

# Developing a national support group



This guide follows on from *Starting a national support group* (Contact a Family, Group Action Pack) which gives advice on the early and most difficult stages of getting a group going. Once you have established a group it is important that all the hard work and energy you have put into it should not be wasted. As the group grows, planning for the future becomes a key issue.

The aim of this factsheet is to look at the next stage in the life of a national group. The immediate priorities may include forming a committee, setting up an area family network and registering as a charity. It will help those involved in the day to day running and management of the group to evaluate progress, consolidate developments and determine priorities for the future.

## Stages of group development

Each group is unique and the speed at which it develops depends on a number of factors including the numbers involved in the day to day running and management of the group, the number of families in regular contact, and the rarity of the condition.

However, there are generally considered to be four stages of development associated with the life of a group. These are:

**Forming:** This is the starting point for groups when parents are getting to know each other. Aims, priorities and individual roles within the group are being established.

**Storming:** Often the most difficult stage the group may experience. For many this will be a time of conflict when issues associated with how the group works may be challenged. Working through this stage is essential if the group is to survive. If handled well this can be a positive experience resulting in an efficient working committee, improved communication, and shared responsibility for making the group work.

**Norming:** At this stage the group is beginning to settle down and get on with the task in hand. Views and feelings can be openly exchanged without fear of conflict and there is a sense of everyone working together.

**contact** a family  
for families with disabled children

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Tel 020 7608 8700 Fax 020 7608 8701

Web [www.cafamily.org.uk](http://www.cafamily.org.uk) e-mail [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Freephone Helpline 0808 808 3555 (Mon-Fri, 10am-4pm)

Textphone 0808 808 3556

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**Performing:** The group is now fully effective, using all the skills and experience available from within the membership.

Some groups move relatively easily through each of the stages whilst others have a more difficult route. Circumstances sometimes make it necessary to step back to a previous stage. Perhaps there has been conflict within the group or a new committee. Whatever the reason, most groups find themselves moving through to the performing stage quite quickly.

## **What is a successful group?**

In the early stages of group development it is encouraging and exciting when families start to make contact. It is reassuring to know that all the hard work was not in vain and that professionals and parents are now aware of the group's existence. However, if the group is to remain effective, time, effort and commitment will be needed by all those involved. Maintaining a national group involves keeping the group in good working order by attending to the needs of the members. Some qualities a successful group should have are:

- clarity about its aims and objectives
- awareness of the commitment required and individual responsibilities
- a determination to succeed
- ability to monitor and evaluate the service provided to the membership
- confidence that a valuable service is being provided
- ability to seek advice and help where necessary
- ability to use members skills effectively
- not be over-reliant on one individual to take responsibility for the workload
- not be frightened to change things where necessary
- ability to cope with conflict
- ability to support each other

The following paragraphs contain practical advice on some key issues which any group will need to address in order to be successful.

## **Keeping in touch with the membership**

The role that the group takes on should be realistic and based on the needs of the members. Whether the group is able to offer a variety of services and activities or concentrates mainly on supporting families, it is important that anyone in contact is clear about what is available.

At a time when families are feeling traumatised after receiving a diagnosis the group can offer understanding, support and a sense of belonging. Image and identity is important, but it is the impression that families get from their early contacts with the group which will determine whether they maintain contact and in turn offer their help and support in the future. This can be difficult for national groups where the contact is mainly by letter and telephone. It is important that families feel part of the group. There are a number of ways of keeping in touch with the membership:

- establish a database of members
- invite new ideas such as suggestions for new written information
- encourage families to keep in touch with regular updates of their situation
- provide feedback from relevant committee meetings
- encourage involvement in decisions about the future of the group
- arrange local 'get-togethers'
- ask families to tell their stories through the newsletter
- encourage feedback on things such as the newsletter
- develop an area family network
- organise a national family day
- consider new methods of communication such as a page on the Internet

### **Keeping in touch with professionals**

One of the most difficult areas for a national group is ensuring that professional workers know about the group and that parents of newly diagnosed children are given information on how to get in touch. There are a number of ways to maintain the group's profile with professional workers:

- establish a mailing list of relevant professional workers to receive regular information
- offer to speak to groups of interested professional workers such as health visitors
- provide an information pack for professional workers
- liaise regularly with other relevant organisations
- display information about the group at relevant local and national conferences and exhibitions
- ensure that the group entry in the *Contact a Family Directory of Specific Conditions, Rare Disorders and UK Support Groups* is kept up to date

## **Forming a management committee**

The management committee has responsibility for making democratic decisions about the maintenance and development of the group whilst working within the finances available. Elected from within the membership, the committee is an essential part of the overall structure of the group. It may be composed of individuals spread across a wide geographic area.

