

## Health and Wellbeing Board: 28<sup>th</sup> January 2015

<b>Title of paper:</b>	The Children with Disability Charter.	
<b>Director(s)/ Corporate Director(s):</b>	Dr Chris Kenny Director of Public Health	<b>Wards affected: all</b>
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<b>Date of consultation with Portfolio Holder(s) (if relevant)</b>	<b>Councillor Norris: September 2014</b>	

### **Relevant Council Plan Strategic Priority:**

Cutting unemployment by a quarter	<input type="checkbox"/>
Cut crime and anti-social behaviour	<input type="checkbox"/>
Ensure more school leavers get a job, training or further education than any other City	x
Your neighbourhood as clean as the City Centre	<input type="checkbox"/>
Help keep your energy bills down	<input type="checkbox"/>
Good access to public transport	x
Nottingham has a good mix of housing	<input type="checkbox"/>
Nottingham is a good place to do business, invest and create jobs	<input type="checkbox"/>
Nottingham offers a wide range of leisure activities, parks and sporting events	x
Support early intervention activities	x
Deliver effective, value for money services to our citizens	x

### **Summary of issues (including benefits to citizens/service users):**

The numbers of disabled children nationally and locally are increasing. At the moment in Nottingham City a single health and social care pathway for disabled and complex children and young people (CYP) does not exist. An in depth exploration, utilising a 'Whole Systems Approach' of the specific needs of vulnerable children and their families along with the services they access was undertaken in 2013: Integrated Children and Young People's Healthcare (ICYPH) Programme (Appendix 1). This robust evidence will shape the next implementation phase of the project. Nottingham City Health and Wellbeing Board have been approached by the Children's Trust Tadworth to consider signing their Children with Disability Charter. There are 7 key statements for the Health and Wellbeing Board to consider:

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.
2. We **engage directly with disabled children and young people** and their participation is embedded in the work of our Health and Wellbeing Board.
3. We **engage directly with parent carers** of disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board.
4. 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.
5. We **promote early intervention** and support for smooth transitions between children and adult services for disabled children and young people.
6. We work with key partners to **strengthen integration** between health, social care and education services, and with services provided by wider partners.
7. We provide **cohesive governance and leadership** across the disabled children and young people's agenda by linking effectively with key partners.

The direct involvement of the Health and Wellbeing Board through the signing of the charter will help shape the overarching governance and leadership structures of the next implementation phase of the delivery of an Integrated Children and Young People's Healthcare (ICYPH) Programme.

**Recommendation(s):**

<b>1</b>	Nottingham City Health and Wellbeing Board should read the attached evidence and consider signing the Children with Disability Charter.
<b>2</b>	<p><b>How will these recommendations champion mental health and wellbeing in line with the Health and Wellbeing Board aspiration to give equal value to mental health and physical health ('parity of esteem'):</b></p> <p>Signing the Disabled Children's Charter and therefore agreeing to comply with the 7 statements will support improved access to services (including emotional, mental health and wellbeing services) for vulnerable children, young people and their families.</p>

**REASONS FOR RECOMMENDATIONS**

The Children with Disability Charter asks that the Health and Wellbeing Board will provide evidence within 1 year against the following 7 specific statements; (supporting evidence from the Nottingham Integrated Children and Young People's Healthcare (ICYPH) Programme (Appendix 1) is in **bold** type):

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.

**Data collection and quality remains problematic in Nottingham however, the Integrated Children and Young People's Healthcare (ICYPH) Programme (Phase 1) for children with disability and additional health needs has significantly improved this. Data collection and analysis along with continued consultation with service users is a central element of the Phase 2 project.**

2. We **engage directly with disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board.**

**Children and families have been involved within the Phase 1 scoping stage of the review and will continue to be involved in developing the proposed integration of services. Progress on the development of the Phase 2 programme will be shared regularly with the Health and Wellbeing Board.**

3. We **engage directly with parent carers of disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board.**

**Children and families have been involved within the Phase 1 scoping stage of the review and will continue to be involved in developing the proposed integration of services. Progress on the development of the Phase 2 programme will be shared regularly with the Health and Wellbeing Board.**

4. 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.

