

Local campaigning



Campaigning for change

Local parents' groups want the best services for themselves and other families who have children with disabilities or additional needs. To get the best can involve local campaigning, which may include any of the following:

- raising awareness about the needs of families who have children with disabilities or additional needs
- changing the way individuals or agencies deliver a service
- trying to get a new or better service

This guide aims to help local groups influence the provision of local services through a range of activities.

Raising awareness

If you are a local parents' group wanting to raise awareness about your families' needs, you will now find that the law is on your side. The Children Act 1989, the NHS and Community Care Act 1990 and the Special Educational Needs and Disability Act 2001, all place a responsibility on local authorities and health authorities to seek the views of parents and children.

Over the last 10 years, there has been an active drive among professional workers health, education and social services to work in 'partnership' with parents and to listen to their views. This has been made even stronger by the Carers and Disabled Children Act 2000; under this law, local authorities will have to assess the needs of parent carers in their own right.



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Practical action your group can take to raise awareness can range over the following:

- invite professional workers along to your meetings to give a talk about their work and to exchange views
- offer to speak on professional workers' in-service training days (don't forget, you can ask for a fee for your group)
- produce a leaflet on the unmet needs of families in your area and circulate to relevant professional workers
- mount an information stand at any local carers' or disability event (parents as carers can often get overlooked)

Did you know?

Every council has to produce a register of children with disabilities. If you ensure the details of your children with disabilities or additional needs are on the register, you will be helping the council form a realistic picture of the services it needs to plan for.

Improving the quality of services

The quality of services on offer to families will differ from district to district, but there are some problems which parents commonly report:

- the diagnosis is given insensitively, with no follow-up support or information
- case reviews put parents in an inferior position even though they are the expert on their child
- there is no single information point to help parents, who tend to find out what is available by accident

In some districts parents' groups have been able to influence and change such badly delivered services.

Here are some possible approaches:

- identify a sympathetic professional worker who has the power to get your group's voice heard in the service you are targeting
- find out if there are any local policy guidelines covering your area of concern - for example, has your health authority got a policy on disclosure of diagnosis?
- invite a key professional worker from the service you are targeting to your group to discuss the problem
- contact any other local parents' groups for support - the more parents the better (Contact a Family can help put you in touch with other local groups)
- join or start a local parent-led Parents Forum. In some areas parents have started these forums to encourage professionals to consult about services with a much wider group of parents. Contact a Family can provide details of these.

Preparing your case

Make sure that you are clear about:

- the problem
- any research or legislation that supports your case (see the back of this guide for suggestions)
- the support you have (from parents and professional workers)
- constructive ways forward

In addition:

- Look out for a local carers' forum or consultation group which might push for change; is there a local community development worker?
- Find out if there is a local Joint Planning Group for Community Care or a Joint Action Group for Children - sometimes these have a sub-group specialising in children with disabilities on which a parent or a voluntary sector representative sits. Their task is to convey the views of parents to that sub-group which in turn influences the planning of services in your area.
- Contact your local Council for Voluntary Service (CVS) or, if it is a health matter, your local Patient Advice and Liaison Service (PALS), and ask for their help.

Contact a Family is in the process of producing detailed guidance for professionals and parents on consulting meaningfully with parents of disabled children. The guidance will be available in 2004 and in the meantime the Contact a Family Development Team will be happy to advise you.

Did you know?

Since 1996 all local social service departments have had to produce an annual Children's Services Plan. You can get a copy free from your council. The plan should say how services for children with disabilities will be developed over the coming year. You can find out how your group can try to influence these plans by asking your director of social services / social work.

