

Making disabled children matter locally www.edcm.org.uk/localaction

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

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

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. EDCM supporters have a key role to play in making this happen where they 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 supporters can take to make sure the '***Aiming High for Disabled Children***' programme translates into measurable improvements to services in every local area in England.

Through the actions set out in this paper, supporters can help make sure their local agencies incorporate the national ***disabled children's indicator*** in their local planning and ***performance frameworks***.

Take action!

There are **four online actions** supporters can take depending on whether their local authority and/or PCT are signed up to the campaign Charters.

For local authorities...

Go to www.edcm.org.uk/la_charter and click on **take action!** Depending on whether or not your local authority has 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**.

For PCTs...

Go to www.edcm.org.uk/pct_charter and click on **take action!** Depending on whether or not your PCT has 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**.

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...!

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 8 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. Substantial funding has also been given to Primary Care Trusts to support this investment.

In addition to this new investment, government also announced, for the first time, a **national indicator** on services for disabled children and their families against which performance will be measured. It is this indicator – National Indicator 54 – that EDCM is urging its supporters to use as a tool to drive service improvement locally.

On 1st 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 9.

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 Children's 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 and www.edcm.org.uk/pct_charter - or by contacting the EDCM campaign team (see contact details at end of this document).

Making the indicator work locally

The ***disabled children's indicator*** is a key tool to focus minds and drive service improvement in every local area – and EDCM supporters have an important role to play in making sure the indicator influences local decision-makers.

The indicator will be based on a survey of parents' experience of service delivery and on delivery of the ***Core Offer*** 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 are:

- clear information
- transparent eligibility criteria and process for accessing services
- multiagency assessment
- participation in shaping local services
- accessible feedback/complaint mechanisms

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's indicator work – local authorities

The new performance framework for local authorities includes the disabled children's indicator 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)***.

LAAs set out an area's priorities over a three year period and the indicators included in them will be more closely monitored. Local partnerships are expected to undertake a ***Joint Strategic Needs Assessment (JSNA)*** to inform decisions about priorities for the LAA. It is therefore extremely helpful if the disabled children's indicator is included in the LAA for every area in England. EDCM understands that the disabled children's indicator is not yet ready for inclusion in LAAs, but local authorities are still able to commit to including it in their LAA when it is ready.

It is therefore important to note that local authorities can agree further local targets in addition to the chosen 35, to support improved local delivery and outcomes. Sign-off on new LAAs is expected by summer 2008.

As well as LAAs, all local authorities must have ***Children and Young People's Plan (CYPP)***. It is equally as important to consult with parents and young people in drawing up this plan as with the LAA. A number of local authorities have told EDCM they will make disabled children a priority in their CYPP.

Supporter action

Firstly...

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.

Find out if your local authority has signed the EDCM Local Authority Charter at www.edcm.org.uk/lacharterlist.

To lobby your local authority to sign up to the Charter, go to www.edcm.org.uk/la_charter and click on **take action!**

Then, once they have signed...

Get your local authority to deliver on the Charter commitments – in particular, the disabled children's indicator

The Charter includes a commitment that local authorities will include targets in their LAA on the level of service to be delivered to families with disabled children. Once the Charter is signed, the local authority should have a plan in place to deliver this commitment. The easiest way for them to do this is to commit to including the disabled children's indicator in their LAA when it is ready.

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)

To lobby your local authority to deliver on the Charter commitments and address the indicators above, go to www.edcm.org.uk/la_charter and click on **take action!**

(The online system will recognise your postcode and direct you to the appropriate action depending on whether or not your authority has signed the Charter.)

Making the disabled children's indicator work – Primary Care Trusts (PCTs)

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 are to be developed in the first instance by March 2008. However, the guidance makes clear that these plans can be revised each year, and further versions of plans are expected once baseline data becomes available.

Alongside local authorities and other partners, PCTs are required to carry out Joint Strategic Needs Assessments (JSNAs) to inform their priority-setting. PCTs are responsible for publishing the results of the JSNA in a **Prospectus**. It is useful to have sight of this document as it informs the public of the services available in their area and informs providers what services they need to bid for. **Local involvement networks (LINKs)** are the key mechanism for PCTs to involve and consult with their local population and this can inform the local commissioning process. Local parent groups can use the LINK in their area to engage with the PCT.

Supporter action

Firstly...

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 PCT Chairs.

Find out if your PCT has signed the EDCM PCT Charter at www.edcm.org.uk/pctcharterlist.

To lobby your PCT to sign up to the Charter, go to www.edcm.org.uk/pct_charter and click on **take action!**

Then, once they have signed...

Get your PCT to include the disabled children's indicator in their Operational Plan

Supporters can write to their PCT Chair, asking them to include the disabled children's indicator in their Operational Plan for 2008/09. If this plan has already been set, the action asks them to consider adding the disabled children's indicator as an additional local priority.

To lobby your PCT to deliver on the Charter commitments, go to www.edcm.org.uk/pct_charter and click on **take action!**

(The online system will recognise your postcode and direct you to the appropriate action depending on whether or not your PCT has signed the Charter.)