The recommendations of the ICCYPH programme (Phase 1) have set a clear strategic vision for all partners involved. This will lead directly into the Phase 2 process of commissioning integrated services.

5. We **promote early intervention** and support for smooth transitions between children and adult services for disabled children and young people.

Early intervention and transition are key priorities within the ICCYPH programme.

6. We work with key partners to **strengthen integration** between health, social care and education services, and with services provided by wider partners.

A wide range of partners from health, social care, the third sector, private sector, education, etc. have already been closely involved with Phase 1 of the ICCYPH programme, this will continue as an integrated model of care is developed.

7. We provide **cohesive governance and leadership** across the disabled children and young people's agenda by linking effectively with key partners.

The recommendations of the ICCYPH programme (Phase 1) support a cohesive governance and leadership vision for all partners. Nevertheless, the direct involvement of the Health and Wellbeing Board through the signing of the Charter will help shape the overarching governance and leadership structures.

## 2. BACKGROUND (INCLUDING OUTCOMES OF CONSULTATION)

Nationally the disabled population increased by 70% in 30 years (1976 –2006), the under 16 disabled population is growing fastest and local trends reflect this. From 2005 to 2011 the number of children having multi-disciplinary assessment and team around the child (TAC) coordination meetings in the Nottingham children's development centre (CDC) almost doubled from 65 in 2005 to 120 in 2011.

At the moment in Nottingham City a single health and social care pathway for disabled and complex children and young people (CYP) does not exist.

An in-depth examination of the specific needs of vulnerable children and their families along with the services they accessed was undertaken by Nottingham City Clinical Commissioning Group, Nottingham City Council and Nottinghamshire County Council in 2013 (final report Appendix 1 and Families statement Appendix 2). This piece of work has given us clear recommendations on how to improve the delivery of an Integrated Children and Young People's Healthcare (ICCYPH) Programme for children with disability and additional health needs: utilising a 'Whole Systems Approach'.

Nottingham City Health and Wellbeing Board have been approached by the Children's Trust to consider signing their Children with Disability Charter. (Why sign the Children with Disability Charter? Appendix 3). There are a series of 7 statements which the Health and Wellbeing Board must agree they can achieve over the next year (Disabled Children's Charter for Health and Wellbeing Boards Appendix 4).

The next development phase to integrate and streamline services is planned provisionally for 2015/16. Coupled with the work already completed in the scoping and consultation phase we suggest that the Health and Wellbeing Board should consider signing the Children with Disability Charter. The direct involvement of the Health and Wellbeing Board through the signing of the Charter will help shape the overarching governance and leadership structures.

3. **OTHER OPTIONS CONSIDERED IN MAKING RECOMMENDATIONS**

N/A

4. **FINANCIAL IMPLICATIONS (INCLUDING VALUE FOR MONEY/VAT)**

N/A

5. **RISK MANAGEMENT ISSUES (INCLUDING LEGAL IMPLICATIONS AND CRIME AND DISORDER ACT IMPLICATIONS)**

N/A

6. **EQUALITY IMPACT ASSESSMENT**

Not needed (report does not contain proposals or financial decisions)

7. **LIST OF BACKGROUND PAPERS OTHER THAN PUBLISHED WORKS OR THOSE DISCLOSING CONFIDENTIAL OR EXEMPT INFORMATION**

See Appendices 1 to 4

8. **PUBLISHED DOCUMENTS REFERRED TO IN COMPILING THIS REPORT**

See Appendices 1 to 4



## How can we improve our services?

We need to make our services easier to get and easier to understand. We must work hard to do what children, young people and families need.



We want these services to work together more closely:

- Children's community nursing services
- Special school nursing
- Occupational therapy
- Physiotherapy
- Speech and language therapy



We will help these services make sure that they are doing the right things for the children, young people and families that they work with. They will think about the safety and mental health needs of the whole family and give them help with this as well if they need it.

All our services will help to protect children. This is also called 'safeguarding'.



We will talk to people who are working on other projects to improve services in health, education and social care. We will make sure that everyone works together to do the same things.

To help us do everything that we want to do and to make our services better we have a 'BIG ASK' – we want everyone to promise to make changes and improve services. We also have an 'EVEN BIGGER ASK' – we want everyone to help us do what we say in our vision.