Campaigning for a new service

The services you will want locally depend on local needs; the following are common concerns:

- insufficient respite care and short-term breaks
- lack of play provision in the school holidays
- insufficient therapy services for children
- too few resources for children with additional needs or special educational needs (SEN) in mainstream schools
- transition to adult services
- cuts in a valued service

Such concerns can lead your group into campaigning. Before you start, you should consider the following:

- Are you sure that there are no plans to provide the service or tackle the concern? It is worth checking because many local authorities are creating new services for children with disabilities. All now have to produce a Children's Services Plan (available in the public library) and this should mention the council's plans for services for children with disabilities.
- How is your local area planning to implement the NSF for Children? See *Sources of Evidence* at end of this guide for details.
- What do you actually want to do about it? You may, for example, be so despaired by council inaction on holiday playschemes that you decide to raise money to provide your own. You should check how much time and energy the group members have and how they wish to use them. Don't be trapped into providing a service if it is too much for your members to take on.
- Do you have a clear aim and do you want to campaign to achieve it? An example of your aim might be 'A play scheme suitable for children with special needs in the summer holidays'.
- How much time do you want to spend on the campaign? Is it to be a short, fixed term campaign or one that you are prepared to be long-term? It may help your group to set some time limits so that your members know what they are committing themselves to.

How local parents have changed services

- The Special Needs Activity Club in Port Talbot was started by two parents who wanted an after school club for their children. The club now runs a purpose built activity centre which offers a programme of social events and activities for children with special needs and their families.
- The Dyspraxia Trust in Warrington successfully campaigned for a Paediatric Occupational Therapist. They worked out that 6,000 children were likely to need the service and took just twelve months to persuade the Health Authority.
- The Sunday Special Club, a parents' support group based in Harrow worked jointly with the Harrow Recreation Ground Users Association in order to persuade Harrow Council to provide specially adapted play equipment in the local playground. They succeeded in making the play area inclusive for children of all abilities.

Running a local campaign

If your group decides to run a campaign, you will want it to be a success. The following basic principles will help to underpin a good campaign:

- choose a good cause which people can easily support
- provide evidence to support the cause
- set realistic objectives that are 'winnable' within the resources which are available locally - for example, a cause which costs £10,000 is reasonable where there is a local budget of £250,000. One which costs £200,000 is not
- develop clear campaign strategies with goals that are regularly reviewed

As a good campaign also requires a lot of work you will also need:

- a co-ordinator to ensure that things get done
- some key people who have the time, energy and enthusiasm to commit to the campaign

Allies

It is always worth checking among your supporters for possible friends and allies to help in your campaign. These might include:

- a local councillor
- professional workers who are sympathetic to your aim
- other local parents' groups
- a local carers' centre
- your Member of Parliament/European Parliament
- the local media
- local voluntary organisations working with children

The target

Your target in a local campaign is likely to be the local council or Strategic Health Authority or Primary Care Trust and the key decision makers in those organisations. It is important to find out who these people are.

Local authorities

Who you target in the council will depend on your cause. If, for example, you are campaigning for extra respite care you would target the Leader of the Council, the Chair (or Convenor) and the Director of Social Services / Social Work. Holiday play provision may fall under education, community or leisure / amenity services.

You can find out the names of the relevant people through your town hall or local library. Also ask your contacts for 'inside' information about who is making the decisions. For example, in some councils, the power lies with the Chair of the Finance Committee or with the Leader of the Council.

You should also find out which council officers are responsible for making recommendations to the councillors. This may be the social services team leader or the principal social worker.

Local councillors

In local authorities it is the elected councillors who take policy decisions, with the paid officers running day to day operations.

In London and the metropolitan areas (Tyne and Wear, Greater Manchester, West Midlands, South and West Yorkshire and Merseyside) the borough or city councils look after social services, leisure and education; elsewhere these are currently looked after by the county council. However, some counties e.g. throughout Wales, the East Riding of Yorkshire and Scotland, have been replaced by unitary authorities (or 'council areas' in the case of Scotland and 'district council areas' in the case of Northern Ireland). You will need to check the arrangements in your area.

The support of councillors can really benefit your campaign as they can:

- take up individual cases with officers and discuss issues with their political colleagues
- speak out on your behalf in committees and council meetings
- attract local media interest if they meet with your group

Councillors are elected on a geographical ward basis. The town hall will be able to tell you the name, address and phone number of your local ward councillors and the times and addresses of their regular surgeries. The council will also publish information on which services it runs and its committees, with dates of regular meetings, names of chairs and members of committees. The town hall should also be able to tell you which council officers have responsibility for the service which concerns you.

You can ask for a delegation to present your case to a committee or council meeting which is making a decision which affects it. Find out if there is a person co-opted to represent disabled children and young people on your social services / social work committee (there is in most councils) and ensure that they support your campaign. If you are allowed to send a delegation to the committee, choose a spokesperson who can put your case clearly and to the point.

