Every disabled Child Matters

Making Disabled Children Matter Locally 2010

A guide for supporters on campaigning to make disabled children and their families a local priority

This guide aims to provide EDCM supporters with the ideas and materials they need to make sure that their ***Local Authority, Primary Care Trust, MP and local councillor*** treat disabled children as a priority.

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1. Introduction

Why campaign?

Disabled children have been denied support for too long, and experience poorer outcomes across the board than their non-disabled peers.

Families with disabled children report high levels of dissatisfaction with social care, health and education services, and 8 in 10 families with severely disabled children surveyed by Mencap described themselves as 'at breaking point'[1].

EDCM wants to see every ***Local Authority, Primary Care Trust (PCT), MP and local councillor*** make a clear commitment to improve services for disabled children and their families. As an EDCM supporter you have a key role to play in making this happen where you live.

How to campaign?

There are lots of different ways that you can campaign for rights and resources for disabled children and their families. This campaigning guide should give you lots of ideas of different ways to campaign and information on who to campaign.

Who to target?

For different issues there are different people/organisations that you need to focus your campaigning on. For example your local authority is in charge of decisions about local services, your Primary Care Trust (PCT) is in charge of decisions about local health services and your MP is your voice in Parliament for national decisions such as the money that is allocated to your area for short breaks. Below is an overview of who you should approach when campaigning on certain issues.

Primary Care Trust

If you want to change health services in your local area then you should contact your PCT. The PCT makes decisions on:

- local hospital and doctor surgeries
- equipment such as wheelchairs
- community nursing
- palliative care
- short breaks services for children with complex health needs

Which PCT do I live in?
http://www.nhs.uk/ServiceDirectories/Pages/ServiceSearchAdditional.aspx?SearchType=PCT&ServiceType=Trust

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[1] Breaking point - families still need a break (2006) Mencap

MP

You can contact your MP about anything you are concerned about as they are your representative in Parliament but they can also raise concerns on your behalf to the Local Authority or your PCT.

Who is my local MP?
http://findyourmp.Parliament.uk/

Local Councillor

Councillors are elected by the local community and are there to represent its views. They are your voice in your local authority or “council”, and can raise your concerns about any local issues.

Who are my local councillors?
http://www.writetothem.com/

Local Authority

Your local “council” is responsible for providing services in your local area such as education, local leisure facilities, street lighting and so on. Therefore your local authority makes decisions on:

- local short break services
- transition services
- local education facilities
- transport – including blue badges
- housing – local decisions about housing allocation
- roads and pavements
- local leisure facilities including parks and playgrounds
- crime and anti-social behavior
- whether you are entitled to DLA, carers allowance etc

Which local authority do I live in?
http://local.direct.gov.uk/LDGRedirect/Start.do?mode=1

2. Know your rights

When campaigning about the local services that you and your family access, it is important to know your rights. This will enable you to hold your local authority, education and health services to account.

Disabled children and the Equality Act

- The Equality Act 2010 will come into force on the 1 October 2010 and brings together all current equalities legislation, including the Disability Discrimination Act (DDA) 1995 and later amendments. The DDA will continue to apply to discriminatory acts until the replacement provisions of the Equality Act are in force – the different parts of the Equality Act will come into force at different times, so you may need advice about whether the DDA or the Equality Act applies to your situation.
- Under the DDA, it is generally **against the law to treat disabled people less favourably** than other people for a reason related to their disability. A wide range of organisations, including schools and service providers, also have to make **'reasonable adjustments'** to the way they deliver their services so that disabled people can use them.
- The Equality Act will keep the core protections of the DDA and is also bringing in a new right that protects the family and friends of a disabled person from '**discrimination by association'**. This means that, for example, it will be illegal to treat an employee unfavourably because they are a carer of a disabled person.

Disabled children and children's services

Universal Services
Disabled children should be able to access all the services available to all children. This will include nurseries, playgroups, playgrounds, leisure services, children's centres and mainstream schools.

Specialist Services

- Your local council has **a duty to assess the needs of all disabled children**[2]. The only assessments which meet this legal duty are 'initial' or 'core' assessments. Assessments should involve all the children and adults in the family and take into account all the needs of different family members. Assessments should primarily identify barriers that prevent the child and family living an ordinary life and then look at what support the local area can give to tackle these barriers.
- Once a needs assessment has taken place, children's services have a duty to provide services to meet those identified needs if the child fulfils the local eligibility criteria. Most local areas have 'eligibility criteria' to decide who is entitled to what services. You are entitled to ask to view this so that it is clear as to why you have been offered the services you have.

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[2] Children's Act 1989

Disabled children and transition

The process of transition to adulthood involves changes in both the law and service provision for disabled young people.