Committees vary in size depending on the number of members and the services offered by the group. Roles may include:

- Chairperson
- Parent contact
- Secretary
- Treasurer
- Fundraising co-ordinator
- Newsletter editor

## **Involving others**

Whilst some groups are successful in sharing the workload and establishing individual roles, others find this difficult. Lack of time and geographical distances are the main reasons why families are often reluctant to become involved. Others may want to help but may not feel they have the relevant skills or confidence. In some cases families need further information on what is involved in being a member of a committee.

It may be helpful to send out a questionnaire to all families inviting views and comments about the group and allowing them to indicate how they would like to be more involved (see the example on page 12).

Before asking for help you may wish to consider:

- Which areas do you most need help with?
- Are any specific skills needed for the vacant roles?
- Is there a requirement to attend meetings?
- Can any roles be merged/split?
- Are guidelines available for each individual role giving information on what is required? (see the example below)
- Will training be available?

## **Example**

### **The \*\*\*\*\* Syndrome Support Group**

#### **Guidelines for the role of newsletter editor**

The newsletter is distributed three times a year to all members.

Specific tasks of the newsletter editor will include:

- collecting information and articles for inclusion in the newsletter
- selecting the topics to be covered in each edition
- seeking permission to reproduce relevant articles from other sources
- deciding on the layout of the newsletter
- writing, editing and proof-reading articles to give cohesion to each issue
- liaison with the printer regarding costs and publication dates
- responsibility for mailing out the newsletter to families
- ensuring the committee are aware of any problems

Arrangements for the payment of production costs are to be decided with the treasurer.

## **Area family networks**

As the number of families contacting the group grows you may want to consider establishing a network of local contacts for group members. The role of the area contact varies with each group. For some the emphasis will be on offering support to families who live in the same region, whilst for others it will include things such as local fundraising and raising awareness of the group in the area.

## **Holding a national meeting**

Organising a national family meeting each year can be difficult but is an effective way of allowing families the opportunity to meet, share information and experiences, and for those involved in the management of the group to keep in touch with the membership. For those groups which are registered charities there is also a legal obligation to hold an AGM each year. Inviting professional workers helps to keep families up to date with current issues around treatment and management of the condition and makes the day informative. By arranging a programme of entertainment for the children you will help to make it an occasion for all the family.

If your group is not registered as a charity it may be preferable to have the family day bi-annually or alternate an information day with a social event each year. Whatever the preference it is important to allow plenty of time for planning.

## Planning for the future

Planning for the future is essential for any group whatever the size. At regular stages in the development of your group make time to evaluate what the group has achieved so far and decide on future priorities. This is especially important when the group is preparing to provide a new service, such as a helpline, or take on a new project.

When planning any project or new development there are three issues to consider:

- What are we trying to achieve?
- How will we do it?
- How will we know whether it has been successful?

Drawing up an action plan will help by providing a framework to work towards. It should identify:

- the broad aims and objectives of the group
- the resources available
- which individual is responsible for which task
- how each task will be achieved
- short and long term targets

## Evaluation

Evaluation can be an effective way of reviewing the development of the group both in general and specific areas. It involves looking critically at what works well, why it is successful and whether there is room for improvement. It can be carried out at any stage and involves looking at the following:

*Outcome:* Have the objectives set for the group been reached?

*Process:* How were they achieved and what methods were used?

One example of this is when those attending family days are asked to comment on all aspects of the day including workshops, venue, location and refreshments.

Reasons for using evaluation include:

- looking at ways of improving your own individual input
- helping others involved in the group to improve their working practice
- justifying the services and facilities offered by the group
- identifying potential projects for the future
- knowing that the group is effective
- establishing whether funds are being used effectively
- helping to identify any unexpected outcomes
- encouraging feedback from the membership
- preventing difficulties arising from insufficient information, poor communication and lack of consultation with others

Evaluation is not difficult and can be carried out in a variety of ways. One method is to draw up a checklist to determine whether the aims of the group are being met. This allows specific areas such as communication, structure of the group, fundraising, publicity and relationships with families and professionals to be assessed.

## **Registering as a charity**

Not all groups register as charities. However under Section 3 of the Charities Act 1993 any group that falls within any of the following categories is obliged to register with the Charity Commission:

- has an income which exceeds £1,000 per year
- has the use or occupation of land or buildings
- has a permanent endowment fund

There are a number of benefits from registering as a charity but all factors should be considered carefully before making a final decision. There is no doubt that achieving charitable status gives groups credibility and is beneficial for things such as fundraising. Businesses and statutory authorities are more likely to give a donation to registered charities.

