

# Leeds Health & Wellbeing Board

Report author: Louise Snowden  
Complex Needs Area Lead - Disability  
Tel: 07891 278030

**Report of:** Deputy Director of Children's Services - Safeguarding, Specialist and Targeted

**Report to:** Health and Wellbeing Board

**Date:** 27 March 2014

**Subject:** Every Disabled Child Matters Charter – Health and Wellbeing Board

Are there implications for equality and diversity and cohesion and integration?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Is the decision eligible for Call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

## Summary of main issues

- The Every Disabled Child Matters (EDCM) campaign is run by four of the leading organisations working with disabled children and their families - Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium. Its aim is to ensure every Local Authority and Health and Wellbeing Board make a clear commitment to improve services for, and to be held accountable by, disabled children and their families.
- EDCM and The Children's Trust, Tadworth have developed a Disabled Children's Charter for Health and Wellbeing Boards to ensure that the local health and social care system meets the needs of disabled children, young people and the families. This has replaced the previous Charter for the PCTs.
- The Health and Wellbeing Board are requested to consider the information contained in this report and make an informed decision about whether to become signatories to the EDCM Charter.

## Recommendations

The Health and Wellbeing Board is asked to:

- Proceed with signing up to the Charter as per process outlined in 3.11 and 3.12.

## **1 Purpose of this report**

- 1.1 This report provides background information on The Every Disabled Child Matters Campaign and Local Authority Charter and requires a decision/approval to proceed as outlined below.

## **2 Background information.**

- 2.1 The Every Disabled Child Matters (EDCM) campaign is run by four of the leading organisations working with disabled children and their families - Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium. Its aim is to ensure every Local Authority and Health and Wellbeing Board make a clear commitment to improve services for, and to be held accountable by, disabled children and their families
- 2.2 EDCM have identified Health and Wellbeing Boards as the important new bodies that play a key strategic role in the new health system which came into effect on April 1st 2013. EDCM believes the reformed system must address long-standing problems which leave too many families of disabled children and young people struggling to have their needs met.
- 2.3 EDCM state on their website that “Disabled children and young people were invisible in early discussions about the future of the health system. EDCM and The Children's Trust, Tadworth produced the 'Disabled Children and Health Reform: Questions, challenges and opportunities' report, to demonstrate the challenges that families with disabled children experience in accessing the services they need.” [www.edcm.org.uk](http://www.edcm.org.uk)
- 2.4 EDCM and The Children's Trust, Tadworth have developed a Disabled Children's Charter for Health and Wellbeing Boards to ensure that the local health and social care system meets the needs of disabled children, young people and the families. This has replaced the previous Charter for the PCTs.
- 2.5 Leeds City Council became signatories to the EDCM Local Authority Charter in March 2013 and are currently working through the process outlined in ( ) to ensure their compliance with the commitments. The Local Authority believes that the public commitment to the EDCM Charter is integral to their aims to a Child Friendly City and the Best City. The Complex Needs Area Lead – Disability is leading this piece of work.

## **3 Main issues**

- 3.1 The Charter (Appendix 1) has been developed to support Health and Wellbeing Boards meet their responsibilities towards disabled children, young people and their families, including children and young people with special educational needs (SEN) and health conditions.
- 3.2 Health and Wellbeing Boards who sign the Charter will agree to meet its seven commitments focusing on improving health outcomes for disabled children, young people and their families, and to provide evidence after one year on how they have met each one.

### 3.3 The Charter commitments are (Appendix 1):

- We have detailed and accurate information on the disabled children and young people living in our area, and provide public information on how we plan to meet their needs
- We engage directly with disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board
- We engage directly with parents of disabled children and young people and their participation is embedded in the work of our Health and wellbeing Board
- We set clear strategic outcomes for our partners to meet in relation to disabled children, young people and their families, monitor progress towards achieving them and hold each other to account
- We promote early intervention and support for smooth transitions between children and adult services for disabled children and young people
- We work with key partners to strengthen integration between health, social care and education services, and with services provided by wider partners
- We provide cohesive governance and leadership across the disabled children and young people's agenda by linking effectively with key partners

### 3.4 EDCM identify the following benefits to Health and Wellbeing Boards of signing up to the Charter and meeting its commitments (Appendix 2):

- Publicly articulate a vision for improving the quality of life and outcomes for disabled children, young people and their families
- Understand the true needs of disabled children, young people and their families in your local area and how to meet them
- Have greater confidence in targeting integrated commissioning on the needs of disabled children, young people and their families
- Support a local focus on cost-effective and child-centred interventions to deliver long-term impacts
- Build on local partnerships to deliver improvements to the quality of life and outcomes for disabled children, young people and their families
- Develop a shared local focus on measuring and improving the outcomes experienced by disabled children, young people and their families
- Demonstrate how your area will deliver the shared ambitions of the health system set out by the Government in 'Better Health Outcomes For Children and Young People: Our Pledge' for a key group of children and young people.