- The duty to assess needs and provide services remains as disabled young people move into adulthood
- Education services should generally take the lead in transition planning unless there has been significant social care or health input in the life of a disabled young person
- The education duties are to produce a **transition plan** following the Annual Review of a child's Statement of SEN at 14 and to carry out a **learning difficulty assessment** in the child's last year at school if they are continuing to college or university
- Government guidance expects a **health action plan** to be developed for every disabled young person with health needs as part of the transition process
- The Mental Capacity Act 2005 applies in almost all respects to 16 and 17 year olds and fully to everyone aged 18 or over. It is essential that the **capacity to make each individual decision** of disabled young people is properly assessed and that if decisions have to be taken on their behalf they are made in the young person's best interests
- If a disabled young person has looked after status they are entitled to a pathway plan and related support under the leaving care legislation to support their transition out of care. This will apply to some disabled young people who are in out-of-borough placements.

Disabled children and education

Disabled children have a right to suitable, effective and appropriate education. The duties not to treat disabled children less favourably and to make reasonable adjustments apply in schools, as elsewhere in their lives and parents can make a claim to the First-tier Tribunal (SEND) if they think the school may have discriminated against their child. Schools must have an accessibility plan that shows how they are improving access to learning and to information for disabled children and how they are improving the physical environment of the school to improve access to education. Local authorities must have a similar accessibility strategy. Schools and local authorities must give you a copy of their plan or strategy when you ask for one.

Most, but not all, disabled children have 'special educational needs' (SEN).
Local authorities also have duties to identify and assess children who have SEN; they must have regard to the SEN Code of Practice; they must publish information about what support schools are expected to provide from their resources and what the local authority provides from theirs; they must tell parents about the information and support available locally from parent partnership services.

If a child is not making ‘adequate progress’ in comparison to their peers and the school thinks they may have SEN, the school must inform the parents. Following discussions between parent and teacher the child may be placed at School Action. At School Action the child should have an Individual Education Plan (IEP) or a similar document, such as a provision map, that sets out learning targets and the support to achieve them.

If the child is not making ‘adequate progress’ in line with the targets and despite additional support, they may be placed at School Action Plus. At this stage, the school should seek advice from an external expert (such as an educational psychologist or a language therapist) who may comment on a new IEP and may recommend further support from services provided by the local authority or other agencies.

Statutory assessment and statements

If, despite action by the school, the child is not making ‘adequate progress’ a parent or school can ask the local authority to carry out a statutory assessment. The SEN Code of Practice sets out the circumstances to be taken into account in deciding whether a statutory assessment should be undertaken. The local authorities published SEN information should make it clear what schools are expected to do from their own resources before approaching the local authority.

Parents and professionals contribute their views to a statutory assessment. If, following a statutory assessment, the local authority decides to draw up a statement, then the local authority must set out the child’s special educational needs and the special educational provision to meet those needs. Parents are invited to ‘express a preference’ for the school where they would like the special educational provision to be made for their child.

Currently there is a general presumption in favour of a mainstream school unless parents do not want that or it would be inconsistent with the ‘efficient education of other children’. Parents have a qualified right to have their child educated in the particular school for which they have expressed a preference, whether it is a maintained mainstream or special school: the school must be able to meet the needs of their child; placement there must make ‘efficient use of resources’; and it must allow for the ‘efficient education of other children’.

Once a child has a statement then there is a legal entitlement to the educational provision that is named in it. The local authority must review the statement every year. At particular points in the process, parents can appeal to the First-tier Tribunal (SEND) against the decisions taken by the local authority.

Exclusions

Children with SEN and disabilities should not be excluded from school except as a ‘last resort’. Where they are excluded on a permanent basis their parents can appeal first to a Governors’ Committee and then an Independent Appeal Panel. Where they are excluded for a fixed term their parents can appeal to a Governors’ Committee and to the First-tier Tribunal (SEND) if they believe that the exclusion amounts to disability discrimination. If a child has a disability which affects their behaviour, the school must have sought to make reasonable adjustments to accommodate this behaviour.

Disabled children and health

Disabled children have the same right as other children to access universal health services. NHS bodies have a duty to engage disabled children and their families in decisions about the planning and delivery of health services

- NHS bodies and Local Authorities must co-operate to make sure that disabled children's health needs are met
- Where disabled children have particularly severe and/or complex health needs, the NHS will have the primary responsibility for providing them with 'continuing care'
- It is always essential to determine whether a disabled child can and does consent to treatment, and to know if a child cannot or does not consent what the appropriate legal route is in each individual case
- Patients have a right to information about healthcare and social services in a format that is accessible to them where it is reasonable for the service provider to provide it in that format.

Disabled children and the right to participation

Participation is the right to be involved in designing services and in making decisions on which services is best for the disabled child and their family.

- Under Standard 8 of the English National Service Framework for Children (see below), Local Authorities, Primary Care Trusts (PCTs) and other NHS Trusts are required to ensure disabled children and their parents are routinely involved and supported in making informed decisions, that there is an ongoing user involvement programme for disabled children and young people in line with the wider patient and public involvement programmes and that facilities, equipment and skilled workers are available to enable children who communicate differently to others to participate in assessment and decision-making processes.[3]
- *Aiming High for Disabled Children* created **parent forums** to help create a new avenue for parents of disabled children to be involved in designing services. You can find information on parent forums and parent participation here: http://www.cafamily.org.uk/families/parentparticipation/index.html
- Article 12 of the United Nations Convention on the Rights of the Child (CRC) guarantees **every child** aged 17 and under has the right to express their views on all matters that affect them. A human rights approach to participation stresses inclusion of all children, respect for their equal worth and the differences that result within the participation process[4].
- The UN Committee on the Rights of the Child has stressed that children with disabilities are entitled to participate on an equal basis with other children;

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[3] Disabled Child Standard, Children's NSF, p30

[4] Listen and change: a guide to children and young people's participation rights (2008) Participation Works

practical measures must be introduced to facilitate their participation, including availability of transport, accessible information, assistive devices, communication aids and interpreters[5].