If you want to find out more or help us with what we are trying to do you can send us an email. If you live in Nottinghamshire County email [childrens.commissioning@nottscg.gov.uk](mailto:childrens.commissioning@nottscg.gov.uk).

If you live in Nottingham City email [deborah.hooton@nottinghamcity.nhs.uk](mailto:deborah.hooton@nottinghamcity.nhs.uk).

This report is different...



## About the Joint Nottinghamshire Integrated Community Children and Young People's Healthcare Programme





# Integrated Community Children and Young People's Healthcare Programme (also known as the ICCYPH Programme)

## Who are we?

We are a group made up of the NHS and local councils. We support families living with a long term condition or disability by giving them 'specialist services' in the community.



Specialist services include, for example, nursing or short breaks services and therapy such as speech and language therapy, occupational therapy and physiotherapy.

'In the community' means we work with families close to their homes and in their homes to give them these services.



We have looked at how services can work together to make families' lives better and easier and called this our 'vision'.

## Why have we written a report about our 'vision'?

Our vision is about what we need to do. We want to give families the services that will help them to do what they want to do and make their lives better and easier.



We know that families with children and young people living with long term conditions and disabilities can need a lot of support from different services. Every year more children and families need specialised health and social care services. It is really important that services work together when there are more people to support.

## What do people say about services now?

Parents and carers say it can be difficult to get the support they need to have the best health possible. They say sometimes it is hard to get services to listen to them and understand them.



Most families want to be listened to, respected and understood by the people who support them and work in health and social care. They want to enjoy normal family life.



Most families are very happy with services but those services don't talk to each other or work together very well. This can be complicated and confusing for families.



It can also be difficult to understand how they can get all the services they need.

Family doctors have asked for more training on how they can help children with a long term health condition or disability. The *Contact a Family* charity has written a guide for the doctors to help them.



# **Nottinghamshire Families' statement of expectations**

## **Our values are...**

1. Respect
2. Collaboration
3. Continual improvement

## **My family's expectations will be met when...**

1. We are consulted and listened to, heard and treated with respect as experts on our/our child's condition and have our views taken into account at all times.
2. We can easily get information, advice and guidance, and the services and supplies that we need, when we need them, so that our family can enjoy the best possible health and fulfilling lives. This should enable and support our roles, lifestyle choices and aspirations.
3. There is collaborative, joined up and timely planning and service delivery, with all parts working as a whole across all organisations and agencies involved in every aspect of our children's care.
4. Each of our children is treated as an individual.
5. There is timely communication and shared documentation including core essential information about our children, their condition and their support between all those who need to be involved.
6. We are confident that there are enough staff, who have the right knowledge, skills and expertise for what they are there to do, and they demonstrate this by empathy and understanding in all contacts.
7. Our children are supported to achieve responsibility for themselves as adults and the family is supported during this period of transition to adulthood and reduced dependence on the family.
8. We can see that everyone involved in our children's care is committed to continually improving what they do.
9. Our children are seen in age appropriate environments furnished and equipped to meet their needs, this takes account of chronological and developmental age.
10. At all times our children are protected from harm.

Developed in consultation with parents and young people as guiding principles for the Nottinghamshire Integrated Community Children and Young People's Healthcare Programme

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Leads for the JointNottinghamCity, Nottinghamshire County Integrated Community children and young people Healthcare programme

## Why sign the Disabled Children's Charter for Health and Wellbeing Boards?

### **Benefits to Health and Wellbeing Boards of signing the Charter and meeting its commitments:**

- 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<sup>1</sup>

### **Who are we talking about?**

The Disabled Children's Charter for Health and Wellbeing Boards and this accompanying document have been developed to support Health and Wellbeing Boards (HWBs) meet the needs of all children and young people who have disabilities, special educational needs (SEN), health conditions, and their families. In this document, when we talk about disabled children and young people we are referring to all the children and young people in this group.

