

## Parent Support Group Action Pack



### Starting a local parent support group

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*“I couldn’t find any helpful information when Hayley was diagnosed. I started a local group so that other parents would know they are not alone. We really support each other through our ups and downs and have a laugh too.”*

#### **Why start a support group?**

Parents with disabled children often tell us that the support they receive from other parents is invaluable. A support group provides an opportunity for parents to share their feelings, problems and ideas with others in a similar situation and to be listened to without feeling judged; to relax and feel useful to the group. This lessens parents’ feelings of isolation.

Local groups vary in terms of the type of service they offer and can be open to parents and carers of children with any disability. Others are for parents whose children have the same condition.

Groups generally offer:

- friendship
- opportunities to socialise
- information and advice
- emotional and moral support
- a listening ear
- a regular meeting place
- activities such as a crèche for siblings or family days out.

This guide aims to equip you with the basic information on what setting up such a group can involve. It should help you through those first stages. Each group will be different so you may find some areas covered here are more relevant than others.

Contact is in touch with hundreds of parent support groups. Our guide is based on the extensive experience of parents of disabled children who have set up local groups and want to encourage and support other parents in their venture.

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## **Before you start**

At this stage, it is helpful to ask yourself a few questions:

### **Is there already a group in your area?**

It is worth checking with:

- other parents
- your local offer
- your parent carer forum
- parent Support Advisors (PSA's)
- your local children's centres
- family support workers
- Sencos
- health visitors.

We may also know of active groups in your area – you can find out by calling our freephone helpline.

### **Do you have the time and energy?**

Supporting others can make a lot of emotional demands. Whilst a mutual support group means you receive as well as give, in the early days it is likely that the main demands will be on you. This can have an impact on your family life. If you are going through a particularly stressful period with your own child, try to weigh up whether you have the emotional energy to spare to support others.

## **We can support you**

You might find it helpful to talk over these and other questions with us. Contact's local group manager can offer support now when you're thinking about it, when you are about to start up, and at every stage of your group's progress. She can also put you in contact with other parents who have gone through this process and who can share their experience. Contact Adele at:

 [Adele.meader@contact.org.uk](mailto:Adele.meader@contact.org.uk)  07920 655 125

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## Section 1: First steps in creating your group

Once you have decided to go ahead, try to test your ideas out on other parents. Making contact with some like-minded people at this stage can reassure you that you are on the right track and spark off new possibilities. Other parents can help to share:

- ✓ experiences
- ✓ ideas
- ✓ the development of the group.

The more ideas at this stage, the more likely your group is to appeal to a wide range of parents, and the more support you will have in running the group.

### Sounding out those first ideas

Local support groups may start off by a couple of parents meeting up and then spreading the word. It is not uncommon to hear of groups who start up 'organically' such as parents wanting to meet up after meeting at a child's birthday party for instance.

But if you're starting from scratch, using your local knowledge and talking to other parents will be a good guide to where and how parents in your area will hear about you. Every neighbourhood has its own particular grapevine of networks and contact points. Get in touch with your local carers' centre, who may already know of support groups, and may be able to put you in touch with parents who want to join your group. They may also be able to publicise your group for you:

You can find your local carers centre at <https://www.carers.org/carers-services/find-your-local-service>

In England your local parent carer forum may also run a support group, know of other local ones, or be able to put you in touch with parents. Why not sign up and promote your group amongst the network?

You can find your local parent carer forum see <http://www.nnpf.org.uk/who-we-are/find-your-local-forum/>

People will also usually be willing to display a card asking parents to contact you in places such as libraries, school and public notice boards, and GP surgeries.

## Professionals

Professionals cannot give out parents' details, but are also an important resource; using their networks will help you to publicise the group to your target audience. They may be willing to pass on a letter or leaflet about your group. There is more about working with professionals later in this guide.

## Be safe

You need to protect your own confidentiality by just giving out your first names and phone numbers, without your address. Send a letter of introduction and some leaflets to professionals in health, care and social settings, asking them to let parents know about the group. You could also ask to add your groups' details on to local community and local authority websites.

## Remember!

The most important aspect of planning your first meeting is deciding what your aims are going to be and what you want to achieve.

