

## Making disabled children matter locally [www.edcm.org.uk/localaction](http://www.edcm.org.uk/localaction)

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

(Updated April 2009)

Note: Text in ***bold italics*** is explained in the glossary on page 9

We recognise this paper is quite long, but each step is clearly set out and the EDCM Campaign Team are available to answer any questions. Read on to find out more...!

#### **Introduction**

EDCM wants to see every ***local authority*** and ***Primary Care Trust*** (PCT) 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. The first step to take is to make sure local authorities and PCTs sign up to EDCM's campaign Charters.

This paper sets out the straightforward steps you can take to make sure the '***Aiming High for Disabled Children***'<sup>1</sup> programme translates into measurable improvements to services in every local area in England.

For more information on AHDC go to [www.everychildmatters.gov.uk/socialcare/ahdc](http://www.everychildmatters.gov.uk/socialcare/ahdc)

#### **Take action!**

You can take our **online actions** depending on whether your local authority and/or PCT are signed up to the campaign Charters.

For local authorities...

Go to [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter) and click on **take action!**

If your local authority has not yet signed the EDCM Local Authority Charter, you can **lobby your local authority to sign up** or if they have already signed, **get them to deliver on the Charter commitments** by sharing their implementation plan.

For PCTs...

Go to [www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter) and click on **take action!**

If your PCT has not yet signed the EDCM PCT Charter, you can **lobby your PCT to sign up** or if they have already signed, **get them to deliver on the Charter commitments** by sharing their implementation plan.

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<sup>1</sup> HMT and DfES (2007) Aiming High for Disabled Children: Better Support for Families;  
[www.everychildmatters.gov.uk/socialcare/ahdc](http://www.everychildmatters.gov.uk/socialcare/ahdc)

## **Background**

The last two years have seen an unprecedented level of political interest in, and action towards, improving services for disabled children and their families.

The case has been made that these children have been left out for too long, and experience poorer outcomes across the board than their non-disabled peers.

Disabled young people are 9 times more likely to be excluded from school than other children, more likely to live in poverty, and more likely to be not in education, employment or training (NEET) beyond the age of 16. 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'.

EDCM has been campaigning since September 2006 to highlight these issues. The government responded through commitments made in the ***Comprehensive Spending Review 2007 (CSR 07)***. Following a review of disabled children's services, *Aiming High for Disabled Children: Better Support for Families* announced a £340 million funding package to transform the way services are delivered to families. This funding was increased to a total of £430 million when an additional £90 million was invested through the government's Children's Plan. £370 million of the £430 million total funding is to improve **short break services** and government has published a breakdown of this funding by each local authority area.

A further **£340 million** was announced in February 2009 by the Department of Health, allocated to Primary Care Trusts for disabled children from 2008 – 2011. The figure has been announced as part of the Child Health Strategy, '**Healthy lives, brighter futures**'<sup>2</sup> bringing the government's **total funding allocation for disabled children to £770 million**.

In addition to this new investment, government also announced, for the first time, a **national indicator (NI54)** on services for disabled children and their families against which performance will be measured.

**For more information** on Aiming High for Disabled Children you can **download our supporter briefing** at [www.edcm.org.uk/aiminghigh](http://www.edcm.org.uk/aiminghigh)

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<sup>2</sup> Department of Health (2009) The Child Health Strategy 'Healthy lives, brighter futures'; [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance)

On 1<sup>st</sup> April 2008 new duties set out in the Childcare Act 2006 came into force to ensure families with disabled children can access **affordable childcare**. There are tips for EDCM supporters on how to make sure their local authority are meeting this duty and how to find out about their local short break funding allocation on **page 7**.

EDCM has also developed its own campaign Charters, the first for local authorities, the second for PCTs. The Charters are a set of commitments that local authorities and PCTs can choose to make to show that disabled children are a priority in their area. They are signed by the Lead Member for Childrens' Services for local authorities and the Chair for PCTs – because these people set strategy and have a responsibility to engage with children and families in their area.

Information about the EDCM Charters, and a list of local authorities and PCTs signed up, can be found at [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter) and [www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter) - or by contacting the EDCM campaign team (see contact details at end of this document).

## **Making disabled children matter locally**

The EDCM charters and ***disabled children's indicator*** are key tools to focus minds and drive service improvement in every local area – and as EDCM supporters you have an important role to play in making sure your local authority prioritise disabled children.