<sup>1</sup> Department of Health (2013), Better Health Outcomes for Children and Young People: Our Pledge



# Commitment 1: We have detailed and accurate information on the disabled children, young people and their families living in our area, and provide public information on how we plan to meet their needs

Statutory drivers

## ***Health and Social Care Act 2012***

Duty to prepare assessment of needs (JSNA) in relation to local authority area and have regard to guidance from Secretary of State

## ***Information***

The quality of data and information used to underpin the planning, commissioning and delivery of services for children and young people with very complex needs is often poor. The difficulty of developing accurate, robust data in a standard format about disabled children and young people is an enduring issue for local areas and for national agencies. Reliable performance information about the use and value of services is critical to commissioning decisions. The Children and Young People's Health Outcomes Forum identified the lack of accurate data as the single biggest challenge in relation to the development of outcomes for children with long-term health conditions, disabilities and life limiting conditions<sup>2</sup>.

In March 2012, the CQC released a report entitled 'Healthcare for disabled children and young people'<sup>3</sup>. This report gave details of primary care trust (PCT) replies to a self assessment questionnaire on services for disabled children.

PCTs demonstrated an extremely worrying lack of awareness of the needs of local disabled children:

- **Five PCTs** claimed that **no disabled children and young people lived in their area**
- **Fifty five PCTs did not monitor whether services allocated as a result of Common Assessment Framework were delivered**
- **Sixty three PCTs didn't know how many children were referred for manual wheelchairs** and **nine said children were waiting over 51 weeks for wheelchairs**
- **Fifteen PCTs** said they **didn't provide short breaks services**

Due to the lack of reliable data on disabled children and young people, their strategic involvement and that of their parents is essential to gain a good understanding of the profile of this group

2 Children and Young People's Health Outcomes Forum (2012), Report of the long term conditions, disability and palliative care subgroup p.2

3 Care Quality Commission (2012), Healthcare for Disabled Children and Young People

and the particular challenges and experiences they face. Their views remain underrepresented in surveys and public and patient involvement in the health service.

## **Meeting Needs**

One of the primary tools Health and Wellbeing Boards have to drive strategic commissioning in their areas is the Joint Strategic Needs Assessment (JSNA). The JSNA will assess the current and future health and care needs and assets of a local population and will underpin a Joint Health and Wellbeing Strategy (JHWS). It will interpret available data to develop an understanding of the causes of health inequalities and a narrative of the evidence.

The JSNA can only be an effective tool for evidence-based decision making if it is based on accurate and meaningful data. The bodies Health and Wellbeing Boards delegate collecting data to as part of the JSNA process, must focus on improving the quality and scope of information on disabled children and young people which they use, including: available national data sets; local information sources such as data from Common Assessment Frameworks; qualitative information from direct engagement with service users.

The JSNA process must develop an understanding of the local population which is sufficiently differentiated to understand the needs of all groups of children, particularly those who face the greatest inequalities or experience multiple disadvantages.

### **How to meet your Charter commitments**

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- The full range of sources of information collected on disabled children, young people and their families which will be used to inform the JSNA process
- The quality assurance process used to ensure that information and data on disabled children, young people and their families used to inform commissioning is sufficiently detailed and accurate
- The way in which the JSNA will be used to assess the needs of local disabled children, young people and their families
- The way in which information on any hard to reach groups is sourced, and action taken to address any gaps of information with regard to local disabled children, young people and their families
- The way in which disabled children, young people and their families are strategically involved in identifying need, and evidence and feedback on their experiences is used to inform the JSNA process
- Public information on how the HWB will support partners to commission appropriately to meet the needs of local disabled children, young people and their families

## Key resources for meeting this Charter commitment

### Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies

Statutory guidance to support Health and Wellbeing Boards and their partners in understanding the duties and powers in relation to Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies.

### NHS Confederation, Operating principles for Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies

Paper designed to support areas to develop successful Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies.

### Child and Maternity Health Observatory: support for commissioners

Help to find the right tools, data and evidence to review, plan and improve services in your local area.

### Child and Maternity Health Observatory: tools and data

ChiMat provides easy access to a wealth of data, information and intelligence through a range of online tools designed to support decision-making.

### Rightcare (2012), NHS Atlas of Variation in Healthcare for Children and Young Adults

Variations across the breadth of child health services provided by NHS England are presented together to allow clinicians, commissioners and service users to identify priority areas for improving outcome, quality and productivity.