- Tips on how to include disabled children: http://www.ncb.org.uk/edcm/Top%20tips%20for%20participation.pdf

More information

Parents and others who want to know more about the law in relation to disabled children, in particular what rights and entitlements children and families have to services and support from different agencies, may be interested in 'Disabled Children: A Legal Handbook', a new legal publication co-authored by former EDCM campaign manager Steve Broach which will be published by the Legal Action Group (LAG) in October 2010.

Publication details are on the LAG website: http://www.lag.org.uk/Templates/System/Publications.asp?NodeID=93342&Mode=display

Making a formal complaint against your local authority

- If you feel that you are not receiving the appropriate services you should request an up to date assessment of your child's needs. This will determine what services your child is eligible for, and will answer any questions you may have about why you are accessing the services you currently are.
- If you feel that your local authority is not meeting its duties, here are the first steps you can take if you would like to make a formal complaint
    - Write to the council - highlighting that you are making a formal complaint and outlining all the issues you have faced. Most councils have an office for complaints to go to – you will be able to find this on your council’s website. Otherwise you can send your letter to the head of the council.
    - When making a formal complaint, copy the Director for Children's Services and the Lead Councillor for Children into your email/letter. Again you will nbe able to find their details on your council’s website.

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[5] See Me, Hear Me: A guide to using the UN Convention on the Rights of Persons with Disabilities to promote the rights of children (2009) Save the Children

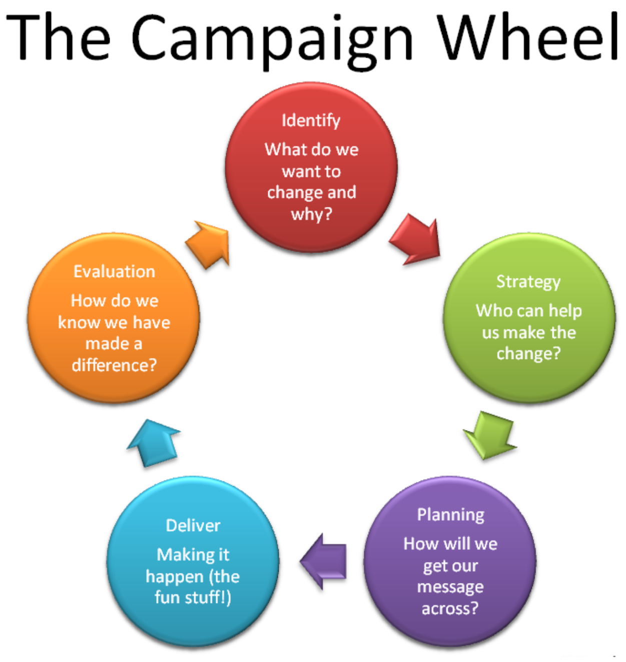
3. Planning and running a campaign

You can campaign about anything that you think needs to be changed. It may be something that you feel passionate about in your local area. For example if a popular local youth group is closing down, if you are unhappy with the way transition happens locally or have concerns about local wheelchair provision. On these sorts of issues you want to run a local campaign to influence your local authority or PCT.

Below is information on helping you organise, build and run your campaign.

Planning your campaign

When you are first thinking about how to run a local campaign there are a series of stages that you need to think through that will help you plan your campaign. These are laid out in the Campaign Wheel:



Stage 1: Identify – What do we want to change and why?

Identify where there is currently a problem or where something isn’t working well, begin to collect evidence and decide what outcomes you want from your campaign.

Stage 2: Strategy – Who can help us make the change?

When designing your campaign you may decide to campaign as a group of parents or young people. Think about what strengths each person has – perhaps someone is good at design and can make posters for your campaign, someone else might be good at public speaking and take charge of communicating your message at meetings etc.

Stage 3: Planning – How will we get our message across?

Decide on the best way to communicate your campaign. Firstly you need to identify who is the decision maker that can make change happen? This is the person you want to convince that change is needed. It is a good idea to begin your campaign by writing to the decision makers and tell them what it is you want changed. If they don't respond to you or won't change things then think about other campaigning methods such as a petition, writing letters to your local paper or even holding a protest.

Stage 4: Deliver – Making it happen

Once you have decided how you want to run your campaign then make it happen!

Stage 5: Evaluation – How do we know we have made a difference?

Once you have run your campaign you need to think about what it was that you wanted to change when you began your campaign. Have you completed what you set out to achieve? If not think about the next stage of your campaign and what you have learnt from your campaign so far.