The national indicator for disabled children will be based on a survey of parents' experience of service delivery and on delivery of the **Core Offer**<sup>3</sup> to families. The Core Offer (as set out in *Aiming High for Disabled Children*) is made up of five elements that government wants to see delivered in every local area. These have been grouped under three headings:

- information and transparency
- assessment
- participation and feedback

Feedback from parents shows that the presence of these elements will improve the quality of services provided to them. Consistent delivery of the Core Offer will also go some way to addressing the 'post code' lottery that currently exists across the country.

## **Making the disabled children matter in local authorities**

### *Get your local authority signed up to the EDCM Local Authority Charter*

The EDCM Local Authority Charter is a set of voluntary commitments that local authorities can make to show that disabled children and their families matter. The Charter is signed by Lead Members for Children's Services (Councillors). Currently, the Charter only covers English local authorities, reflecting the differences in the UK nations following devolution.

### **Take action!**

Find out if your local authority has signed the EDCM Local Authority Charter at [www.edcm.org.uk/lacharterlist](http://www.edcm.org.uk/lacharterlist)

To lobby your local authority to sign up to the Charter, go to [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter) and click on **take action!**

Once your local authority have signed...

### *Get your local authority to deliver on the Charter commitments*

Once the Charter is signed, the local authority should have a **plan in place to deliver these commitments**. The Charter includes a commitment that local authorities will include targets in their local area agreement on the level of service to be delivered to families with disabled children.

<sup>3</sup> DCSF (2008) National Core Offer; [www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer](http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer)

The performance framework for local authorities includes the disabled children's indicator (NI54) as one of 198 indicators that local authorities are required to monitor and report on to central government. Local authorities, with their partners, are also required to choose up to 35 indicators to include in their **Local Area Agreement (LAA)**.

EDCM would like to see all local authorities include the disabled children's indicator as one of their targets in their local area agreements to demonstrate their commitment to making disabled children a local priority.

### **Take action!**

To lobby your local authority to deliver on the Charter commitments and address the indicators above, go to [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter) and click on **take action!**

If your local authority has signed the charter the online system will direct you to an appropriate action which asks your Lead Member to provide evidence of a delivery plan and whether they will include NI54 in their local performance framework.

### **Disabled children have the right to be included**

As well as making disabled children a priority through the disabled children's indicator, there are several other indicators that have the potential to make a difference to the lives of disabled children. Some of these are listed below, under the **five Every Child Matters outcomes**:

#### **BE HEALTHY**

NI 57: Children and young people's participation in high-quality PE and sport

#### **STAY SAFE**

NI 69: Children who have experienced bullying

#### **ENJOY AND ACHIEVE**

NI 114: Rate of permanent exclusions from school

#### **MAKE A POSITIVE CONTRIBUTION**

NI 110: Young people's participation in positive activities

#### **ACHIEVE ECONOMIC WELL-BEING**

NI 116: Proportion of children in poverty

NI 117: 16 to 18 year olds who are not in education, training or employment (NEET)

As well as local area agreements, all local authorities must have **Children and Young People's Plan** (CYPP). It is important that local authorities consult with parents and young people in drawing up local area agreements and Children and Young People's Plans. A number of local authorities have confirmed that they will make disabled children a priority in their CYPP. EDCM welcome the proposals within the **Apprenticeship, Children, Skills & Learning Bill** to make CYP Plans the responsibility of the Children's Trust Boards, and to strengthen Children's Trust arrangements by putting them on a statutory footing.

## **Making the disabled children matter in Primary Care Trusts (PCTs)**

### Get your Primary Care Trust signed up to the EDCM PCT Charter

By signing the EDCM PCT Charter, PCTs are committing to make health services for disabled children a priority. The Charter should be signed by the PCT Chair.

#### **Take action!**

Find out if your PCT has signed the EDCM PCT Charter at [www.edcm.org.uk/pctcharterlist](http://www.edcm.org.uk/pctcharterlist).

To lobby your PCT to sign up to the Charter, go to [www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter) and click on **take action!**

Once your PCT have signed...

### Get your primary care trust to deliver on the Charter commitments

Once the Charter is signed, the PCT should have a **plan in place to deliver these commitments**.