### LGA (2011), Joint Strategic Needs Assessment: Data Inventory

Offers practical help to councils, clinical commissioning groups and other members of health and wellbeing boards.

### Children and Young People's Health Outcomes Forum (2012), Making data and information work for children and young people

Factsheet on making data and information work for children and young people, including resources.

### Contact A Family (2012), Health and Wellbeing Boards: making the case to target disabled children services

Briefing for Parent Carer Forums on the reasons why the Health and Wellbeing board in their area should target disabled children in their Joint Strategic Needs Assessment (JSNA) and Joint Health and Wellbeing strategy (JHWS).

## Commitment 2: We engage directly with disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board

Statutory drivers

### ***Health and Social Care Act 2012***

Duty to involve third parties in preparation of the JSNA:

- Local Healthwatch
- people living or working in the area
- for County Councils – each relevant DC

Duty to involve third parties in preparation of the JHWS:

- Local Healthwatch
- people living or working in the area

### **Article 12 of the United Nations Convention on the Rights of the Child (UNCRC)**

- The child has the right to express his or her opinion freely and to have that opinion taken into account in any matter or procedure affecting the child.

### **Article 7 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)**

- Children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.

Health and Wellbeing Boards should ensure that the voice of disabled children and young people is always heard when decisions are being made that affect them. Health and Wellbeing Board members should use their influence to embed engagement with disabled children and young people throughout the health and care system and in the context of a continuous and current partnership.

The benefits of embedding participation of disabled children and young people are huge: better services will be developed driven by feedback from the people who know and use them; resources are not wasted on services that are not taken up or valued; services will be more child and young person friendly and accessible; disabled children and young people will have insight into the diverse needs and barriers faced by marginalised and vulnerable groups; improved accountability to children and young people as stakeholders; and direct benefits to disabled children and young people themselves such as increased knowledge of services,



confidence, and skills<sup>4</sup>.

It should be recognised that many disabled children and young people may face significant barriers to their involvement, particularly in mainstream settings. Recent research from the VIPER project found that young disabled people's participation is still not embedded at a strategic, service level or individual decision-making. It found barriers to participation including a lack of understanding of what participation is and how you make it happen, lack of funding, inclusive practice, resources, time and training, and lack of consistent systems and structures<sup>5</sup>.

All disabled children and young people communicate and have a right to have their views heard and this may require targeted approaches and the involvement of Voluntary Sector Organisations (VSOs).

## How to meet your Charter commitments

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- Evidence of the way in which the HWB or its sub groups have worked with disabled children and young people in the JSNA process, and next steps for JSNA engagement
- Evidence of the way in which the HWB or its sub groups have worked with disabled children and young people in the preparation and delivery of the Joint Health and Wellbeing Strategy (JHWS), and next steps for JHWS engagement
- Evidence of partnership working with any local groups of disabled children and young people

## Key resources for meeting this Charter commitment

[The NHS Confederation, Royal College of Paediatrics and Child Health and Office for Public Management \(2011\), Involving children and young people in health services](#)

This report highlights the key findings and recommendations from an event held in September 2011 to discuss the key priorities for child health.

[VIPER \(Voice.Inclusion.Participation.Empowerment.Research\)](#)

VIPER is a three-year project funded by the Big Lottery Fund, to research young disabled people's participation in decisions about services. It began in Summer 2010.

[VIPER \(2012\), The Viper project: what we found](#)

Findings and key messages arising from the research activities of the VIPER project.

[VIPER \(2012\), The Viper project: what we found from the survey](#)

Summary of the findings and key messages from the research activities. The research summarised in this report was carried out between 2010 and 2012.

4 Participation Works (2008), How to involve children and young people in commissioning, p.6.

5 VIPER (Voice, Inclusion, Participation, Empowerment and Research) (2013), Hear Us Out, p.23.

## Participation Works

Enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives.

### Participation Works (2008), How to involve children and young people in commissioning

An introduction to commissioning from a variety of perspectives. It describes the different parts of the process and ways to support children and young people to participate in all aspects of commissioning.