The decision to proceed usually rests with the committee but there are a number of points to consider:

- it should be clear that the group's aims and objectives, as stated in the constitution, are charitable
- trustees are obliged to run the charity within the relevant Acts of Parliament
- once a constitution has been adopted it is essential that the group works within the terms as agreed
- that all the available information about what is involved in becoming a registered charity is circulated to all relevant members
- the decision to go ahead must be fully discussed and agreed

The process of registration and adopting a constitution can be slow. It is also important that anyone considering becoming a Trustee should be fully aware of the legal requirements and their individual responsibilities. For further information on charity registration click on:

<http://www.charity-commission.gov.uk/registration/default.asp>

and for the role of the trustees:

<http://www.charity-commission.gov.uk/publications/pdfs/welctrust.pdf>

or phone the Charity Commission on 0870 333 0123.

Contact a Family's group development service can also help with registration and have a model governing document available for use. Tel: 020 7608 8700 or email

[info@cafamily.org.uk](mailto:info@cafamily.org.uk) for more information.

## **Holding an annual general meeting**

All registered charities are required to have an annual general meeting. Most national groups choose to hold it at the same time as their annual family day. It is an opportunity to report to the membership progress made to date, along with any new developments. This is also the stage when under the terms of the constitution elections must take place for specific roles within the group. The chairperson is responsible for the proceedings and, as with committee meetings, an agenda must be circulated to all the membership 21 days before the meeting, along with notification of the election and an invitation for nominations. For more information on holding an AGM see the Charity Commission guidance at:

<http://www.charity-commission.gov.uk/publications/cc48.asp>.

## **Producing reports**

### **Annual report**

When producing an annual report there are a number of basic guidelines to follow:

- be clear about who the report is aimed at, e.g. the members or potential funders
- decide on what should be included well in advance
- give plenty of time for contributions
- presentation should be simple but effective
- content should be clear and concise
- diagrams and pictures can help to make information clearer
- simple desk top publishing can be as effective as something produced professionally

Your local Council for Voluntary Service may be able to advise on local design and print companies offering competitive rates to small charities.

## **Business plan**

You may find it helpful to produce a business plan. This could help you plan the development of the group and may be particularly useful when applying for funding.

It is highly likely that this will be read by individuals who have no or little experience of medical terminology. The guidelines for writing annual reports are also relevant for a business plan. Specific information should include:

- a simple description of the condition/s covered by the group
- the aims of group
- details of the services provided
- details of the group structure and membership numbers
- development to date
- future priorities
- current financial details
- financial projections: budgets and cash flow expectations

## **Fundraising**

Fundraising is a constant area of concern for national groups. There is an increasing number of small groups looking for funding and more time is now required to explore all potential sources. Small local fundraising events are a valuable source of income but for some projects long term funding may be required. For further information on all aspects of fundraising see the guide *Fundraising* (Contact a Family, Group Action Pack).

## **Involvement in research**

When families are given a diagnosis, often one of the first things they want to know is whether there is any research being carried out. This is especially important for those families caring for a child with a very rare condition. Discovering that there is no research currently being undertaken can be frustrating. Although a very small number of groups do fund research, the commitment required to secure the substantial funding necessary is huge.

There are other ways that groups can have a positive involvement in research:

- explore the possibility of raising funds to buy a small piece of equipment
- liaise with professional workers involved with research to explore other ways of helping
- inform families about any current research
- consider involvement with research being conducted abroad
- ensure that any research findings are passed on to the membership
- inform families how they can help with any projects currently underway

If approached by a researcher please remember not to give out any information about individual families without prior permission. You may suggest they might like to write an article for the newsletter requesting families to contact them directly for further information. Alternatively, discuss the possibility of having details prepared that can be forwarded by the group to the families. This should include providing all the necessary stationary and postage.

## **Do we need an office?**

The majority of groups find themselves having to operate from a room in somebody's house. After a while this can become difficult to manage and as the group develops the need to find other premises becomes a priority. Having an office can have both advantages and disadvantages.

The first task is to determine whether there is enough funding available to cover rent and running costs. The next stage involves making a decision about where the office is to be located and who will be responsible for running it. The preferred choice is to base it near to the national co-ordinator who has responsibility for the main contact with the families. Your local Council for Voluntary Service may be able to advise on premises that are available locally.

Finding equipment for the office can also be a problem. As commercial offices are often upgrading and replacing equipment it may be worth asking local businesses if they can help. Advertising in local newspapers or on local radio may also prove useful.

## **Employing a paid worker**

The decision to take on a paid worker is usually made when the amount of work generated by the group increases and becomes difficult to manage in a voluntary capacity. There are advantages and disadvantages to taking on someone in a paid role:

### **Advantages**

- continuity
- commitment
- availability during the day
- central point for all communication
- worker responsible for tasks that are more difficult for families because of the specific skills required or time restraints

### **Disadvantages**

- finding funding to continue with post
- responsibility for supervision and management of worker
- fear of members losing roles to which they have been committed

## **Equal opportunities**

All organisations, however small or large, should ensure that they comply with current anti-discrimination legislation on race relations, sex equality and equal treatment for people with disabilities. In addition, it is advisable to have a clear statement of equal opportunity policy and practice relating to the employment of staff. Contact a Family can make our Statement of Principles available as an example.