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## Setting up your group's aims

One of the most important aspects of setting up a new group is to be clear about what you want to achieve through this. It may help to draw up a brief list of aims. This can clarify why the group is being set up and provides a base from which to develop. It also gives you a framework for deciding what needs to be done to move the group forward. Keep your aims short and simple.

### ***Aims of the \*\*\*\*\* Support Group***

To offer support to other families affected by \*\*\*\*\*

To raise awareness of \*\*\*\*\* with professional workers and other interested individuals

To raise awareness of the \*\*\*\*\* Support Group

Setting out the group's aims will enable you to avoid any problems or misunderstandings among yourselves. It will also help you to create a clear image of the group and its role which you can present to the outside world, including potential members. Some groups start with a very specific aim; others are more broadly-based. The majority of groups have some or all of the following aims:

- ✓ supporting parents in similar situations
- ✓ sharing information and exchanging ideas
- ✓ raising awareness of the needs of children and families
- ✓ campaigning for better services for children and families.

“Our aim is to inform, encourage and support parents, allowing them to grow in strength and knowledge so that they are better equipped to give the best possible help to their children.”

Multi-disability group

“To support and provide information to Asian women who have and care for children with a range of special needs. To organise educational and recreational activities for these women and their children. To meet on a weekly basis including during the holidays. To remain independent and represent the views of Asian parents of children with special needs.”

Multi-disability group

Your aims are a reminder of what holds you together as a group and a base on which to build your publicity. They need not be fixed in stone but you may want to make changes as the group develops. When you’ve decided on your aims, you can then think about how you will go about achieving your aims in practice – this can form your objectives. Again these don’t need to be fixed in stone and can be developed as you grow.

#### **EXAMPLE GROUP AIM**

To support families with disabled children

#### **EXAMPLE OBJECTIVES**

- To hold a monthly meeting and evening social events.
- To bring carers together to share experiences and reduce isolation.
- To have a contact list enabling members to support each other in-between meetings.
- To expand knowledge of local and national services.
- To provide activities during school holidays.
- Develop personal skills of carers.
- Develop links with other carers support groups within the city and surrounding area.
- Maintain a safe environment for our children - Child Protection Plan in place.

A group can do both, providing everyone is clear about what your aims are and you can maintain a balance with which everyone feels comfortable. It can be of help, though, not to be too ambitious to start with and so give the group time to develop. Small steps can lead to a more lasting and stable group.

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## Planning your first meeting

Your first meeting may feel a little daunting regardless of the type of group you run. There are however, a few tried and tested ways of making meetings more manageable. With good preparation, a clear idea of its purpose and a positive approach on the day, you have a much better chance of holding a successful meeting. The most important aspect of planning is deciding what you want to achieve in the meeting. At the first meeting of the group, the aims will probably be short and simple, for instance:

- to share your ideas on starting a group and to hear from other parents
- to get names and addresses of those interested in forming a group
- to set the date of a second meeting.

You could also prepare a simple agenda, for example:

<b>Agenda</b> for meeting on .....	
1.	Welcome
2.	Introductions
3.	Starting a group <ul style="list-style-type: none"><li>• your ideas so far</li><li>• are people interested in a group?</li><li>• what would they like the group to do?</li></ul>
4.	Refreshments
5.	Next meeting <ul style="list-style-type: none"><li>• date</li><li>• topic for discussion</li></ul>
6.	Any other business
7.	Take names and addresses
8.	Close meeting

At a later stage, your agenda can include items on developing your group, time for mutual support and sharing, and guest speakers.

If you are holding informal meetings to provide mutual support, you are unlikely to need an agenda, but it can be helpful to have a basic structure in place so you know what needs to

happen when, for example, greeting people, introducing yourselves, break, wrap up and date of next meeting.

## **What to do in advance of your first meeting - the practicalities**

### **Considering venues**

Bear in mind the following points when choosing a venue:

- a central location, if possible served by public transport and with car parking space physically accessible
- a flexible enough space to use for your various needs - formal and informal meetings, private conversation, a crèche etc
- comfortable in terms of seating, heating and sound levels
- available at a time to suit the group's needs
- access to a kitchen if you provide refreshments
- storage space for your equipment or literature if required

Don't forget to check if any cost is involved for the hire of the venue and whether there are any concessions or help with funding.