Getting Started

Writing a letter

You can write to your MP, local councillor, local authority or PCT either by letter or email setting out any concerns or queries that you may have. Top tips for writing a campaign letter are:

- Stick to one issue per letter – keep it short and simple
- Ask them to do something e.g. meet with you to discuss the issue further.
- Write in your own words, talking about your own experiences.

Holding a meeting

Holding a meeting is a good way to talk to someone about your campaign and to tell your story. Holding a meeting helps you build a relationship with decision makers, enables you to set out your case, educates the decision maker and gives them an initial opportunity to respond. It can also help you decide on the next steps for your campaign. For example if a councillor says 'I can make the case for change if you can gather more information from local families' then you can do this following the meeting. Top tips for holding a meeting are:

- Book an appointment before you go.
- Tell them what you want to discuss before you meet with them so they can do a bit of research first

- Tell them what you would like them to do – for example, sign up to something or raise your issue in Parliament/council
- Write down some points before you meet up so you don't forget what you want to say!

Organising an event

To raise awareness of your campaign, you may like to organise an event in your local area. You can invite decision makers along to hear from local families and to respond to your campaign. You may also like to invite the local media along to write a story about your event and information about your campaign (for more tips on dealing with the media see page 11).

Ideas include:

- Inviting local decision makers along to an event that you already have planned (like a summer or Christmas fete) for them to meet local families, hear about your campaign and to talk about what they will do in response. You could invite the local media along to report on their speech.
- Organise a sponsored walk/bake sale/fancy dress party (whatever you can think of!) and raise money for your local disability charity. Invite local decision makers and your MP along to meet some local families and disabled children to hear from them about their experiences.

Other campaign ideas

You can be really creative with thinking about the sort of campaign you want to run. Here are a few more campaign ideas:

Make use of social media

Lots of people use Facebook to campaign. It's a brilliant way to share information with other people about your campaign, and to get lots of people to support it. You need to set up a group or fan page which talks about your campaign. Then invite people to join.

Go to www.facebook.com for more information, check out www.facebook.com/everydisabledchildmatters for ideas.

Twitter is another popular way to keep campaign supporters up to date with you campaign. It gives you 160 characters to write an update of what is going on so you can tell people about meetings you've had, evidence or commitments you've gained.

Go to www.twitter.com see www.twitter.com/ncbtweets for ideas.

Make a film

Making a film is another effective way to campaign. You could make a film by yourself or with a group of friends. It doesn't have to be expensive – all you need to do is borrow a video camera and have a great idea. You can then post it on a website such as YouTube (www.youtube.com) and invite people (including your MP and local councillors) to watch it and ask for them to respond to it.

You can see some of EDCM's campaign DVDs at http://www.ncb.org.uk/edcm/campaigns/participation.aspx

Also one of EDCM's young campaigners Adam Stafford made a You-Tube film about a meeting he organised with Ed Balls http://www.youtube.com/watch?v=YlB3i_0_2CA

Hold a demonstration or march

These can be a bit harder to organise but can still be effective. You can make banners and signs for you and your friends to hold whilst you're marching. Invite the local media down to get coverage of your march.

Start a petition

Collect names locally and present them to your local council/PCT/MP to show the level of local support for your campaign. Outline your campaign at the top of the petition with information that describes the situation, suggests what is needed, and explains why it is needed. Finishing with a sentence such as:

"We, the undersigned, believe the Sunnyoaks Children's Centre to be a vital local resource and call upon Councillor Davies to rescind his department's decision to close it".

Then collect people's names, addresses and their signature, and submit it to the relevant decision maker.

If you are campaigning on a national issue you can register petitions on the 'number 10' website. If you get more than 500 signatures then your petition will get a response from officials that work for the Prime Minister or for Government Departments such as the Department of Health. Go to http://petitions.number10.gov.uk/ to register your petition.

Undercover research

This is a good way to collect evidence about a service or attitudes.

You and your campaign group could go out and record your experiences of services and attitudes. For example you could record your experiences of attitudes on transport or work opportunities. Then write down your experiences. You can then tell your MP or the local media about your findings and what needs to be changed.

These are just a few ideas. There are lots of ways to campaign and we would be really interested to hear about other campaigns you run. Keep in touch at info@edcm.org.uk

Getting media coverage

The media is one of the best ways of spreading your campaign message. You can use the local media to publicise an event you have organised, tell people about your campaign and increase public support, and to share with people what you achieved. Below is information on some ways you can get media coverage of your campaign.

Press release

A press release is the most effective means of communicating with the media. It is the main way to inform your local paper or radio station about the campaign that you are running and to get them to write a story about it. Press releases need to inform journalists about the key points of a story; and to highlight why they should write a news story on your campaign.