The new framework to measure the performance of PCTs was announced in January 2008 and is called '**Vital Signs**'. Vital Signs sets out NHS priorities and directs PCTs to deliver these and set their own local priorities.

There are 3 tiers of priorities set out in Vital Signs. Tier 1 and tier 2 are those indicators that have been identified as national priorities. Tier 3 indicators are priorities that PCTs need to choose, in consultation with local partners, as local priorities.

The disabled children's indicator is a tier 3 indicator. The guidance makes clear that the Department of Health would not expect to be involved in performance management of priorities in tier 3. PCTs are expected to set out their priorities in Operational Plans, which can be revised each year.

#### **Take action!**

To lobby your PCT to deliver on the Charter commitments, go to [www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter) and click on **take action!**

If your Primary Care Trust has signed the PCT charter the online system will direct you to an appropriate action which asks your PCT Chief Executive to include the disabled children's indicator in their Operating Framework. If this plan has already been set, the action asks them to consider adding the disabled children's indicator as an additional local priority.

## **More online actions to make disabled children matter locally**

### Disabled children and short breaks

'Aiming High for Disabled Children' committed £370 million to be spent by English local authorities over the 3 year spending period (2008-2011) to transform short break services. Government has published a breakdown of allocations for each local authority, which can be found at [www.edcm.org.uk/aiminghigh](http://www.edcm.org.uk/aiminghigh).

In the first year the majority of funding was allocated to the 21 pathfinder areas with all other local authorities receiving an average of £50,000 to help them prepare to transform their short break services from 2009.

The pathfinder areas are: Bradford, Bolton, Bournemouth-Dorset-Poole (joint pathfinder), Brighton, Dudley, Derbyshire, Enfield, Gloucestershire, Gateshead, Halton, Kent, North Yorkshire, North Tyneside, Nottinghamshire, Norfolk, Sutton, Sunderland, Telford & Wrekin.

Additionally, the Children and Young Persons Act 2008 received Royal Assent on 13 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!**

You can help make disabled children's short breaks services a priority for local authorities **by taking our online action to campaign for improved short breaks.**

The online action asks 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/cypact](http://www.edcm.org.uk/cypact)

### Disabled children and childcare

On 1<sup>st</sup> 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 will 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.

EDCM welcomes these much needed new duties, and encourages supporters to **ask their local authority what is being done to meet this duty.**

Disabled children and health

The government made a commitment in the Children's Plan in December 2007 to publish a Child Health Strategy jointly between DH and DCSF. In line with this commitment, *Healthy lives, brighter futures* ([www.edcm.org.uk/health](http://www.edcm.org.uk/health)) was published in February 2009.

The strategy clarified that £340 million has been given to primary care trusts for disabled children from 2008 – 2011 to invest in palliative care and end of life services, short breaks, community equipment and wheelchair services.

The strategy stated that £30 million of the funding is for palliative care services including capacity-building, 24 hour crisis support and short breaks in order to implement the '*Better Care: Better Lives*' strategy.

Unlike the funding for local authorities, the funding announced for primary care trusts is not ringfenced – it is part of their 'baseline allocations'. The government has stated that it is for each PCT to set 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!**

You can take our online action which enables them to **ask your PCT** how much money they are spending on disabled children. **Take action** at [www.edcm.org.uk/health](http://www.edcm.org.uk/health)

## **More advice on local campaigning**

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

### **For the local authority:**

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

### **For the PCT:**

- PCT children's lead officer
- Manager of Child Development Centre
- Manager of Children's Community Nursing Service
- Manager of Children's Therapy Services

## **Alternative actions you can take to encourage your local authority and/or PCT to sign up 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.
- Write to your Lead Member or Director of Children's Services / PCT Chair, to highlight other local authorities / PCTs near you who have signed up. The names of these local authorities are on the EDCM website ([www.edcm.org.uk/lacharterlist](http://www.edcm.org.uk/lacharterlist) and [www.edcm.org.uk/pctcharterlist](http://www.edcm.org.uk/pctcharterlist)).
- Arrange a meeting with the Lead Member or Director of Children's Services / PCT Chair, to discuss the Charter and explain the need to prioritise disabled children locally. EDCM has a template campaign presentation that we can send you – email [info@edcm.org.uk](mailto:info@edcm.org.uk)
- 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.
- Your PCT is the key agency to target with the PCT Charter. However, all Strategic Health Authorities (SHAs), whose role it is to manage the NHS locally, have a post-holder that leads on children's health. Targetting the SHA children's lead may also be helpful.