Many groups feel that independence and a place where parents feel they can talk freely is one of the most important considerations in choosing where to meet.

### **Practical tasks**

Decide in advance how to share out practical tasks - this can avoid confusion on the day. If you are an individual parent who is at the stage of testing out potential interest in a group, think about asking a friend or relative to help you with some of the practicalities.

Practical details to consider include:

- who will welcome parents as they arrive
- think about your seating arrangement in the type of room you have – what is more friendly? A circle or horseshoe shape may be more friendly than rows of chairs and encourages discussion
- who will put notices on the door to direct people
- who will deal with refreshments
- who will chair the meeting
- who will take names and addresses of interested parents
- what notes do you want to take and who will take them?

It can also be helpful to ask local services for families with disabled children to send you information about their services. You can take the leaflets to the venue for parents to look

through and talk about – some parents may already use them so can recommend (or not!) to others.

For information on how to run your first meetings, encouraging discussions, chairing meetings and coping with any problems, see our guide to ***Holding effective meetings***.

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## **Section 2: Your first parent support group meeting**

### **Welcoming people**

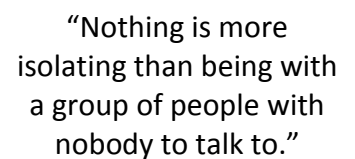
A friendly, accepting atmosphere is vital to members' well-being. The group needs to be a haven for members, therefore it is a good idea to form some ground rules for your members and have them on display during each session. Here are some examples you could list:

- remain sensitive to each other's emotional needs
- listen to everyone's point of view
- allow time to share feelings
- support each other through crises
- do not form cliques.

### **Being the newcomer**

As well as being a 'stranger', it is likely that when you are setting up a group, the parents coming along will be experiencing some or all of the following:

- low confidence/self-esteem
- that their parenting skills are under scrutiny
- a feeling that their knowledge of their child is not valued
- anxiety about their child
- a need for support and information
- hopes that the group can help
- anxious about walking into a room of strangers
- feeling excluded because group members all know each other.



“Nothing is more isolating than being with a group of people with nobody to talk to.”

Make sure you greet each person, offer them a drink (if you can) and introduce any other parents there informally. It is helpful to have some information handy that might be useful to them – for example information about local services and support you've gathered.

### **Top tips**

- Can you offer to meet newcomers beforehand or take them along to their first meeting?



- Consider having a map of the venue meeting times and information on public transport to send out

As your group develops, it can be helpful to have one or two members who will:

- welcome new parents
- introduce new parents to other members
- find out what new parents would like from the group
- Encourage discussion

Make sure you greet each person, offer them a drink (if you can) and introduce any other parents there informally. It is helpful to have some information handy that might be useful to them – for example information about local services and support you’ve gathered.

## **Opening the meeting**

In opening the meeting, ask everyone introduce themselves briefly. It is worthwhile saying that if anyone prefers not to speak at this stage, this is all right.

Take into account the number of people present. If there is a large number, individual introductions could take a long time: in that case, you could start by keeping your own introduction brief and moving on to someone else who will follow your lead.

The agenda will indicate what you hope to achieve from this meeting. Be clear about why the meeting has been called. This will help people to focus their contributions. You might also like to ask if there is anything else people would like to discuss on this occasion and add it to the end of the agenda as ‘Any other business’ (AOB).

## **Getting to know each other**

When parents first come to your group, it is likely that they will spend time talking about your children, their experiences, the difficulties they have overcome and the ones still to be faced. Allow parents time to get to know each other and listen to each other’s personal stories. One of you may have battled through the assessment and statementing process. Another may have a child who needs frequent medical care at the hospital 50 miles away. Someone else may be worrying about how to divide their time between their disabled child and their other children.

Ways to encourage people to join in include:

- making sure that you make eye contact with everyone
- addressing people by name
- referring back to what someone said earlier, such as, “I think you said when you were introducing yourself ...”

- linking different ideas, for instance, “What you were just saying reminded me of what Jill said earlier. Has anyone else found ...?”

## **After each session**

Thank everyone for coming and acknowledge everyone’s contributions.