### Participation Works (2008), How to build a culture of participation

Information and practical ideas about how to embed participation throughout your organisation in a way that brings about change.

### Participation Works (2010), Listen and Change - a guide to children and young people's participation rights

Aims to increase understanding of children and young people's participation rights and how they can be realised in local authority and third sector settings.

### Making Ourselves Heard (MOH)

MOH is a national project to ensure disabled children's right to be heard becomes a reality.

### Council for Disabled Children (2009), Making Ourselves Heard

Based on a series of eight seminars with local authorities this book sets out the current policy context for disabled children and young people's participation, outlines the barriers and challenges to effective participation and highlights what is working well.

### Franklin, A. and Sloper, P. (2009) Supporting the participation of disabled children and young people in decision-making

Presents research exploring factors to support good practice in participation and discusses policy and practice implications.

### DfEs (2003), Building a culture of participation: research report

Many of the case studies in this research are attempting to make participation more integral to their organisation.

## Commitment 3: We engage directly with parent carers and their participation is embedded in the work of our Health and Wellbeing Board

Statutory drivers

### ***Health and Social Care Act 2012***

Duty to involve third parties in preparation of the JSNA:

- Local Healthwatch
- people living or working in the area
- for County Councils – each relevant DC

Duty to involve third parties in preparation of the JHWS:

- Local Healthwatch
- people living or working in the area

The purpose of parent participation is to ensure that parents can influence service planning and decision making so that services meet the needs of families with disabled children. Effective parent participation happens when parents have conversations with and work alongside professionals, in order to design, develop and improve services<sup>6</sup>.

The benefits of effective parent participation are well established: resources are not wasted on services that are not taken up or valued; parent carers' insight can help develop cost-effective solutions to local problems; a shared view can be developed between parents and professionals of how to support families within funding limitations; more costly interventions can be avoided in the future; and complaints can be reduced by Parent Carer Forums monitoring services and alerting commissioners and managers if problems occur. The Contact A Family resources below contain a wealth of evidence and case studies into how effective parent participation has benefited the local areas where it has been implemented.

Health and Wellbeing Boards should ensure that parent carers are involved in decisions that affect them at a strategic and service level. Health and Wellbeing Board members should use their influence to embed engagement with parent carers throughout the health and care system and in the context of a continuous and current partnership.

It should be recognised that parent carers may face significant barriers to their participation in mainstream settings but that this should not prevent their involvement in decision-making.

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<sup>6</sup> Definition from Together for Disabled Children (2010), How to guide to parent carer participation: Section 1 – parent participation as a process, p.2.

## How to meet your Charter commitments

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- Evidence of the way in which the HWB or its sub groups have worked with parent carers of disabled children in the JSNA process, and next steps for JSNA engagement
- Evidence of the way in which the HWB or its sub groups have worked with parent carers of disabled children in the preparation and delivery of the JHWS, and next steps for JHWS engagement
- Evidence of partnership working with local parent groups, including the local Parent Carer Forum(s)

## Key resources for meeting this Charter commitment

Together for Disabled Children (v2.0 2010), Parent carer participation: How to guide.

A guide to support parent carer forums, commissioners and managers to develop parent carer participation. It can be downloaded in the following separate sections:

[Section 1 - The Process](#)

[Section 2 - producing information](#)

[Section 3 - consultation](#)

[Section 5a - successful meetings Together for Disabled Children](#)

[Section 5b - how to reach and engage parents](#)

[Section 5c - supporting parent representatives](#)

[Section 6b- for strategic leaders](#)

[How parent participation and parent carer forums leads to better outcomes for disabled children, young people and their families 2011](#)

[Contact A Family \(2012\), Parent Carer Participation: An overview](#)

This short guide provides examples of successful parent carer participation

[Contact A Family, Improving Health Services](#)

Resources to support the commissioning and management of health services.

[Contact A Family, Resources](#)

Resources, case studies and information for professionals to help them improve how services are delivered, so they better meet families' needs.

[Contact A Family \(2013\), Parent carer forum involvement in shaping health services - second report](#)

Report into Parent Carer Forum involvement with the health service in the lead up to the new health system coming into effect.