- 3.5 EDCM encourages supporters to challenge their Health and Wellbeing Boards and their compliance with the Charter and provides a Supporters Guide (Appendix 3) to facilitate this.
- 3.6 As of the date of this report only one Health and Wellbeing Board has notified EDCM that they will not sign. Their letter is attached (Appendix 4).
- 3.7 Signatories to the Charter have use of the EDCM logo (provided electronically), a press release template that contains a quote by Christine Lenehan, Director, Council for Disabled Children, and individual support for promotional activities.
- 3.8 EDCM state on their website that “disabled children and young people are disproportionate users of health services and often use a wide range of different services provided by the NHS. However, disabled children, young people and their families currently experience significant barriers to accessing health services.” They also reference the 'Disabled Children and Health Reform' launched in 2011 that provided evidence of:
- Poorly coordinated appointments
  - Poor communication across the system
  - Delays to accessing specialist services and equipment
  - Disputes between agencies about funding for services
  - A confusing transition to adult services
- 3.9 It has been agreed that the Children’s Trust Board will, on behalf of the Health and Well-Being Board, take forward and monitor the implementation of the Charter. They will report back to the Health and Wellbeing Board on activity.
- 3.10 It is proposed that the Children’s Trust Board replicate the approach taken by the Local Authority for the LA EDCM Charter which is outlined below (3.11 and 3.12). A telephone conversation with EDCM on the 10<sup>th</sup> December 2013 confirmed their approval of the process to underpin the activity required by the Health and Wellbeing Board.
- 3.11 The Chair of Health and Wellbeing Board signs the Charter document which is returned to EDCM to register the Board. The Health and Wellbeing Board is recorded on the EDCM website as a signatory with another thirty Health and Wellbeing Boards that are currently registered. An audit is completed using the Charter commitments and an action plan developed and monitored to ensure full compliance within twelve months. At the end of the twelve months a final report is produced to evidence compliance and is reviewed on an annual basis.
- 3.12 This is set out in more detail in the suggested resourced action plan below:

<b>Activity</b>	<b>Action/Timescale</b>	<b>Resource</b>
Official signing up to commitments by Lead Member of Children's Service and registering with EDCM	Action sign up and registering with EDCM by April 2014	Complex Needs Area Lead - Disability
Review of situation within Leeds against EDCM commitments	Audit of current activity and identification of key pieces of work to be completed by September 2014	Project support to develop audit tool, circulate and collate responses from key stakeholders
Review findings of above	Report and proposed action plan produced for approval to progress by end of October 2014	Project Support. Approval by Health and Wellbeing Board
Action key areas of development	Project Management of identified workstreams or co-ordination/links with ongoing activity	Project Support reporting to Complex Needs Area Lead – Disability and Health and Wellbeing Board
Confirm to EDCM adherence to charter commitments by end of March 2015	Review of activity and progress and final report produced by end of March 2015	Project support/ Complex Needs Area Lead – Disability with final report endorsed by Health and Wellbeing Board
Ongoing review and evaluation of compliance	Continuation of any identified actions within the EDCM action plan underpinned by an annual review	Project Support reporting to Complex Needs Area Lead – Disability and Health and Wellbeing Board

#### **4 Health and Wellbeing Board Governance**

The Health and Wellbeing Board are held accountable for the Charter as per Supporters Guide (Appendix 3).

##### **4.1 Consultation and Engagement**

4.1.1 Consultation and engagement with key stakeholders, particularly children and families will be integral to the suggested process outlined in

##### **4.2 Equality and Diversity / Cohesion and Integration**

4.2.1 Signing up to the Charter is a public demonstration of the commitment of the Health and Wellbeing Board to include children and young people with disabilities/SEN and their families as part of their planning, development and commissioning activities.

##### **4.3 Resources and value for money**

4.3.1 The audit, delivery of the action plan and monitoring will have some implications in terms of staff time although it is not anticipated that this will be onerous.

##### **4.4 Legal Implications, Access to Information and Call In**

4.4.1 The EDCM Charter commitments cover a range of legislation, statutory requirements policy and guidance. These include the Health and Social Care Act 2012 (amends the Local Government and Public Involvement in Health Act 2007), Equality Act 2010, Children Act 2004, Article 12 of the United Nations Convention

on the Rights of the Child, Article 7 of the UN Convention on the Rights of Persons with Disabilities and the Children and Families Bill which is due for royal assent in early 2014.

- 4.4.2 The document, "Why sign the Disabled Children's Charter for Health and Wellbeing Boards" (Appendix 2) sets out the statutory drivers for each commitment as well as key resources for meeting them.
- 4.4.3 Any implications for governance, policy and resources will be identified from the audit and will form part of the proposed action plan.

#### **4.5 Risk Management**

- 4.5.1 There is a potential risk to reputation and credibility of the Health and Wellbeing Board if they do not sign up to the Charter.

#### **5 Conclusions**

- 5.1 The benefits of signing up to the Charter are outlined in
- 5.2 There does not appear to be a significant reason not to proceed.

#### **6 Recommendations**

- 6.1 The Health and Wellbeing Board is asked to:
  - Proceed with signing up to the Charter as per process outlined in 3.11 and 3.12.

#### **Further Information**

1. Why sign the Disabled Children's Charter for Health and Wellbeing Boards  
<http://www.edcm.org.uk/media/140961/why-sign-the-disabled-childrens-charter-for-health-and-wellbeing-boards.pdf>
2. Disabled Children's Charter for Health and Wellbeing Boards: Supporter's Guide  
[http://www.edcm.org.uk/media/141020/hwb-charter\\_supporter-guide\\_web.pdf](http://www.edcm.org.uk/media/141020/hwb-charter_supporter-guide_web.pdf)