While the meeting is still fresh in your mind, it is worth discussing with the core group how you felt about it and how far your aims were achieved. At this early state, it can be helpful to avoid falling into fixed roles. For instance, some groups make a conscious decision to rotate the Chair, or to have a rota for tea making. This allows everyone to try something new and build up their confidence and feeling of ownership of the group.

Recording the content and conclusions of the meeting can be as formal or informal as you wish. It will be useful, however, to keep some written record for future reference.

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## **Do you need a committee?**

At this stage in the life of the group, you may want to keep the business as simple and informal as possible and not have all the usual titles involved if you have a committee - chair, secretary, treasurer.

However, it can be helpful to look at what jobs need doing. In the early days, you will want to do some or all of the following:

- create and distribute publicity
- talk to new parents
- make practical arrangements, e.g. booking a meeting place
- gather information
- look after any finances
- raise funds
- talk to professional workers about the group
- make contact and network with useful organisations specific to your group.

These tasks can be carried out formally or informally. It’s important to share responsibilities so parents feel a sense of ownership of the group, and so the work doesn’t fall to one or two people.

Some of these tasks can be done by all group members, such as publicising the group. But it may be more effective to have just one person responsible for some tasks, such as looking after

finances. Other activities can be done by a number of members in rotation, such as making practical arrangements, or leading the group.

Allow for everyone to try something new and build up their confidence and feeling of ownership of the group.

Sharing out the tasks can help you decide whether or not you need a formal structure to run the group, like a committee. If you decide you would like to set up a committee see our guide to [Legal structures for parent support groups](#).

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## Keeping in touch with everyone

It's worth thinking at this early stage how you're going to make families feel part of the group, and regular contact with your group members can help to make them feel involved and connected to you. There are a number of ways to make keeping in touch with people easier:

- keep a database of members, so that everyone's contact details are all in the same place. It doesn't have to be a fancy database, a spreadsheet would also work well
  - ask parents for ideas of what information they'd like to receive – for example you might get news from around your local area of interest you can pass on – this could be the start of a newsletter!
  - Think about arranging local 'get-togethers'
  - consider the various methods of communication – eg Facebook, Twitter, website, text, email – and find out what works best for your group.
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## Finances

The person who starts the group often bears the initial cost out of their own pocket. To overcome this, many parents' groups like to have some funds available so that all members can participate fully without making too much impact on the family budget.

The cost of running a group at this stage can include the following:

- stationery
- phone calls
- photocopying/printing
- room hire
- refreshments

## Sources of funding

Grants from the public sector may include 'starter grants' from local and district councils and grants from trusts or private companies. This will depend on what sector of the community they wish to support.

Your Local Infrastructure Organisation should have information about local sources of funding and will hold details of large and small grant-making bodies, as well as resources available to small groups at a reasonable cost. If you decide to apply for a grant, staff there may be able to help you prepare your application. Many voluntary bodies, such as the Round Table and Rotary, like to support local good causes, including smaller ones like your new group.

Many groups use their own resources, contacts and ideas to raise money. These can include car boot sales, raffles, social activities and sponsored events. But before you put a lot of energy and resources into fundraising, be clear about what you want the money for, so that fundraising does not become an end in itself, if that is not one of your group's main aims.

For further ideas on fundraising, see our guide, [Fundraising for parent support groups](#).

### How two new groups raised money and resources

One parent approached her local authority under the Aiming High 'short breaks' programme for parents and their children to access activities during the school holidays. A grant of £5,000 allowed the group to provide a service, hence identifying a need within that particular authority and leading to extra provision and further grants.

Another group held an open afternoon at a local pub. On the day, £280 was raised from raffles and other stalls. A pub customer who heard about the event was also a member of the amateur dramatic society which 'adopts' a local cause each year, through fundraising at its productions. During their first full year, the group received £350 this way, and additional publicity.

## Help in kind

Members or friends may be able to offer help in kind rather than in cash, such as providing photocopying, envelopes and paper or a raffle prize. Local publicity will sometimes result in offers of help, so when talking about the group use the opportunity to mention ways in which people can assist.

## Looking after your money

Your group has a responsibility to its members and donors to keep an accurate, current record of finances. This does not have to be an elaborate or complicated exercise, just a simple, clear account of money coming in and going out.