## Commitment 4: 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

Statutory drivers

### ***Health and Social Care Act 2012***

Duty to prepare a JHWS for meeting needs included in JSNA in relation to LA area and to have regard to guidance from Secretary of State

Power of the HWB to give its opinion to the local authority which established it on whether the authority is discharging its duty to have regard to relevant JSNA and JHWS

CCG is under a duty to involve HWB in preparing or significantly revising the commissioning plan – including consulting it on whether the plan has taken proper account of the relevant JHWS

Duty to provide opinion on whether the CCG commissioning plan has taken proper account of the JHWS. Power to also write to NHS England (formerly the NHS Commissioning Board) with that opinion on the commissioning plan (copy must also be supplied to the relevant CCG). Duty to review how far the CCG has contributed to the delivery of any JHWS to which it was required to have regard and to consult HWB on this

Duty in conducting the performance assessment, to assess how well CCG has discharged duty to have regard to JSNA and JHWS and to consult HWB on its view on CCGs' contribution to delivery of any JHWS to which it was required to have regard (when conducting its annual performance assessment of the CCG)

In response to the report of the Children and Young People's Health Outcomes Forum, the Government set out its ambitions for improving health outcomes for children and young people by launching 'Better Health Outcomes For Children And Young People: Our Pledge'<sup>7</sup>. Health and Wellbeing Boards will play a key role in delivering on these ambitions.

Disabled children and young people will provide a crucial test of the effectiveness of the new health system and improving the outcomes they experience, including those in the NHS and Public Health Outcomes frameworks, will require concerted strategic leadership. However, if a Health and Wellbeing Board can improve integration for local disabled children and young people, who frequently test the interface between multiple services and agencies, it can deliver for all children and young people.

For the JSNA and JHWS process to make a positive impact on the outcomes faced by disabled children, young people and their families, it is essential that the evidence collected through the JSNA process reflects the outcomes that are most meaningful to them. Health and Wellbeing Boards should use the JSNA process to develop a shared understanding of the needs of disabled children, young people and their families, and the causes of the poor outcomes and inequalities

<sup>7</sup> Department of Health (2013), Better Health Outcomes for Children and Young People: Our Pledge

they experience. They should set clear strategic outcomes for partners to meet and ensure that mechanisms are in place to measure and monitor progress towards achieving them.

The JHWS should address how the needs of disabled children, young people and their families should be met and make recommendations on cost-effective approaches to reducing the health inequalities they experience. However, if this group is not identified as a priority in the JHWS, the Health and Wellbeing Board should demonstrate how it is providing strategic direction for partners to meet the needs of disabled children and young people.

## **How to meet your Charter commitments**

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- Public information on the status of outcomes for local disabled children and young people based on indicators such as the NHS Outcomes Framework, the Public Health Outcomes Framework, etc.
- Public information on the strategic direction the HWB has set to support key partners to improve outcomes for disabled children and young people. This may be encompassed by the JHWS, but would need to be sufficiently delineated to demonstrate specific objectives and action for disabled children and young people.

## **Key resources for meeting this Charter commitment**

[NHS Confederation \(2012\), Children and young people's health and wellbeing in changing times](#)

The purpose of this report is to support implementation of the health reforms to improve children and young people's health and wellbeing.

[Report of the Children and Young People's Health Outcomes Forum \(2012\)](#)

The Children and Young People's Health Outcomes Forum was established by the Secretary of State for Health and tasked with responding to the challenges set out in Sir Ian Kennedy's report published in 2010 'Getting it right for children and young people'.

[Report of the Children and Young People's Health Outcomes Forum - report of the long-term conditions, disability and palliative care sub-group \(2012\)](#)

Report discussing the challenges around improving outcomes for this group of children.

[Report of the Children and Young People's Health Outcomes Forum - inequalities in health outcomes and how they might be addressed \(2012\)](#)

Report commissioned by the co-chairs of the Children and Young People's Health Outcomes Forum from Maggie Atkinson, Children's Commissioner for England.

[Children and Young People's Health Outcomes Forum \(2012\), Health and wellbeing boards and children, young people and families](#)

Poster produced in June 2012 by the health and wellbeing board learning set for children and young people.

