

Professional workers and parents' support groups



This guide is for you if you are a professional working, or planning to work with local support groups for parents of children with additional needs. It is also directed at parents' support groups, both to use as a resource for them and to pass on to professional workers. The guide:

- outlines the role of parents' support groups and networks and the benefits they bring to parents of disabled children
- looks at how professional workers can support these groups

The term 'professional workers' is used here broadly to mean people working in a professional way and being paid for this work. You will most probably work in health, social services or education, or may be employed by a voluntary organisation.

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 with a parents' support group is appropriate. What feels right for one group might not feel comfortable to another group. It is better for both you and the group to think about this at the beginning and so be able to manage it.

Parents' support groups - the benefits

For parents of children with additional needs the main benefits of being in a support group include one or more of the following:

- mutual support through contact with other parents of disabled children or children with medical conditions
- sharing information which helps in caring for their child
- building confidence
- an opportunity to help other parents of disabled children
- the chance to influence service provision



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The strengths of parent-led groups

A parents' 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 is a greater commitment of 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, when a group is led by a professional worker, it can be difficult for parents to feel responsible for the group's success. This can mean that they miss out on receiving and giving support and access to valuable information that other parents of children with additional needs might be able to share with them.

Parental involvement is also important in building the confidence of parents, by achieving successes and helping others. Confidence raising may 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 any more than turn up for meetings.

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

Stepping back

If, as a professional worker, you have set up a local parents' group you may wish, at some stage, to withdraw from it – indeed you may have set up the group with that in mind. Professional workers may also need to withdraw for other reasons, for example time pressures or a change of job.

Parents involved in a professional worker-led group, or one in which there is close professional worker involvement, often see the worker as crucial to the group, and may feel anxious about its future without them. Such anxiety often stems from lack of confidence and feeling unable to take on the tasks the professional worker has successfully done to take the group forward.

For professional workers it can be comparatively easy to get on with the practicalities of running a group - finding a meeting room, spreading the word about the group, photocopying materials - because of your professional knowledge, contacts and understanding of organisational structures and systems. You may feel that it's easier and quicker to get on with these tasks yourself, rather than explaining to parents how they can go about them.

However, if the parents have been encouraged from the start to be active in the group and take on responsibilities, it will be easier for you to withdraw. So, if you are planning to set up or become closely involved in a group, think carefully about how to encourage parental involvement and participation at the earliest stage and make sure that your relationship with the group is clear from the beginning.

If you wish to withdraw from a group it can be helpful to:

- discuss with the members whether or not they wish the group to continue
- encourage open and honest discussion on the future shape of the group

- review the aims of the group and its activities
- identify any parents willing to work on taking the group forward (not necessarily one group leader)
- share out group responsibilities and tasks amongst the parents
- think about whether the meeting place will continue to be appropriate (especially if the group currently meets at your work site)
- withdraw gradually if possible
- set a date for withdrawal from the group
- plan a programme of withdrawal for this period
- consider inviting an outsider with group skills to discuss these issues with the group (ask Contact a Family for advice on whom you can approach)

A positive role

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

Reaching parents

Most groups want new members at some time or other to help it survive and thrive. Welcoming new members to the group also gives parents an opportunity to help other parents of children with additional needs.

Parents hear about groups in different ways, but nearly all rely to some extent on professional workers telling other parents about the group. For the group, it is important that parents are given information about the support group but allowed to make the choice as to whether to become involved or not. This is not something the professional worker should decide.

Groups are also looking for procedures for established organisation-wide procedures which enable parents to be put in touch with them. Such procedures mean that parents are not dependent on the good practice of an individual professional worker, who will move on at some point.

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.

Helping to reach parents

- set up a procedure between your organisation and the parents' support 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
- allow 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

Practical support

Parents need practical help to set up groups, and keep them going. Much of this will be provided by the group members, but outside help is often also needed. Professional workers can help with practical support, making it easier for the group to get on with addressing its aims and supporting its members.

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
- advice on form filling and letter writing
- put groups in touch with any helpful professional workers, other organisations or sources of support

Being accessible

Parents and groups often say how difficult it is to get hold of professional workers. Making it easier for a group to contact you can ease the problem. This doesn't mean being available at all times, rather, it means letting the group know how and when to reach you.

For example, you might tell the group that the best way to reach you is by phoning you between 9.00 and 9.30 on Monday mornings when you are always in your office.

Helping to be accessible

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

Getting to know each other

A good relationship between you and a support group will require good communication and understanding. You will need to have some knowledge of each other. This may be most easily achieved by meeting together from time to time. It can be difficult to tell

parents about a group if you know very little about it yourself. Likewise, it is difficult for parents to convey their views to professionals if they feel anxious about talking to you.

A solution could be if your team invited a group to one of its monthly meetings to share information about both your areas of work.

Helping to know each other

- hold open meetings for parents and professional workers
- offer to talk to groups or accept invitations to do so
- invite parents to talk to you
- invite parents to sit on committees or forums
- avoid jargon

Moral support

Such practical support and help from professional workers are clearly beneficial to local support groups. But moral support and encouragement can also be very helpful. A group's confidence in its work will grow when it knows that it is appreciated and valued and its efforts are recognised.

Helping with morale

- provide a listening ear to groups
- be there to share ideas
- make suggestions and give tips
- offer encouragement
- give honest feedback

The benefits for professional workers

Both professional workers and parents' support groups benefit when they work together.

In this guide we have explained how groups can benefit from your support. Professional workers can also identify benefits for themselves, such as:

- better understanding of the needs of parents caring for a child with additional needs
- 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

This guide is part of the Contact a Family Group Action Pack. For more information please visit www.cafamily.org.uk or telephone 020 7608 8700.

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