EDCM's Disabled Children's Charter: Parent's Guide

What is the EDCM Local Authority Disabled Children's Charter?

EDCM has created a new 'Local Authority Disabled Children's Charter' for 2011/12, to help local authorities renew their commitment to local disabled children and their families. It reflects some of the changes in policies and duties for local authorities since the 2010 General Election. Similarly to the previous Charter, the Local Authority Disabled Children's Charter, or the 'Charter' is a set of commitments that local authorities can sign up to show that local disabled children and their families matter. By signing the Charter local authorities pledge to delivering its 11commitments within a year. We are asking all local authorities that have signed EDCM's Charter in the past to resign up to this new Disabled Children's Charter to renew their commitment to local disabled children and their families.

You can use the Charter as a starting point to drive up the standard of services for disabled children and their families in your area. This fact sheet will give you some ideas about how to do this, as well as how to challenge your local area when they are not providing services to meet your needs.

Please note: The Charter only covers English local authorities, reflecting the differences in the UK nations following devolution.

This fact sheet tells you how about:

- Asking your local authority to sign up
- What to do if your local authority doesn't sign up
- Supporting your local authority to deliver on their commitments
- Challenging your local authority if they don't deliver on the commitments
- Information on what the Charter Commitments mean and why your local authority should be delivering them

Asking your local authority to sign up

EDCM supporters in England can ask their local authorities to sign up to the Charter. The Charter must be agreed and signed by the **Lead Member for Children's Services** (or equivalent), who must also agree to deliver the Charter within one year of signing. The signed Charter then needs to be sent back to the EDCM office.

The easiest way to do this is through the online action on the EDCM campaign website – go to www.edcm.org.uk/charters to find out more.

What to do if your local authority doesn't sign up

Whilst many local authorities have shown their commitment to local disabled children and their families in the past. Other local areas have been resistant to signing the Charter. Below is a list of ideas on how you can persuade your local authority to sign up.

Speak to influential local people

A range of key local decision-makers can influence whether or not a local authority signs up to the Charter. The names and titles of professionals and services will vary between local areas, but some of these will include:

- Director of Children's Services
- 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

There will also be key professionals within health agencies such as the Primary Care Trust in similar roles, and in bodies that bring agencies together such as children's trusts and children and young people's strategic partnerships.

Talk to Councillors from the political party who are not running the council. If you can get the opposition parties to support the Charter, 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 to sign the Charter. You might want to arrange to meet them at their local Surgery. You can find out who your MP is on: http://findyourmp.parliament.uk/

Arrange a meeting

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 can deliver those elements. This is particularly helpful if Councillors are being advised by officers that the Charter is too ambitious. Following this meeting you might be able to get parent and voluntary organisations to put articles about the campaign and the Charter in local newsletters.

It may also be a good idea to arrange a meeting with the Lead Member or Director of Children's Services, to discuss the Charter and explain the need to prioritise disabled children locally. You can use your own experiences to say why it's important.

Tell them about other areas

EDCM has produced a document which outlines how helpful the Charter has been to local authorities in the past. This is a good way to present evidence that the Charter is helpful to local authorities as well as to parents. See EDCM's website to download this.

The Charter as an agenda item

Try to get the Charter onto the agenda for a meeting of the Children and Young People's Strategic Partnership Board, or another relevant meeting. You, or a professional you trust, could talk the Board about the Charter.

Speak to the local media

Talk to local media contacts about the Charter and why your local authority should sign – but always remember that the media has their own agenda, so think about how they might present your story. Consider local newspapers, TV and radio stations. You can find tips on writing to your local media through Making Disabled Children Matter Locally 2010.

Involve local disabled children and young people

Get children and young people's voices heard – perhaps through a group meeting or making a film. You can find tips on this in our Easy read campaigning guide

Be constructive

We have found that parent groups tend to get a more positive response from the local authority if they offer to work with them to see what steps they need to take in order to be able to sign the Charter. This doesn't have to require much of your time – possibly an initial meeting to share ideas, with a follow-up meeting a month or two later. You could also point out to your local authority that if they sign up to the Charter, EDCM can help them with press releases that will generate positive publicity.

Supporting your local authority to deliver on their commitments

This is the tricky part – and of course the most important part. It can be (relatively) easy to persuade local authorities to sign up to charters and other voluntary commitments. The hard part is making sure that they deliver on these commitments.

If (when!) your local authority signs up after all your work to persuade them, make it clear to the people you have been in contact with that you will be expecting to see genuine steps taken to deliver the Charter commitments in an implementation plan. EDCM will publish any implementation plans we receive on our website.

Before signing the Charter, Lead Members must insert a delivery date within one year of signing. But by signing up, the authority is accepting in principle that these objectives are correct – so you can and should expect to see your authority acting according to the spirit of the Charter from the moment they sign up.

Actions you can take to make sure that your local authority delivers on their commitments:

- Put out a press release when your local authority signs up so that local media highlight this new commitment – email info@edcm.org.uk for a template media release.