Top tips for writing a press release include;

- Summarise the main points in the first paragraph.
- Point out the who?, what?, when?, where? and why? in the first paragraph to catch the journalist’s attention.
- Stress the local angle of your story.
- Add a quote from a spokesperson leading the campaign who can highlight key messages, and a quote from a case study to give a personal perspective and show how real people are affected.
- Make sure that the heading 'Press Release' is displayed prominently at the top of your document. Give your press release a date and a title that explains the essence of your campaign. When the press release is finished write ‘End.’[1]

Letter to newspapers

Letters are an excellent way of getting an issue into the local paper. Letters pages are often one of the most widely read parts of the paper and can spark debate and generate wider coverage of an issue. You can send a letter to a local paper instead of a press release. This allows the message to be more personal. A letter to a newspaper will be printed in the ‘letters to editor’ section rather than written up as a news story.

Calling a local radio station

Local campaigning can be attractive to local radio and TV. To approach a radio or TV station to cover your story you need to create a press release.

Top tips for speaking to your local radio station:

- If you secure an interview, ask questions when you are first contacted which will help you feel more in control, such as:
    - Is the interview live or pre-recorded?
    - How long will the interview be?
    - What's your angle on the story?
    - Where will the interview take place?
    - Who is the interviewer?
    - When will it be broadcast?
    - Who else have you spoken to and what have they said?
- Prepare two, at most three main points including how the audience can support your campaign.
- Be clear about what you can/are prepared to talk about.
- Give short answers that are to the point.[1]

4. Lobbying your Local Area

Challenging Local Cuts

The UK is facing a record deficit and all local areas and Government departments are under pressure to make cuts to local services to save money. Unfortunately our supporters tell us that this has resulted in some valued local services that support disabled children and their families having their funding reduced or stopped completely.

If you want to challenge the closure of services in your local area then it is important that you: get your voice heard, are involved in any consultations/meetings about the decision, and that you communicate the impact that service closure will have on the children and families that use the service.

Many of the campaign ideas mentioned in this document would be useful in campaigning against cuts. When your first hear that a cut is planned and you would like to challenge you can:

- Write to your local authority and outline your concerns. You may like to ask for a meeting and to be involved in all discussions about the future of the service.
- Ask your local councillors and MPs to come and visit the service to see how it is used and to hear from young people and families about the value of the service.
- Closure of valued local services is something that can be of interest to local media. You may like to write to your local paper and invite them to visit the service and discuss the impact of its closure with you and others that use the service.

About your local area

Your ‘local area’ is made up of all the people that make decisions about local services. The main organisations/people that make decisions in your local area about services include:

- Primary Care Trust
- Local Authority
- Local Councillors

Primary Care Trust

If you want to change health services in your local area then you should contact your PCT. Currently there is no-one elected by local residents that sits within the Primary Care Trust.

Helpful contacts include:

- PCT children's lead officer
- Manager of Child Development Centre
- Manager of Children's Community Nursing Service
- Manager of Children's Therapy Services
- All Strategic Health Authorities (SHAs), whose role it is to manage the NHS locally, have a post-holder that leads on children's health. Targeting the SHA children's lead may also be helpful.

You can find out who holds the above position by searching on your local PCT website or by calling your PCTs switchboard and asking them.

Primary Care Trusts only function in England only due to devolution. Devolution is the process of powers that have previously sat with central Government being given to regional bodies. For example decisions on health used to be taken by the Westminster Government but are now taken by the Welsh Assembly Government for Wales and the Scottish Parliament for Scotland.

Local Councillor

Councillors are elected by the local community and are there to represent its views. Each councillor represents an area called a ward, serving for four years. They are your voice in your local authority or "council", and can raise your concerns about any local issues, particularly those listed under 'local authority'.

The work of a councillor includes holding surgeries to help local people, supporting local organisations, campaigning on local issues, and developing links with all parts of the community. If you want to discuss any issues with your local councillor, you can contact them via your local authority or attend the councillor's advice surgery. Advice surgeries are available for local people to ask for help or advice, make a complaint or enquire about local authority services. Your council will have a list of the councillors' names and contact details.[6]

Local Authority

Your local authority or "council" is responsible for providing services in your local area such as education, local leisure facilities, street lighting and so on.

Councils have different ways of making decisions. Since 2000 most councils in England have had a small executive group that is responsible for the overall business of the council. Its decisions are subject to scrutiny by a different group of councillors who meet in overview and scrutiny panels, to check and monitor what the council does.

Helpful contacts:

- Director of Children's Services (and for the PCT)

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[6] DirectGov 2010

- Manager of Disabled Children's social care team
- Manager of the Special Educational Needs service
- Manager of Children's Information Service
- Manager of Parent Partnership Service
- Opposition Councillors – from the political party who are not running the Local Authority.

You can find out who holds the above position by searching on your local councils website or by calling your councils switchboard and asking them.

Local Elections

In a local election, you vote for the councillors who run your local services. Local elections take place at least every four years.

When you vote for your local councillor you are electing them to be your voice in your local council. In the lead up to an election when they are trying to gain local support it is a good idea to build a relationship with them. This makes it easier to talk about your campaigns once they are elected. You may also like to ask them to support disabled children and their families during their time as a councillor if they get elected. Gaining this support before they are elected gives you more leverage if they become elected.