Political contacts

Don't forget to check if any of your members belong to a local political party. Local party activists can raise issues at ward meetings and put resolutions which then go forward to councillors of the same party. Be careful, though, not to allow your group to become identified too closely with one political party. Always aim for cross party support - this is particularly important if you are campaigning as a registered charity.

The local council: your rights

Always remember that councillors are elected to represent your interests and you have a right to contact them.

The Freedom of Information Act 2000 provides you with a general right to access information held by public authorities, including local councils. Being able to access information relating to decisions made on issues such as housing, health, education and planning can add extra weight to your campaign.

In addition, from January 2005, any individual who makes a request to a public authority for information will have the right to be told whether the authority holds that information, and (subject to any exemptions under the Act) to be supplied with that information.

Also, the Local Government Access to Information Act 1985 requires local authorities to give the public access to council meetings and publish all agendas, reports and papers of those meetings. Under the Act:

- all council meetings (committees and sub-committees) are to be publicly advertised five days before they take place
- all agenda and background papers are to be available for public inspection before meetings
- the public are allowed to attend all council, committee and sub-committee meetings
- all council minutes, agendas and reports are to be available to the public for at least six years after the meetings have taken place and background papers for at least four years

The council has the right to keep private any matters which relate to allocation of resources to individual members of the public - so it is better to campaign on a specific issue of widespread concern rather than an individual case.

The structure of the NHS

If you are campaigning on a health issue, it is advantageous to identify the person who will be responsible for making the relevant decision and then target them directly. Since devolution took place, the structure of the NHS in England, Scotland, Northern Ireland and Wales is different. Those responsible for making decisions varies greatly depending on which nation you live in.

Taking England as an example, Strategic Health Authorities (SHAs) are responsible for overseeing and supporting the NHS locally; they also ensure that there is a link between the NHS and the Primary Care Trusts. Primary Care Trusts (PCTs) are responsible for deciding exactly which health services the local population needs (e.g. GPs, hospitals, dentists, pharmacies etc) and for guaranteeing these services are provided. PCTs are also responsible for purchasing hospital and specialist services from the local NHS Hospital Trusts; NHS Hospital Trusts are the main providers of hospital-based services.

So, if you wanted to campaign for a new or improved paediatric service, you would target whoever was responsible for purchasing local services, and this is usually the PCT. Every PCT (and SHA) should have a named person taking the lead for children's services, as well as a chief executive, and these would be the people to concentrate your campaign on.

However, in the case of specialist hospitals such as Great Ormond Street Hospital or the Royal Marsden Hospital, you would target the relevant NHS Hospital Trust, as such specialist hospitals are funded by all the PCTs in England.

Every NHS Hospital Trust and PCT in England should have a Patient Advice and Liaison Service (PALS) attached to it. PALS are an impartial and strictly confidential service offering advice to anybody with concerns about the health services they, or their family, receive. PALS are an excellent service to contact initially. Not only can they give advice and information about local health services, but all comments and concerns are noted and passed on to the relevant Trust, with a view to improving services. They will also be able to give you the correct contact details of the most appropriate person to address in your campaigning.

Community Health Councils, Local Health Councils and Health and Social Councils are able to assist in a similar way to PALS in Wales, Scotland and Northern Ireland respectively.

In addition, soon each NHS Trust and PCT will have a Patient and Public Involvement Forum (PPI Forum). These Forums will influence decisions made about local and national service provision and aim to get the views of patients and the public heard. As a parent of a disabled child, you can apply to be a member of a PPI Forum - if you would like more information about this, call 0845 120 7111.

More information about the structure of the NHS in each of the four nations of the UK can be found on the following websites:

Northern Ireland: <http://www.dhsspsni.gov.uk/hss>

Scotland: <http://www.scotland.gov.uk>

Wales: <http://www.wales.nhs.uk>

England: <http://tinyurl.com/3fy7z>

Contact a Family staff at our nation offices in Scotland, Northern Ireland and Wales are also happy to answer any queries you have about NHS structure and campaigning on health matters. Their contact details can be found on the Contact a Family website at: <http://www.cafamily.org.uk> or by calling Contact a Family's UK office on 020 7608 8700.