If you anticipate raising a large sum of money each year, it is worth contacting the Charity Commission. Their contact details are: <http://www.charity-commission.gov.uk>

If you have a bank account in the name of your group, ensure you have two signatories, not related to each other.

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## Creating an identity

Once you have decided to form your group, you need to establish its identity through choosing a name and, possibly, a logo or visual image. Choosing a name can be fun. A name might arise from your discussion of the role and aims of the group. For instance, a group may decide on a name that indicates:

### Who they are for

Families and Friends

Jawaan Aur Azaad ('young and free', group for disabled young people)

Asian Deaf Children's Group

### The area they cover

Edgbaston Mother and Baby Group

Bordsley Integration Group where they meet

Parents at '93

Millwood Parents' Group

### When they meet

First Thursday Group

### Their aims

Parents for Parents

SCOL: Supporting Children in Ordinary Living

Dhek Bhal ('looking after'/'caring for')

Time Out Social Group

## **The atmosphere they want to create**

Bridges

Positive Parents

Connect

Open Door

Oasis

In your discussion about names you may find that parents differ in their reaction to words commonly used about you and your child, for example:

- learning disability
- sufferer
- self-help
- special needs
- additional needs
- disabled
- support
- carer
- problem

If you do disagree about such terms, you should bring all your ideas into the open and listen to each other's feelings. Try to find a name that:

- reflects what you are as a group
- you all feel comfortable with
- doesn't give offence to others, or put them off
- is reasonably 'catchy' and memorable

A couple of points to remember when choosing a name:

1. Avoid a name used by another well-known group (if they are a charity, you would not be allowed to use the same name).
2. If you are linked to a national group, and want to take their name, be clear what that means for your group's independence, fundraising and other commitments to the national organisation.

As well as a name you may also wish to decide on a logo – a visual image – for your group. This can range from the choice of typeface and/or colour for your letterheads/posters etc, up to an illustration or 'mascot' which you can incorporate into your publicity material. You may have a member with IT or design skills which can be useful here. Some groups use computer clip art cartoons.

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## Contact's Local Parent Support Group Affiliation Scheme

At this early stage you may be wondering if it would help to join a national charity, by affiliating or becoming a local branch (if it is a specific condition such as autism). You will need to explore any obligations attached to this.

Contact has an affiliation scheme for local groups which offers both a free and paid membership. The scheme has the advantage of covering all disabilities and does not stop your group from joining other organisations as well.

If you join our affiliation scheme, we'll help to promote your group so you can reach new members, give you access to discounted training, and a dedicated enquiry service from our Local Groups Manager.

You can say your group is a member of the Contact Local Parent Support Group Affiliation Scheme, to give it some local credibility in the early days.

We'll also give you our Affiliation Scheme logo to use on your communications and publicity material. For more information about the scheme please visit [www.contact.org.uk/supporting-groups](http://www.contact.org.uk/supporting-groups) or download our brochure at [www.contact.org.uk/affiliation-scheme](http://www.contact.org.uk/affiliation-scheme)



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## Publicity

You will need to have some way of publicizing your group - whether you decide to have a hand-written poster illustrated by one of your children, or to create a poster on the computer.

### The five “Ws” of good publicity

If your poster or leaflet includes the five “Ws” - what, why, when, where, who - you will have all the essentials you need to publicise the group.

**WHAT:** Sparkhill Parents’ Group  
**WHY:** Support, friendship and information for parents of children with learning disabilities  
**WHEN:** We meet on the second Tuesday of each month from 10.00am - 12 noon  
**WHERE:** At the Community Centre  
**WHO:** For more information, contact Sue on 43272 or Judy on 43115

Children welcome: crèche available.  
We look forward to meeting you!

You will also need to have it photocopied or printed. Check if anyone in the group has any relevant skills, experience or contacts. Someone in the local community may be willing to give the group support in kind by printing your posters and leaflets, such as:

- the schools your children attend
- a local printing firm or copy shop
- local charities
- a supportive professional worker
- a local business or company wishing to support community initiatives

Your local infrastructure organisation may advise you about where to go for cheap printing and have someone who can help you with layout and design. For more information about publicizing your group, including leaflets and social media, see our guide to ***Producing leaflets, posters and newsletters.***

Once your posters are up, your leaflets circulated and the ‘word’ is out, check their effectiveness by asking new members where they heard about you. That information can feed back into your planning for future events or meetings. Don’t forget to amend your posters when necessary, especially if the contact name or dates and times change. It is helpful to keep a record of where you put them all!