Below is information about some of the campaigns that you may like to run in your local area. If you want to campaign on something not included in the following pages see the 'Planning a local campaign' section for how to plan and run a campaign.

Charters

EDCM has developed campaign Charters for Local Authorities and Primary Care Trusts (PCTs). The Charters are a set of commitments that local authorities and PCTs can sign up to, to show that disabled children are a priority in their area. They are signed by the people that set strategy and have a responsibility to engage with children and families in their area.

The Local Authority Charter is signed by Lead Members for Children's Services (Councillors). The Primary Care Trust Charter is signed by the PCT Chair.

Information about the EDCM Charters, and a list of local authorities and PCTs signed up, can be found at www.edcm.org.uk/lacharter and www.edcm.org.uk/pctcharter.

The Local Authority and Primary Care Trust Charters are limited to England only due to **devolution**. Devolution is the process of powers that have previously sat with central Government being given to regional bodies. For example decisions on health used to be taken by the Westminster Government but are now taken by the Welsh Assembly Government for Wales and the Scottish Parliament for Scotland.

Getting your Local Authority or PCT to sign the Charter

You can check whether your PCT or Local Authority has signed up to the Charter on the EDCM website at www.edcm.org.uk/charters. If they have not yet signed up then you can use EDCMs online tool to write to your Lead Member for Children's Services/PCT Chair and ask them to sign it.

If your Lead Member for Children's Services/PCT Chair is unsure about signing up to the Charter then it might be effective to meet up with them to discuss the Charter and explain the need to prioritise disabled children locally. EDCM has a template campaign presentation that we can send you for you to use in your meeting – email info@edcm.org.uk

If you have written to your PCT Chair/Local Authority lead and invited them to meet with you and you have still not gained a satisfactory outcome you can think about other campaigning ideas. Alternative actions you could take include:

- Arrange a meeting with groups of local parents to discuss what elements of the Charter are most important in your area, and make a plan to show how you think the local authority / PCT can deliver those elements. This is particularly helpful if Councillors or PCT Chairs are being advised by officers that the Charter is too ambitious.
- Highlight your campaign to the local media (see page 11 for more information)
- Write about the campaign in local newsletters. EDCM has sample text – email us at info@edcm.org.uk
- For the Local Authority Charter, talk to opposition Councillors – from the political party who are not running the local authority- as this can put more pressure on your Lead Member to sign up.
- Approach your MP to ask them to support the campaign and lobby your local authority / PCT to sign the Charter(s). You might want to arrange to meet them at their local surgery.

Getting your PCT and LA to deliver on Charter commitments

Once your Local Authority/PCT has signed up to the Charter you can place pressure on them to ensure that they fulfill their commitments within the one year time frame that they have agreed to. Here are some ideas on how you can encourage them to do so:

1. When your Local Authority signs up to the Charter issue a press release to the local media to highlight this new commitment – email info@edcm.org.uk for a template press release. The more people that know they have committed to it the more people will want to know what they have done!

2. Use EDCM's campaign tool to ask if your Local Authority/PCT has a plan in place to deliver the Charter commitments, and ask to see a copy. See www.edcm.org.uk/charters

3. Try to get the Charter(s) as a standing agenda item on any local planning boards you may be involved with, asking Officers to report to the board on progress towards delivering the objectives.

4. Ask the Councillor who chairs your Children's Services Scrutiny Committee to review progress on delivering the Charter objectives.

Short Breaks Duty

The Children and Young Persons Act 2008 became law in November 2008. The Act introduces a new legal duty on local authorities to provide short break services – the first time the law has required local authorities specifically to provide breaks. The duty is expected to come into force in April 2011.

Take Action! EDCM has created an online action asks that local authorities how they are **planning their short break services** for when the new Children and Young Persons Act duty comes into force in 2011. Take action at www.edcm.org.uk/getinvolved

Disabled children and childcare

On 1st April 2008 new duties came into force to ensure families with disabled children can access **affordable childcare** that meets their children's needs. The new duties stem from the **Childcare Act 2006**, which states that local authorities should secure sufficient childcare to enable parents to work, with particular regard to childcare for families with disabled children.

Local authorities also have a duty to provide **information, advice and assistance** to parents of children and young people up to the age of 20 on childcare and other services, particularly for the parents of disabled children.

Take Action! Ask your local authority what is being done to meet this duty.

Disabled children and health funding

Unlike the funding for local authorities, the funding announced for PCTs is not ring-fenced – it is part of their 'baseline allocations'. The Government has stated that each PCT sets their own spending priorities, including how much they spend on services for disabled children and children with palliative care needs. It is therefore hugely important that EDCM supporters campaign locally to make sure the funding is spent on its intended purpose.

Take Action! Write to your PCT and ask them how much money they are spending on disabled children.

5. Lobbying your MP

Who is my local MP? Find out at http://findyourmp.Parliament.uk/

You elect your MP to be your voice in Parliament. They can also play a vital role as an advocate for your campaign towards your local authority or primary care trust. They can also make an impact on issues that are decided by central Government, for example:

- budgets for disabled children's services
- guidance for local authorities and PCTs on best practice
- the welfare and benefits system.