Lobbying your MP

MPs can sometimes be a powerful influence on those making local decisions, particularly if they are in the same political party. They can write to represent your views or ask questions of GPs, managers of social services, education and health and local benefits offices. They can also bring publicity to your case as the local media is always interested in the local MPs' views and activities.

You can find out who your local MPs are (your group may have members who have different MPs) and how to contact them through the local Citizens Advice Bureau, public library or town hall.

Visiting your MP

A personal discussion with your MP is best if you can manage it.

MPs hold regular 'surgeries' in their constituencies. Details of these are sometimes advertised in the local paper or can be obtained from the town hall or local party headquarters. It is best to write beforehand to let your MP know what you wish to discuss.

If the MP does not hold surgeries, you could invite him/her along to a group meeting.

The following points will be of help:

- if you are going as a group to see an MP ensure that you all live in his/her constituency as MPs will only take up issues from their own constituents
- decide in advance who will speak about which issue
- do not argue on a party political basis - seek to persuade, not to confront
- be clear on your facts and keep to the point
- include your personal experience if you can as this makes the most impact

Writing to your MP

If you cannot visit, it is worth writing to your MP:

- spell his/her name correctly
- if several people are writing to the same MP, make the letters individual and not copies of each other – provide different personal examples
- be polite, not aggressive
- present your problem clearly and say what you would like the MP to do about it

You can write to your MP at his/her constituency office or at the House of Commons, London SW1A 0AA.

Using the local media

Involving the local media in your campaign is useful because local councillors and MPs are always keen to have a favourable press.

When contacting the media it is best to keep to the basic principles of the campaign (cause, evidence, objectives) and show how you are trying to achieve them (strategy). Don't forget to approach local radio and TV stations, as well as free sheets, in addition to the local papers. You can:

- write a letter to the press about your cause (mark it "for publication")
- contact the relevant reporter (for example, one with an interest in health or children) and let them have updates on the campaign
- issue news releases at each stage of your campaign to involve the media and the public and to keep your targets on their toes

For more information about producing a news release see the Contact a Family Group Action Pack guide *Writing a news release*.

Campaign tactics

The tactics you choose for your campaign will depend on your local circumstances. The following case study illustrates the possibilities for a local campaign. It is based on an actual example but modified to illustrate the points in this guide.

Case study

Cause: A local parents' group was concerned about the long waiting list for portage as children were losing out on help at a vital stage of their development. They decided to campaign for an extra portage worker who would absorb the whole waiting list.

Evidence: Portage in early years has a significant effect on children's development and supports parents constructively. The group cited recent research. The educational psychologist also supported this view.

Realistic objective: The group worked out that it would cost the Council £15,000 to employ a worker to cover the waiting list - a small amount compared to other services and a long-term saving on educational costs.

Strategy: The group identified a councillor who, as trustee of a local opportunity group, was sympathetic. She gave them some inside information about the council and how and who to contact. She was also primed to ask questions in key budget meetings.

Following a letter to the local MP, a delegation of five parents went to see him at his surgery. The MP received them sympathetically.

The group also wrote to every councillor a week before the meeting of the Education Committee. On the day of the meeting a number of supporters handed out leaflets outside the Town Hall and made sure every councillor was aware of their case. Placards were prepared to create a good picture for the local paper which had been informed in advance.

No decisions were taken at this meeting but the outcome looked possibly favourable and so the group issued a press release saying how pleased they were with the Education Committee's sympathetic response. They also mentioned the MP's response.

At the next Education Committee meeting they repeated the tactics but this time had a bigger crowd of about 30 supporters.

Result: The Council appointed an extra portage worker.

Sources of evidence

Legislation

Children Act 1989

Children with disabilities are included in this Act under the term "children in need". If your child is regarded as being in need the local authority has a duty to provide a range of services to help you. These include information and advice, holiday provision and day care for children, help with transport, recreational activities, home help (including laundry service), help with holidays, financial help.

Councils are meant to provide:

- accommodation for children in need, including respite care
- information on services in their area for children with special needs

They should also maintain a Register of Children with Disabilities to help them plan services.