Remember that publicity is more than just posters and leaflets. Many new members will hear about you by word of mouth as you promote the group when talking to friends, other parents at the school gate and professional workers. More ways of reaching new members is in our guide to ***[Attracting and keeping members.](#)***

For more information on how to run your meetings, encouraging discussions, chairing meetings and coping with any problems, see our guide to ***[Keeping your group going.](#)***



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## **The role of professional workers**

The relationship between parents' support groups and professional workers is very important, although the strength of the links and the level of communication will vary, depending on both the group and the worker.

From the outset, it is very important to think about how close a relationship a professional should have with your parents' support group. What feels right for one group might not feel comfortable to another group. If a professional worker is involved in starting and running a parents' group, it is better for both the worker and group to think about this at the beginning and so be able to manage it.

## **The strengths of parent-led groups**

A parent support group which is led by the parents themselves tends to be very different from one led by a professional worker. In a parent-led group there can be a greater commitment from parents; they become more involved in the group and have a sense of ownership. This, in turn, can bring greater benefits to parents.

In contrast, in a group led by a professional worker it can be difficult for parents to feel responsible for the group's success. Members may miss important opportunities to gain skills. Confidence raising can be more difficult in a group run by a capable and efficient professional worker, where parents may feel that they do not need to do more than turn up for meetings.

Parents may also feel that they have more chances to influence service provision in their 'own' group. The greater confidence parents can gain in a parent-led group can help them to develop the coordinated and determined approach they need to influence local services. And, of course, it may be difficult for members to be open and honest in their views of local services if a local service provider is running, or closely involved in, the group.

## **A positive role**

Professional workers can support and help groups without becoming directly involved in running the group. They play a vital role by helping to reach parents and build membership, offering practical support and making themselves available to the group.

Groups are always looking for procedures which allow organisations to put parents in touch with them. Such procedures mean that parents are not dependent on the good practice of an individual professional worker, who might of course move on. For example, a system could be

implemented whereby all parents attending a clinic for the first time are routinely given information about support groups and can then choose if and when to make contact.

## **Getting together**

A good relationship between your support group and professionals will develop by a good understanding. You therefore need to have some knowledge of each other, and this may be best achieved by meeting together from time to time. It can be difficult for professionals to tell parents about a group if they know very little about it.

Likewise, it is difficult for parents to convey their views to professionals if they feel anxious about talking to them.

You may find it helpful to have a list of tips for professionals on how they can help your group flourish. Here are some – your members may well have more ideas.

### **Tips for professionals**

On helping to reach parents:

- set up a procedure between your organisation and the parents' group
- be clear about how this will operate
- tell parents about groups and support networks early on
- give written as well as verbal information to parents
- support the parent to make the choice
- make sure you have adequate and up to date group information
- make introductions on behalf of the parent, if requested
- keep the group informed
- tell colleagues about the group so that they can also inform parents.

On helping with practicalities:

- provide a meeting room
- display posters
- hand out information to other parents
- offer financial help, where possible
- provide or arrange transport
- help with photocopying
- offer advice on form filling and letter writing
- put groups in touch with any helpful professional workers, other organisations or sources of support.

On being accessible:

- suggest a good time for contact
- suggest the best means of contact
- keep groups informed of any changes.

Helping with morale:

- suggest parents bring a friend or relative when first attending
- provide a listening ear to groups
- be there to share ideas
- make suggestions and give tips
- offer encouragement
- give honest feedback.

It helps to know each other:

- have open meetings for parents and professional workers
- offer to talk to professionals or accept invitations to do so
- invite professionals to talk to you
- sit on committees or forums
- don't accept professional jargon.

## A win-win situation

There are many benefits for professional workers in encouraging your group to thrive. These are:

- understanding better the needs of parents caring for a disabled child
- having access to parents' views
- getting feedback on services
- having an additional source of available support for parents
- reducing inappropriate demands by parents
- broadening skills and experience.

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We hope this has given you a flavour of things to think about in starting a parent support group.

The follow up guide this is [Keeping your group going](#).



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