Your MP will be interested in any campaign you are running so that they are knowledgeable about what is going on in the local area. They are your voice in Parliament therefore may highlight your campaign to demonstrate national trends that the Government can legislate on. For example if you are campaigning against the closure of a local service, this is something that your MP could raise as an indicator of national trends and the need for more money from central Government to fund these services.

Constituency Pledge

EDCM launched its constituency pledge in the lead up to the General Election in 2010. We asked supporters to email their political candidates asking them to commit to taking action to benefit disabled children, young people and their families by signing up to EDCM's Constituency Pledge. The Pledge is a series of five commitments that we are asking new and re-elected MPs to carry out. These are:

1. Meet with disabled children, young people and their families to discuss key issues of concern to them

2. Raise these issues of concern, and promote rights and resources, for disabled children, young people and families from my constituency in Parliament

3. Visit local services for disabled children and their families on a regular basis

4. Support measures to transform services for disabled children and their families, such as the Aiming High for Disabled Children (AHDC) programme in England

5. Find out how funding is being used in my constituency to improve services for disabled children, young people and their families

We had a fantastic response from supporters and more than 20 per cent of MPs have signed the pledge. You can see if your MP has signed the pledge at http://www.ncb.org.uk/edcm/constituency_pledge/mps_signed_up.aspx

If your MP has not yet signed up you can write to them asking them to sign up by using EDCM's online tool at: http://e-activist.com/ea-campaign/clientcampaign.do?ea.client.id=6&ea.campaign.id=5798

If they have already signed up why not ask them if they have carried out any of the pledge commitments yet? If you have a disabled child in your family (or are a disabled young person yourself) you could offer to help them achieve some of the pledge commitments. For example offering to meet with them or inviting them to visit the local services that you use.

If your MP has signed the pledge this is a tool for you to use. It is a public commitment that they have made and you, as a local resident, are entitled to hold them to account on it.

6. Online Action

One of the main ways that EDCM helps its supporters to get involved in campaigning is through its online campaigning tools. These are a series of campaigns that we have created on our website that support the wider work of EDCM and enable EDCM supporters to write to their MP, Local Authority or Primary Care Trust.

The actions are written in a way that allows supporters to edit the letters that are sent to ensure that they represent their views. This also gives an opportunity to write about your family's experiences. MPs, local councillors and PCTs like to hear about how issues affect local people and are more likely to respond if they know about how the issues are impacting on local people.

On going online campaigns that are on EDCM's website include:

- **Upcoming duty to provide short breaks for disabled children under Children and Young Persons Act 2008 -** Email your local authority to ask how they are planning their short break services now and beyond 2011

- **Constituency Pledge -** Email your local MP and ask them to sign up to EDCM's Constituency Pledge

- **Ensuring disabled children have things to do -** Email your council to ask how they will make sure disabled children and young people have good things to do and places to go

- **Help make disabled children a local priority**
- Get your local authority signed up to our LA Charter, or if they have signed it ask how they are implementing it.
- Get your PCT signed up to our PCT Charter, or if they have signed it ask how they are implementing it.

EDCM regularly updates its website with online campaigns. You can find the above campaigns and more at www.edcm.org.uk/getinvolved. If you sign up to become an EDCM supporter we will email you whenever we launch a new campaign. You can sign up to become an EDCM support on the 'Get Involved' page of our website.

You can also keep up to date with EDCM's news and actions by becoming a fan of our Facebook page. You can become a 'fan' of this page at www.facebook.com/everydisabledchildmatters

7. Glossary

Aiming High for Disabled Children: Better Support for Families Government report published in May 2007 that committed a £340 million funding package to services for disabled children and their families. Also announced the disabled children’s national indicator.

Campaigning is about changing things for the better. It means recognising a problem, making people aware of the problem and making people take action to solve the problem. Campaigning is something you can do on your own or by working together in groups.

Children and Young People’s Plan (CYPP) A single, strategic, overarching plan for all services affecting children and young people. Production of the plan is lead by the local authority. Plan includes clear targets and priorities for all services affecting children and young people, to identify the actions and activities needed to achieve them, and ensure delivery.

Children's Services Scrutiny Committee Responsible for scrutinising the statutory children's services functions of the Council.

Core Offer Set out in *Aiming High for Disabled Children*. A ‘policy statement’ that will encompass minimum standards on information, transparency, participation, assessment and feedback, to make it clear what entitlements and services disabled children, young people and their families can expect. Government expects local authorities and their partners to consider the Core Offer in their local planning and provision of services, and ensure that it is published and accessible to the local community.

Disabled Children’s Indicator National Indicator 54 (NI 54) - one of 198 national indicators from the National Indicator Set and the first ever national indicator on disabled children’s services. It measures parents’ experience of service delivery and on delivery of the Core Offer.

Local Area Agreement (LAA)LAAs set out the priorities for improving services and the quality of life in a place. They are an agreement between central Government and a local area (the local authority and 13 Local Strategic Partnership) and other key partners at the local level. This includes health agencies and voluntary organisations.