- Write to your Lead Member or Director for Children's Services asking if the Local authority will produce a delivery plan for the Charter. If there is a delivery plan, ask if it is a public document, or if not, if you can share it in confidence locally and with the EDCM team. The easiest way to do this is through the online action on the EDCM campaign website – go to www.edcm.org.uk/charters to find out more and to view other local authorities' implementation plans.

- Try to get the Charter 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.

Challenging your local authority if they don't deliver on the commitments

There are several ways you can use the Charter to challenge your local authority to meet the needs of disabled children and their families. Many of the commitments in the Charter are based on legislation and duties that local authorities have to meet.

If you want to challenge your local authority because they have signed up to the Charter, but are not meeting one of the points, you could write them a letter or email. Below are some guidelines of what the letter could include.

- Send the letter to the Lead Member for Children's Services, Director of Children's Services, any professionals (such as a social worker) you've had correspondence with. You could also copy in your MP and info@edcm.org.uk

- Subject: Every Disabled Child Matters – Local Authority Disabled Children's Charter

- Opening paragraph: "As the councillor with lead responsibility for children's services in our authority, I am writing to tell you that you're not meeting the commitments within the Every Disabled Child Matters campaign's Local Authority Disabled Children's Charter."

- Next outline which point of the Charter they are not meeting and explain why. You can use the policy and legislation outlined in the section above to support your points. Include the name and date of birth of your child for their reference.

- Include details about any previous correspondence you've had with anyone at the local authority.

- Remind them they should have an implementation plan in place for how they are delivering the elements of the Charter, and that you would like to see a copy.

Information on what the Charter Commitments mean and why your local authority should be delivering them

Below is a list of the Charter's commitments, along with any policy/ legislation supports it. You can use this information to tell your local authority why they should be implementing every point of the Charter.

- *We know how many disabled children live in our area and all agencies in our area are working together to plan services based on this knowledge*

Children Act 1989: Part III Local Authority Support for Children and Families 'Provision of services for children and their families'; Section 17 'Provision of services for children in need, their families and others'

The Children Act 1989, states that every local authority has the general duty to provide a range and level of services appropriate to children 'in need'. For the purposes of this Act, all disabled children are classified as children 'in need'. The Act also states that local authorities need to promote your child's welfare, listen to the views of children 'in need' and take into account financial situations of families.

National Service Framework for Children, Young People and Families Standard 8

Standard 8 of the National Service Framework for Children, Young People and Families states children and young people who are disabled or who have complex health needs should receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, promote social inclusion and, where possible, enable them and their families to live ordinary lives.

In particular, section 8.8 'Planning and Commissioning Services' states local authorities should ensure that there is a locally based multi-agency database that contains core data on disabled children. The data collected should be used to help plan and evaluate services.

- *We have an identified lead with specific responsibility for services for disabled children and families*

Children Act 2004, Section 10 'Co-operation to improve well-being'

Section 10 of the Children Act 2004, came into effect from April 2005 and introduced a duty to cooperate for local agencies working with children, young people and their families. The purpose of the duty to cooperate is to make sure local agencies work together in the best interests of children and young people. This Act states that the local authority has the lead responsibility to promote cooperation. Other 'partners' in the local area (including the Primary Care Trust) have a shared duty to cooperate.

- *We are providing clear information to support choice and control for parents that explains how we provide specialist services and also make all universal services accessible*

Support and Aspiration: A new approach to SEN and disability

The Government's Green Paper on Special Educational Needs (SEN) and Disability (published March 2011), proposes new measures to give parents more choice and control about services they can access. One proposal is that local authorities will have to set out a 'local offer' of the support that is available for disabled children, children with SEN and their families. There is an example of Wiltshire's Local Offer for accessing short breaks on the Department for Education's website

UN Convention on the Rights of Persons with Disabilities

This UN Convention was agreed to by the UK in June 2009. Article 23, requires that there should be 'early and comprehensive information, services and support (provided) to children with disabilities and their families'

- *Parents and carers in our area have access to transparent information on decisions made about their child, and have access to mechanisms for providing feedback*

Aiming High for Disabled Children, Core Offer

In '*Aiming high for disabled children: better support for families*' the Government established a core offer for disabled children and their families. The core offer sets out what the minimum standard families can expect with regards to information, transparency, assessment, participation and feedback. These standards make it clear what entitlements and services disabled children, young people and their families can expect, and how they should experience those services. Although the Aiming High programme has come to an end, Council's should continue to work with these standards.

- *Disabled children and their families are involved in the planning, commissioning and monitoring of services in our area, including both specialist and universal services*

National Service Framework for Children, Young People and Families Standard 8

National Service Frameworks (NSFs) are policies set by the National Health Service to define standards of care. Standard 8 of the NSF for Children, Young People and Families states that local authorities should ensure that 'there are arrangements which encourage multi-agency strategic planning of services for disabled children including the joint commissioning and delivery of services, making maximum use of pooled budgets and other Health Act flexibilities.'