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

Actions you can take offline 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 and 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
- 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
- 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.

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 offline 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 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.
- 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.

Making disabled children matter locally – short breaks and childcare

Short breaks

'Aiming High for Disabled Children' committed £370 million to be spent by English local authorities over the next 3 years (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.

In the first year the majority of funding will be 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.

Supporters can help make disabled children a priority locally **by asking their local authority how that funding will be spent.**

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 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.**

For both of the above issues, supporters can write to their **Director of Children's Services** or **Lead Member for Children's Services.**

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

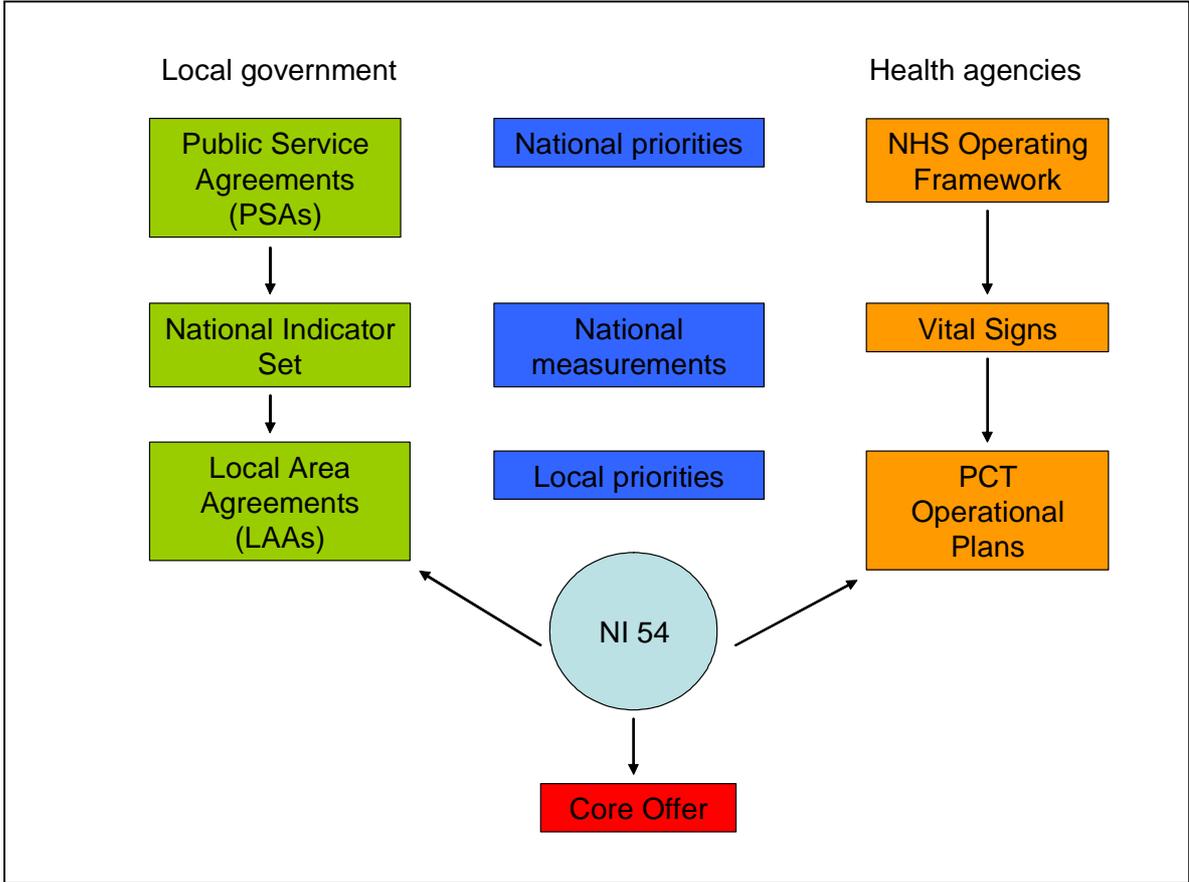
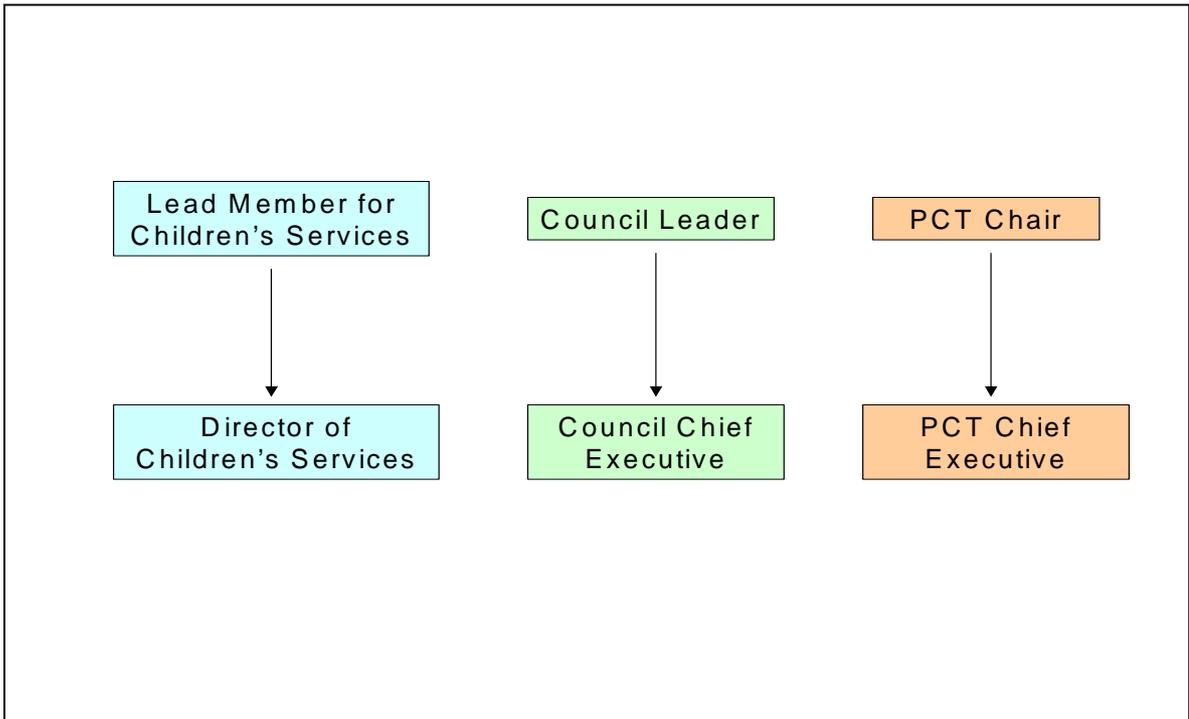