A paid worker will not be able to take on all the roles currently being undertaken by other families and this should be taken into account when putting together the job description. The role of the paid worker is dependent on the needs of the group. This may include:

*Development officer:* the main point of contact for families. Also raises the group's profile amongst professional workers and other agencies. This post may require help with secretarial and administration duties.

*Administrator:* have office skills and be able to deal with initial enquiries.

*Secretary:* responsible for secretarial work initiated by the development officer and other members of the committee.

## **Becoming an employer**

The initial stages involve:

- job description – lists the areas of work and responsibilities of the worker
- person specification – details the specific skills needed
- terms and conditions of employment should be agreed prior to the interview
- tax and National Insurance scales – information can be obtained from your local tax office

The next stages involve:

- advertising the post – the recruitment sections of newspapers and journals are the most popular. However this can be very expensive so you may want to explore the possibility of recruiting from within the membership
- identifying the most suitable applicants and inviting them to attend an interview
- organising the interview panel – usually consists of at least three members of the committee. If necessary somebody from outside the organisation can be used
- making provision for the supervision and management of the paid worker – this is the responsibility of the committee

## **Linking worldwide**

As the number of parent support groups grows worldwide, there is now the opportunity for groups in other countries covering the same conditions to be in regular contact and to exchange information. This is especially helpful for groups covering rare conditions where the expected incidence is low. More international conferences are now organised which encourage closer linking between the groups and a greater awareness of new research and treatments in other countries. It also gives families the opportunity to hear from other recognised medical specialists.

## Using new technology

More groups are making use of computers for keeping a database of the current membership and designing and producing information. Please remember that if you intend to hold information about individual families on the computer you may need to register under the Data Protection Act. For more information see *Data protection* (Contact a Family Group Action Pack.) Advances in technology have opened up a new area for national groups. The Internet and use of electronic mail are two new methods of communication now being used by groups.

This is however an area that is changing rapidly. To keep up to date with new developments the main sources of information are current computer magazines and newspapers.

If you would like to know more about using your computer then you may want to consider further training. For further information ask your Adult Education centre or Council for Voluntary Service office for details of courses available locally.

## Helpful addresses

- **The Charity Commission**

For information about charity registration organisations established in England with expected or actual incomes below £10,000 should contact:

Charity Commission, 20 Kings Parade, Queens Dock, Liverpool L3 4DQ

Larger organisations, with incomes over £10,000 should contact:

Charity Commission, Woodfield House, Tangier, Taunton, Somerset TA1 4BL

General enquiries: 0870 333 0123 Minicom: 0870 333 0125

**enquiries@charitycommission.gsi.gov.uk**

**<http://www.charity-commission.gov.uk>**

- **Community Network**

Telephone conference provider for the voluntary sector.

Ground Floor, 12-20 Baron Street, London N1 9LL Tel: 020 7923 5250

**enquiries@community-network.org** **<http://www.community-network.org>**

- **National Council of Voluntary Organisations**

Provides information, advice and support for the voluntary sector in England.

8 Regents Wharf, All Saints Road, London N1 9RL

Tel: 020 7713 6161 Helpdesk: 0800 2798798

**ncvo@ncvo-vol.org.uk** **<http://www.ncvo-vol.org.uk>**

## ***Example questionnaire to families***

### **The \*\*\*\*\* Syndrome Support Group**

If the \*\*\*\*\* Syndrome Support Group is to be developed, we need some brief aims to guide our work.

Please 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 on ***** Syndrome            |  |
| Additional information, e.g. benefits                  |  |
| Regular newsletter                                     |  |
| Fundraising material                                   |  |
| Information on current research                        |  |
| Occasional national meeting for families               |  |
| Other (please state and list in order of priority)     |  |

To take the group forward, we do need a small number of committed parents able to meet quarterly. If you feel that you are able to give your time in this way please tick the items in the section below:

|  |  |
|--|--|
| Become a members of the committee                              |  |
| Link with other families                                       |  |
| Compilation and distribution of information on ***** Syndrome  |  |
| Work on a group newsletter                                     |  |
| Fundraise for research/group activities                        |  |
| Help to organise a national meeting of ***** Syndrome families |  |
| Other (please state)   |  |

This guide is part of the Contact a Family Group Action Pack. For more information please visit [www.cafamily.org.uk](http://www.cafamily.org.uk) or telephone 020 7608 8700.

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