You have a right to see everything that is written about your child.

Under this Act your local authority should produce a Children's Services Plan which shows priorities for children in need over the forthcoming year. Ask to see it and check what it says about plans for children with special needs. This will help you know how realistic your campaign is in the light of local priorities.

Some councils consult parents about the content of these plans and so it is worth asking what consultation processes exist in your area.

Special Educational Needs and Disability Act 2001

This Act lays down clear rights for parents to be consulted about their child's special education. In addition, a local education authority must arrange for the parent of any child in their area with special educational needs to be provided with advice and information about matters relating to those needs.

Carers and Disabled Children Act 2000

This Act gives parents and carers an enhanced right to an assessment of their own needs (even when the person they care for does not wish to be assessed). It also makes provision for vouchers and direct payments to be provided to parents and carers of disabled children where they have been assessed as needing a service.

Disability Discrimination Act 1995

The Disability and Discrimination Act aims to end discrimination towards people with disabilities by incorporating rights in the areas of employment, access to services, transport and housing. Under the Act it is unlawful to refuse to serve a disabled person, provide a service to a disabled person on less favourable terms or in a less favourable manner. From October 2004, these rights will be extended and service providers will have to consider changing physical features which makes it unreasonably difficult for disabled people to use their services.

Research and useful publications

- **Services for disabled children**, a report by The Audit Commission, 2003
A review of services for disabled children and their families

Having listened to 240 disabled children, young people and their families about their experiences of services, the Audit Commission produced this significant national report.

It confirms that the so called 'postcode lottery of care' is still very much in evidence with everything depending on where families live and how hard parents are willing to push for services. If you are campaigning to improve services in your area, this report will help you make your arguments more strongly.

Copies (priced at £15) can be ordered by calling 0800 502030 and quoting stock code: GAR3074 and ISBN:186240 455 0

Alongside the report, The Audit Commission have also produced a variety of tools to help drive improvement. These include a series of factsheets for families and carers, a child-friendly summary giving disabled children advice on getting their views across and an improvement pack for service providers. All the tools are available at the following website address:

<http://www.auditcommission.gov.uk/disabledchildren>

The Law

- **Disabled Children and the Law: research, the law and good practice**, Janet Read and Luke Clements, 2001

This is a comprehensive introduction to the legal responsibilities of social services, health services and education and includes research on the needs of disabled children and young adults to demonstrate how the law can be used to facilitate good practice and policy development.

(available from all good bookshops, published by Jessica Kingsley Publishers; ISBN: 1853027936)

Disclosure of diagnosis

- **Right from the start**: good practice in sharing the news, Scope, 2003

Excellent guidance on how news of a disability should be broken to parents (available from Scope Library and Information Unit, 6 Market Road, London N7 9PW <http://www.rightfromthestart.org.uk>)

Respite care

- **Breaking point** A report on caring without a break for children and adults with severe or profound learning disabilities. This useful guidance also includes campaigning tips. From Mencap, 123 Golden Lane, London EC1Y 0RT; <http://www.mencap.org.uk/breakingpoint>

Education

- **Special Educational Needs Code of Practice 2001**

(available from the Department of Education and Skills, tel no. 0845 602 2260, please quote ref 581/2001).

- **Special Educational Needs - A guide for parents and carers**

(available from the Department of Education and Skills, tel no. 0845 602 2260, ISBN: 1841856444).

Statistics

15,000 children with disabilities are born in the UK each year and 4 million children and adults are affected by rare disorders in the UK.

For local figures, find out what your own local authority has researched and published. For example, how far advanced is the register of children with disabilities?

Other useful research and websites

The Social Policy Research Unit at the University of York has carried out a considerable volume of research into the needs of disabled children and their families. These are published in their *Findings* series which is listed on their website <http://www.york.ac.uk/inst/spru>

The Children's National Service Framework is being developed by the Department of Health. It will be a key driver for change in the NHS and is based on key NHS Plan values <http://tinyurl.com/3fy7z>

- Modernisation
- Breaking down professional boundaries
- Partnership between agencies.

An External Working Group has been working on Disabled Children Services and their evidence and progress is listed on the website <http://tinyurl.com/2ljke>

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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