- *Our Parent Carer Forum is instrumental in developing and reviewing services in our area and promoting choice and control for parents*

Support and Aspiration: A new approach to SEN and disability

The Government's Green Paper on SEN and Disability (published March 2010), states that the 'Department for Education will continue to fund parent forums in every local area to build on the good practice that has been developed'. This indicates that local areas should continue to use parent forums as sources of expertise.When EDCM wrote to local areas in February 2011 to ask about their local budgets, many stated how important it was to work with parents when establishing local services. You can find out details of your local Parent Carer Forum on the National Network of Parent Carer Forums website.

- *We actively include disabled children and young people in any decisions made about them and the services that they access, that might affect them.*

UN Convention on the Rights of Persons with Disabilities (UNCRPD)

Article 7 of the UNCRPD is about the rights of disabled children. Point three of this Article states that "children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right". The fact that it says that children should "be provided with disability and age-appropriate assistance to realize that right" – places the responsibility on the local authority to ensure that everything is in place to ensure the active participation of disabled children and young people in making decisions about their lives.

Equality and Excellence: Liberating the NHS

The Government's White Paper *Equity and Excellence: Liberating the NHS* (published July 2010) sets out that a principle that "shared decision making should be the norm". It also states that children and young people "must be offered opportunities to speak of their experiences and say what in their view has and has not made a difference to their lives".

- *Parents in our area benefit from our Parent Partnership Service (PPS), which is able to provide impartial advice and support to parents of disabled children and young people*

Exemplification of minimum standards

Local Authorities are responsible for overseeing, monitoring and reviewing their local PPS. They are also responsible for ensuring there are adequate resources and staffing to meet the needs of parents in their area. The National Minimum standards document sets out the Government's expectations of good practice. They include information on how PPS's can achieve best practice in funding and budgets; management; working with parents; information and publicity; training, advice and support; networking and collaboration; informing and shaping local policy and practice and location.

- *Our staff receive both disability equality training and training to ensure that they have core competencies to work with disabled children*

Equality Act 2010

The Equality Act 2010 brought together all existing laws about discrimination into one Act. It also introduced the Public Sector Equality Duty which states that public bodies must have an awareness of equality and take steps to minimise disadvantage.

We have produced a short break services statement that has been drawn up in partnership with disabled children and their parents and have made it widely available

The Breaks for Carers of Disabled Children Regulations 2011

In January 2011, Parliament passed regulations that put a **duty on local authorities to provide short breaks** services in their local area. These came into effect on 1 April 2011. **Guidance on how to implement** the duty has also been published. The regulations and guidance give a clear message to local authorities about the services they should be providing, and how they should decide who will be eligible to receive support. They state that by 1st October 2011, local authorities must prepare a short breaks services statement for carers in their area that sets out details of:

- the range of services provided;
- any criteria by which eligibility for those services will be assessed; and
- how the range of services is designed to meet the needs of carers in their area.

When writing the statement, local areas must "have regard to the views of carers in their area". This means that local authorities should collect the views of local carers and design services around these views. The statement also needs to be placed on the local authority's website and be reviewed and updated regularly.

- *We have regard to the provision of services suitable for disabled children, when assessing the sufficiency and supply of childcare in their area*

Childcare Act 2006

Under the Childcare Act 2006 there is a duty on local authorities to secure sufficient childcare for working parents. The duty states that local authorities 'must secure, so far as is reasonably practicable, that local childcare provision (whether run or not by them) sufficiently meets the requirements of parents in their area who require childcare to work or participate in education or training. There is a specific duty on local authorities to ensure there is suitable childcare provision for disabled children.

- *We are working together with disabled young people and adult service providers in our area to ensure a smooth transition to adult services for disabled young people preparing for adulthood*

When disabled young people become adults, there is still a duty to assess and provide services to meet their needs. There is a wide range of government guidance that requires a multi-agency approach to effective transition planning for disabled young people. Unless there has been significant social care or health input in the life of a disabled young person, education should generally take the lead in transition planning. Below we list some of the guidance relating to transition:

Disabled Persons (Services, Consultation and Representation) Act 1986

This Act mainly refers to disabled children who have a statement of special educational needs. It states that when a child reaches 14, the relevant social services officer should be contacted so that a social care assessment of the young person's needs is undertaken. This should result in services being in place when the young person leaves education.

Valuing people now: a new three-year strategy for people with learning disabilities states the Government's commitment to 'supporting local authorities and partner agencies develop a person centred approach to the statutory transition planning process' (point 3.33). This means disabled young people should have the opportunity to take decisions about their lives with necessary support. This includes education and employment.

A transition guide for all services - This document explains how services should work together with the disabled young person so that they are supported during transition in the best possible way.

For more information on the rights of disabled young people during transition, please see Chapter 10 of Disabled Children: A Legal Handbook.

contact a family
for families with disabled children

Council for disabled children

mencap
The voice of learning disability

special educational consortium