Illustration of key people to influence locally



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. 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 - £340 million – over the next three years (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:

<http://www.edcm.org.uk/aiminghigh>

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.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**, published in December 2007, announced that disabled children would be one of four local priority groups for service improvement in the NHS. The Framework sets priorities for NHS bodies in England, including Primary Care Trusts (PCTs). Health services for all children, including reducing health inequalities, are included as a key national

priority. 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:

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

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.

50 English Local Authorities signed up to the Charter before January 2008. Local Authorities are now being invited to sign up now and set their own delivery date before the end of 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 add a section here 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).

You can find the Local Authority Charter at 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.

If you are able to sign up to the Charter, please download and print a copy from 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, call 020 7843 6318 or email info@edcm.org.uk

I look forward to your reply.

Lobby your Councillor to deliver on the Charter commitments – in particular, the disabled children’s indicator

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 three key questions about implementation.

1. 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).

I understand from EDCM that NI54 is not yet ready for inclusion in LAAs. I would therefore be grateful if you could reply to this email to confirm that NI54 will be included in our LAA when it is ready, as our signature to the EDCM Charter promises. I would also be grateful if you could confirm if you have chosen to make disabled children a priority in our LAA in any other way. If so, could you also tell me when you plan to start collecting data on parent’s views and how will you ensure the views of disabled children and young people inform your self-assessment?

2. I understand that we 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.

3. Many other indicators relating to children and young people are of particular relevance to disabled children and young people. These include:

- NI 57: Children and young people’s participation in high-quality PE and sport
- NI 69: Children who have experienced bullying
- NI 110: Young people’s participation in positive activities
- NI 114: Rate of permanent exclusions from school
- NI 116: Proportion of children in poverty
- NI 117: 16 to 18 year olds who are not in education, training or employment

I would be grateful if you could also let me know how you will ensure disabled children and young people will be included in the measurement of these indicators.

If you would like any further information about the Every Disabled Child Matters campaign, you can go to www.edcm.org.uk, call 020 7843 6318 or email info@edcm.org.uk. All the information about the EDCM Local Authority Charter is at www.edcm.org.uk/la_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.



Lobby your PCT to sign up to the PCT Charter

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.

(You can add a section here 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).

You can find the Primary Care Trust Charter at 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, sign it and post it to:
Every Disabled Child Matters Council for Disabled Children 8 Wakley Street
London EC1V 7QE

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

Many thanks - I look forward to your reply.

Lobby your PCT to deliver the on the Charter commitments and include the disabled children's indicator in their Operational Plan.

Dear [PCT Chief Executive]

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

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 framework for 2008-9 establishes 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 whether you will you have included NI 54. If your plan has already been set, please let me know if you will consider adding this indicator as a local priority.

If you would like any further information about the Every Disabled Child Matters campaign, you can go to www.edcm.org.uk, call 020 7843 6318 or email info@edcm.org.uk. All the information about the EDCM PCT Charter is at 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.

Contact EDCM

For more information or support in making disabled children matter locally you can get in touch with Louise Franklin, Campaign and Policy Officer:

E: louise@edcm.org.uk

T: 020 7843 6108