**If these direct approaches do not work, you might want to think about these other tactics that some parent groups have found helpful in terms of making disabled children more of a priority locally:**

- Talk to local media contacts about the Charter(s) and why your local authority and PCT 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.
- Get parent and voluntary organisations to put articles about the campaign and the Charter(s) in local newsletters. EDCM has sample text – email us as [info@edcm.org.uk](mailto:info@edcm.org.uk)
- For the Local Authority Charter, talk to opposition Councillors – from the political party who are not running the local authority. 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 / PCT to sign the Charter(s). You might want to arrange to meet them at their local surgery.
- Get children and young people's voices heard – perhaps through a group meeting or making a DVD. See EDCM's campaign briefings '***If I could change one thing...***' and '***Going Places***' made with disabled children and young people  
[www.edcm.org.uk/onething](http://www.edcm.org.uk/onething)  
[www.edcm.org.uk/goingplaces](http://www.edcm.org.uk/goingplaces)

We have found that parent groups tend to get a more positive response from local agencies if they offer to work constructively with them to see what steps they need to take in order to be able to sign the Charter(s). This need not 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 or PCT that if they sign up to the Charter(s), EDCM can help them with press releases that will generate positive publicity.

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

- Put out a press release when they sign up so that local media highlight this new commitment – email [info@edcm.org.uk](mailto:info@edcm.org.uk) for a template media release.
- Write to your Lead Member or Director for Children's Services / PCT Chair asking if they 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. We are happy to promote local delivery plans on our website.

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

## **GLOSSARY OF TERMS**

### ***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.

### ***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.

### ***Comprehensive Spending Review (CSR)***

The CSR is a review of government expenditure that determines departmental allocations over a 3 year period. The last CSR was in 2007 and determined spending from 2008 – 2011. Plans for preparation for the following spending review will probably take place in 2009/10.

### ***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.

### ***Five Every Child Matters outcomes***

*Every Child Matters* (ECM) is the government's approach to the well-being of children and young people from birth to age 19. ECM sets out five outcomes that government wants every child to achieve: be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being.

### ***Joint Strategic Needs Assessment (JSNA)***

Local authorities and PCTs have a duty to undertake a JSNA of the health and well-being needs of the local community. This is a crucial tool for local partnerships to use in identifying the priorities included in the Local Area Agreement.

### ***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

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.

### **National Indicator Set**

A new set of 198 national indicators was announced in the Comprehensive Spending Review 2007. The indicators are used to measure national priorities that have been agreed by Government.

### **NHS Operating Framework**

A Framework that sets priorities for NHS bodies in England, including PCTs. The 2007 Framework includes disabled children as one of four priority groups.

### **Operational Plan**

PCT plan that sets out local targets with definitions of success and milestones.

### **Performance Frameworks**

The Performance Frameworks for local government and health agencies are set by central government so that they can measure whether they are achieving specified objectives.

