnaire as it will be important for our future. Thank you!

**1. Please tick anything you would like to see retained; a double tick if it is especially important to you!**

a. Which of our aims do you value?

- Supporting each other
- Raising awareness of children's needs
- Providing information
- Campaigning for better services

Any others?

b. Which activities do you enjoy?

- Evening meetings with a speaker
- Family outings
- Coffee mornings
- Social events

Any others?

**2. Please could you list the group aspects you would most like to see developed in order or priority:**

- Linking families in similar circumstances
- Sympathetic listening ear for newly diagnosed families

- User friendly information for families with disabled children
- Additional information, e.g. benefits
- Regular newsletter
- Fundraising events
- Information on current research
- Family activities

Other (please state and list in order of priority)

**3. To take the group forward, we need a small number of committed parents to help run the group. Are you able to help with any of the following?**

- Booking the room
- Booking the speakers
- Photocopying
- Help writing leaflets/posters
- Transport for people without cars
- Organising tea and coffee
- Putting up posters
- Looking after the money
- Taking notes at meetings
- Becoming a member of the committee
- Accompanying a new members to early meetings
- Working on a group newsletter
- Fundraising for group activities/becoming a member of the Fundraising sub-group
- Helping to organise a family activity days/other group events

Any other ways? (please state)

Your name: \_\_\_\_\_

Telephone number: \_\_\_\_\_

**Thank you for completing this questionnaire.  
Please return it to \*\*\*\*\* by \*\*\*\*\***