Local authority Also known as local council. Agency responsible for delivering children’s social care and education services. In some areas, there is a split between county and district councils. County councils are responsible for delivering health and social care services, but district councils have responsibility for other services that matter to families, including leisure services. In these areas, it is the county council that needs to sign the EDCM Charter, but will need to work closely with its district councils to deliver it.

Primary Care Trust (PCT) Agency responsible for delivering health services to all children. Services are generally commissioned from provider trusts and the voluntary or private sectors or sometimes provided directly by the PCT.

Vital Signs Guidance for PCTs from the Department of Health on how to measure local progress against national priorities. Includes the disabled children's indicator as an optional 'local priority'.

8. Further Explanation and Background

Aiming High for Disabled Children: Better Support for Families

Aiming High for Disabled Children is the report from the Government's disabled children's review and was published in May 2007. This was a joint review between HM Treasury and DfES, aimed at improving services for disabled children in England.

The report commits Government to providing significant additional resources - £430 million – over the three year spending period (2008-11). This money should start to transform services across the country. The money is backed by a package of system reform measures, including:

- A new national indicator on disabled children within the local Government performance management framework
- A 'core offer' for families with disabled children
- Work to improve data collection at a local and national level

Useful links:
www.edcm.org.uk/aiminghigh
www.hm-treasury.gov.uk./media/C/2/cyp_disabledchildren180507.pdf

Disabled children's indicator and the Core Offer

The indicator is National Indicator 54: Services for disabled children, one of five indicators that sit under PSA Delivery Agreement 12: Improve the health and wellbeing of children and young people. The PSA Delivery Agreement states:

> The indicator will be based on parents' experience of services and the 'core offer' made in Aiming High for Disabled Children: clear information; transparent eligibility criteria and process for accessing services; multiagency assessment; participation in shaping local services; and accessible feedback/complaint mechanism.
>
> The measure will cover the families of all children with disabilities and ask about all services provided by their local authority and Primary Care Trust (PCT). By 2011, disabled young people and their parents should be able to report a more favorable experience of these services: baseline and comparison data will drive best practice and improvements.

Useful links:

http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer
http://www.hm-treasury.gov.uk/media/9/6/pbr_csr07_psa12.pdf

The local Government performance framework from 2008

The 2007 Comprehensive Spending Review (CSR) announced 30 Public Service Agreements (PSAs) that set out the key priority outcomes the Government wants to achieve in the next spending period (2008-2011). Responsibility for achieving each PSA is shared across Government departments.

Each PSA is also underpinned by a set of national performance indicators, that will be used to measure progress towards each PSA. There are a total of 198 indicators, which define all the Government's priorities for councils. For the first time, a national indicator on services for disabled children and their families was announced in the Comprehensive Spending Review 2007. This sits under the Child Health and Well-Being PSA.

Useful links:

http://www.communities.gov.uk/publications/localGovernment/youngpeople
http://www.communities.gov.uk/publications/localGovernment/health

Local Area Agreements

Local Area Agreements (LAAs) set out the priorities for a local area (the local authority and Local Strategic Partnership). Councils have the flexibility to choose (in negotiation with the relevant Government office) 35 of the 198 indicators to include in their LAA.

In addition to the chosen 35, each LAA must also include 16 statutory education and early years indicators. The LAA can also include other purely local targets, on issues not covered by the national indicator set.

Useful links:

http://www.lga.gov.uk/lga/aio/20595

Monitoring performance

Although not all indicators will feature in LAAs, Councils will be required to monitor and report on all 198 indicators locally.

The new Comprehensive Area Assessment (CAA) replaces the Comprehensive Performance Assessment from 2009. The CAA will look at how councils and all the organisations subject to the duty to co-operate are contributing to achieving local ambitions, and the prospects for the place to improve. It will have a big emphasis on local people's views about their area and its services.
A key element of the CAA is that it will include the annual publication of the comparative performance of all areas against all indicators – it will not be confined just to those included in the LAAs.

Each year a joint risk assessment will be published by the inspectorates that will look at the likelihood of local and national priority outcomes being achieved.

Useful links:
http://www.audit-commission.gov.uk/cpa/cpatransition.asp

The health performance framework from 2008

The NHS Operating Framework sets out the priorities for the NHS each year. The 2008-09 and 2009-10 Frameworks clearly state that children should be one of four national priorities for the NHS, alongside cancer, stroke and maternity. Disabled children are mentioned as a priority in both documents. As is the case for the national indicator on disabled children, this is the first time disabled children have featured in the health performance management framework.

The Department of Health issued guidance in January 2008 – 'Vital Signs', which is issued to NHS bodies to help them develop local operational plans, to deliver against the national priorities set out in the Operating Framework. Parents' experience of services for disabled children is one of the Vital Signs under the heading 'Reputation, satisfaction and confidence in the NHS.'

Useful links:

Operating Framework 2008-09
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081094

Operating Framework 2009-10
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445

Vital Signs and Operational Plans
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082542

Thank you!

Contact EDCM

For more information or support in making disabled children matter locally you can get in touch with EDCM team:

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w. www.edcm.org.uk