### **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.

### **Public Service Agreement (PSA)**

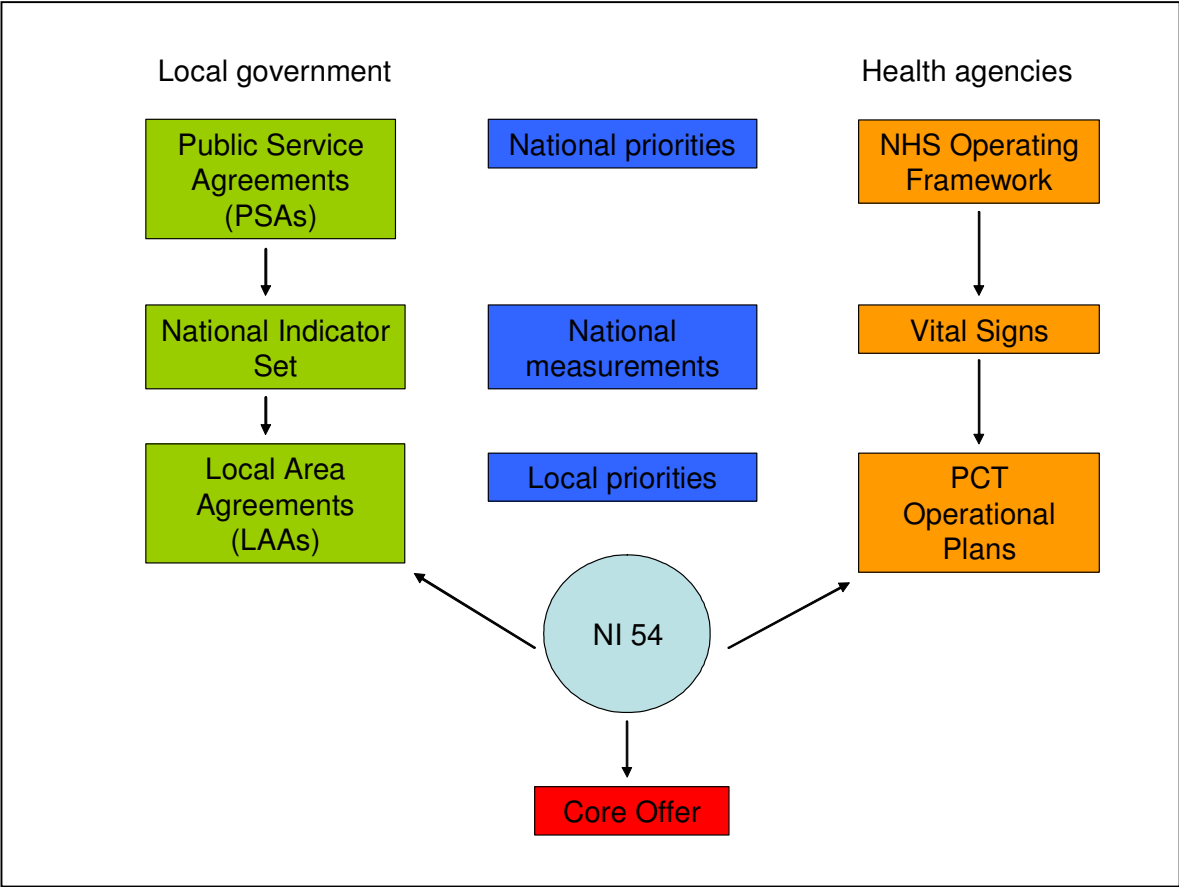
PSAs reflect the Government's high-level priorities. They set out the specific improvements that the Government wants to achieve and the performance indicators which will be used to measure progress.

### **Vital Signs**

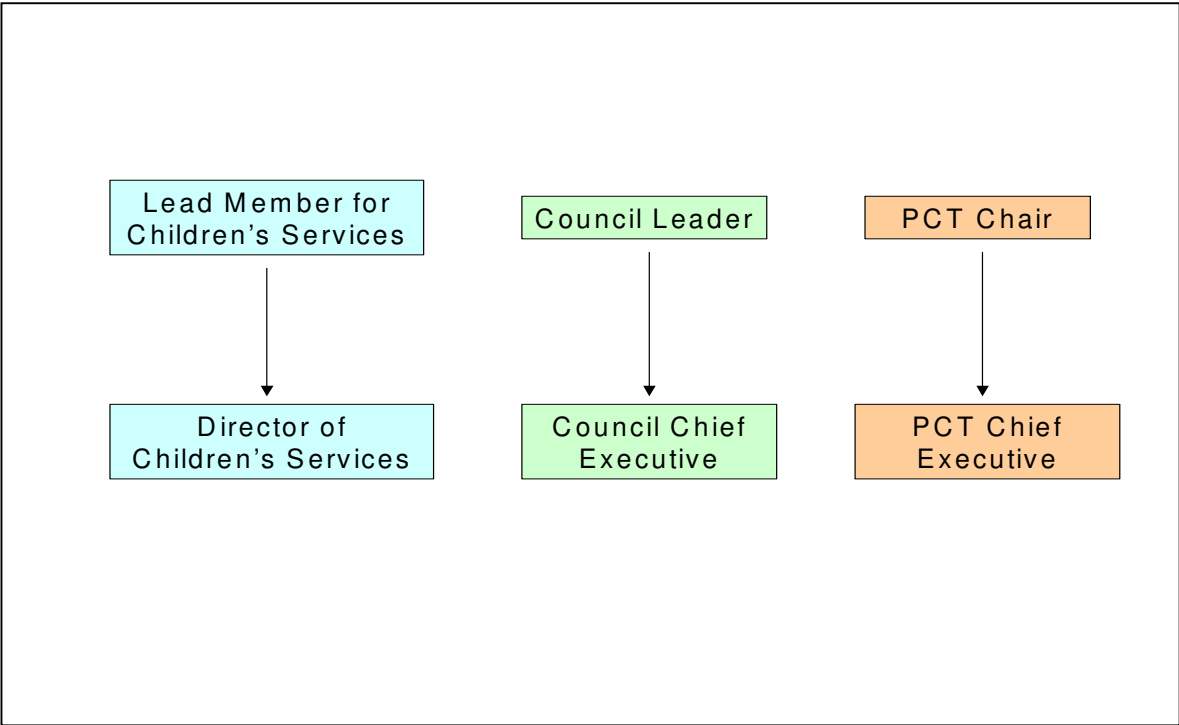
Guidance for PCTs from the Department of Health on how to measure local progress against national priorities. Includes the disabled children's indicator as an optional 'local priority'.

**ANNEX 1 – Further explanation and background**

**Illustration of the local government and health performance frameworks**



**Illustration of key people to influence locally**



### **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](http://www.edcm.org.uk/aiminghigh)

[www.hm-treasury.gov.uk/media/C/2/cyp\\_disabledchildren180507.pdf](http://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](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

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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

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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](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](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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082542)

## **ANNEX 2 – Template letters for supporter action**

Supporters should note that all these actions can be taken online – go to <http://www.edcm.org.uk/getinvolved>

### **Lobby your Councillor to sign up to the LA Charter**

You can include a section in the template letter on your family experiences or the local situation - any issue that really matters to you or to families with disabled children in your community that will get your Councillor's attention.

Dear [Councillor]

As a resident of your local authority, I am writing to ask you to support the Every Disabled Child Matters campaign. In particular, as the councillor with lead responsibility for children's services, I am asking you to sign up on behalf of our authority to the campaign's Local Authority Charter.

Half of all English local authorities have now signed up to the Charter. All remaining Local Authorities are now being invited to sign up and set their own delivery date by December 2009.

Every Disabled Child Matters is the campaign to get rights and justice for every disabled child. This campaign is needed because too many disabled children and their families are struggling to get the support they need - and that should be theirs by right.

You can find the Local Authority Charter at [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter). I would ask you to discuss the charter with your officers who are responsible for services for disabled children and their families, and reply to me as soon as possible to let me know if you are able to sign up.

I am aware that many local areas are now recognising support for disabled children and their families as a priority as part of the Aiming High for Disabled Children programme. Signing the campaign charter is an ideal way for local authorities and PCTs to transparently demonstrate their commitment to families.

If you are able to sign up to the charter, please download and print a copy from [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter), sign it and post it to: Every Disabled Child Matters, Council for Disabled Children, 8 Wakley Street, London EC1V 7QE.

If you would like any further information about the Every Disabled Child Matters campaign, you can go to [www.edcm.org.uk](http://www.edcm.org.uk), call 020 7843 6318 or email [info@edcm.org.uk](mailto:info@edcm.org.uk)

I look forward to your reply.

## **Lobby your Councillor to deliver on the Charter commitments**

You can include a section in the template letter on your family experiences or the local situation - any issue that really matters to you or to families with disabled children in your community that will get your Councillor's attention.

Dear [Councillor]

As the councillor with lead responsibility for children's services in our authority, I am writing to congratulate you on signing up to the Every Disabled Child Matters campaign's Local Authority Charter and to ask you two key questions about implementation.

1. I understand that our local authority should already have a delivery plan in place for the Charter. I would be grateful if you could send me a copy of the plan or any other documentation to show how we are meeting the Charter commitments.

2. By signing up to the Charter, our authority has committed to including a target on disabled children within our Local Area Agreement (LAA). This target is National Indicator 54 (NI54) on services for disabled children, which resulted from the government's Aiming High for Disabled Children review (see [www.edcm.org.uk/aiminghigh](http://www.edcm.org.uk/aiminghigh)).

I would be grateful if you could tell me if our local authority will include NI54 in our local area agreement and if not how else will you prioritise the needs of disabled children in our local planning framework, including in our Children and Young People's Plan.

If you would like any further information about the Every Disabled Child Matters campaign, you can go to [www.edcm.org.uk](http://www.edcm.org.uk), call 020 7843 6318 or email [info@edcm.org.uk](mailto:info@edcm.org.uk).

All the information about the EDCM Local Authority Charter is at [www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter).

Thank you again for your commitment to improving services and support for disabled children and families in our area. I look forward to your reply with the information I have requested.

## Lobby your PCT to sign up to the PCT Charter

You can add a section in your letter on your family experiences of local health services - any issue that really matters to you or to families with disabled children in your community that will get your PCT Chief Executive's attention.

Dear [PCT Chief Executive]

I live in your primary care trust (PCT) area and am writing to ask you to support the Every Disabled Child Matters campaign. In particular, I am writing to ask that our PCT signs up to the campaign's Primary Care Trust Charter.

Every Disabled Child Matters is the campaign to get rights and justice for every disabled child. It has been set up by four national organisations working with disabled children - the Council for Disabled Children, Contact a Family, Mencap and the Special Education Consortium.

This campaign is needed because too many disabled children and their families are struggling to get the support they need - and that should be theirs by right. The PCT Charter is a set of commitments that show that disabled children and their families matter. This includes a commitment that there is an identified children's lead with specific responsibility for services for disabled children and families within the PCT and a commitment that families receive accurate and timely information and advice on the services available to them.

As you will know, disabled children are a clear priority in the Child Health Strategy, **'Healthy lives, brighter futures'**. Signing the PCT charter is an ideal way for PCTs to transparently demonstrate their commitment to disabled children and their families.

You can find the Primary Care Trust Charter at [http://www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter). The Charter must be signed by our PCT Chair. I would ask you to discuss the Charter with our Chair and your officers who are responsible for services for disabled children and their families, and reply to me as soon as possible to let me know if our PCT is able to sign up.

If our PCT Chair is able to sign the Charter, please ask them to download and print a copy from [http://www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter), sign it and post it to: Every Disabled Child Matters Council for Disabled Children 8 Wakley Street London EC1V 7QE

EDCM also have a local authority charter. I would be grateful if you would consider working with your local authority partners to jointly sign the charters (if they haven't already done so) and so demonstrate local commitment to effective partnership working on this issue. The Local Authority Charter can be downloaded at [http://www.edcm.org.uk/la\\_charter](http://www.edcm.org.uk/la_charter)

If you need any information about Every Disabled Child Matters, you can call 020 7843 6318 or email [info@edcm.org.uk](mailto:info@edcm.org.uk)

Many thanks - I look forward to your reply.

## Lobby your PCT to deliver the on the Charter commitments

You can add a section in your letter on your family experiences of local health services - any issue that really matters to you or to families with disabled children in your community that will get your PCT Chief Executive's attention.

Dear [PCT Chief Executive]

As PCT Chief Executive, I am writing to congratulate you on signing up to the Every Disabled Child Matters campaign's PCT Charter on behalf of our PCT.

By signing up to the Charter, our PCT has committed to making disabled children a priority.

I understand that our PCT should have a delivery plan in place to demonstrate how it will meet the commitments in the Charter. I would be grateful if you could send me a copy of the plan or any other documentation to show how we are meeting the Charter commitments.

I am pleased to hear that the NHS Operating Frameworks for 2008-9 and 2009-10 prioritise disabled children as one of four local priority groups for PCTs. This is supported by the *Vital Signs* indicator set, which includes National Indicator 54 (NI 54) on services for disabled children as a priority indicator for local action.

I understand that all PCTs are required to produce Operational Plans that set out local priorities. I would be grateful if you could send me a copy of that plan stating how you are prioritising disabled children in our PCT and whether you are including NI54 in your Operational Plan.

If you would like any further information about the Every Disabled Child Matters campaign, you can go to [www.edcm.org.uk](http://www.edcm.org.uk), call 020 7843 6318 or email [info@edcm.org.uk](mailto:info@edcm.org.uk). All the information about the EDCM PCT Charter is at [www.edcm.org.uk/pct\\_charter](http://www.edcm.org.uk/pct_charter).

Thanks again for your commitment to improving services and support for disabled children and families in our area. I look forward to your reply with the information I have requested.

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## Contact EDCM

For more information or support in making disabled children matter locally you can get in touch with Pamela Shaw, Campaign Officer:

E: [pamela@edcm.org.uk](mailto:pamela@edcm.org.uk)  
T: 020 7843 6318