## Children and Young People's Health Outcomes Forum (2012), Commissioning in the new NHS for children, young people and their families

Poster setting out the Children and Young People's Health Outcomes Forum's vision for successful commissioning for children, young people and their families in the new NHS.

## Department of Health (2013), Improving Children and Young People's Health Outcomes: a system wide response

The Children and Young People's Health Outcomes Forum report made recommendations, aimed at DH, DfE and a wide range of health system organisations, to improve health outcomes for children and young people. This document contains the system-wide response setting out the action already undertaken, in progress and planned in response to the recommendations.

## Department of Health (2013), Better health outcomes for children and young people: Our Pledge

Government response to the report of the Children and Young People's Health Outcomes Forum, setting out shared ambitions across the NHS to improve outcomes and services for children and young people.

## Contact A family and Strategic Network for Child Health and Wellbeing in the East of England (2012), Principles for commissioning and delivering better health outcomes and experiences for children and young people so that they are comparable with the best in the world

Poster showing 6 principles for commissioning and delivering better health outcomes and experiences for children and young people, developed by the Strategic Network for Child Health and Wellbeing in the East of England.

## Department of Health (2010), The NHS Outcomes Framework 2011/12

The outcomes and indicators which make up the first NHS Outcomes Framework, following the consultation Transparency in outcomes – a framework for the NHS.

## **Commitment 5: We promote early intervention and support smooth transitions between children and adult services for disabled children and young people**

The report of the Children and Young People's Health Outcomes Forum emphasised the importance of early intervention and transitions within a life-course approach to reducing health inequalities<sup>8</sup>. This is particularly significant for disabled children and young people and their families, who often struggle to obtain a diagnosis and access appropriate support at an early age and when transitioning to adult services, which affects their outcomes throughout their lives.

It should be emphasised that disabled children and young people may transition to adult services up to the age of 25. Health and Wellbeing Boards should consider the needs of disabled children and young people from 0-25 as well as ensuring smooth transitions to adult services.

### **How to meet your Charter commitments**

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- The way in which the activities of the HWB help local partners to understand the value of early intervention
- The way in which the activities of the HWB ensure integration between children and adult services, and prioritise ensuring a positive experience of transition for disabled young people

### **Key resources for meeting this Charter commitment**

[Graham Allen MP \(2011\), Early Intervention: The Next Steps](#)

An independent report to Government, which argues that many of the costly and damaging social problems for individuals can be eliminated or reduced by giving children and parents the right type of evidence based programmes between 0-18 and especially in their earliest years.

[Graham Allen MP \(2011\), Early Intervention: Smart Investment, Massive Savings](#)

Graham Allen MP's second independent report to the Government sets out how early intervention programmes can be paid for within existing resources and by attracting new non-government money.

[Child and Maternity Health Observatory, Knowledge Hub: Transitions](#)

The transitions to adulthood hub brings together a range of resources and evidence relating to young people's transition process into the adult world. It is constantly updated with new resources.



## Early Support

A way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

### [Early Support \(2012\), Key working: improving outcomes for all - Evidence, provision, systems and structures](#)

A summary of the key evidence and consistent elements of a key working approach. It presents an analysis of the implications of key working that cuts across health, social care and education.

### [Ofsted \(2013\), Good practice resource - Early intervention through a multi-agency approach: Sheffield City Council](#)

Sheffield City Council has developed a creative and innovative approach across the children's workforce by introducing a multi-agency perspective in providing preventative services to children and families.

### [C4EO, Improving the wellbeing of disabled children through early years interventions \(age 0–8\)](#)

This section contains the following resources in support of improving the wellbeing of disabled children through early years interventions (age 0–8) priority: links to online tools; key online publications from C4EO partners and other organisations.

### [Institute of Public Care \(2012\), Early Intervention and Prevention with Children and Families: Getting the Most from Team around the Family Systems](#)

Briefing paper arguing that effective local systems to identify families who would benefit from additional support and to coordinate support from a range of agencies is as important as delivering effective services.

## Transition Information Network (TIN)

An alliance of organisations and individuals who come together to improve the experience of disabled young people's transition to adulthood. TIN is a source of information and good practice standards for disabled young people, families and professionals.

### [TIN Resource Library](#)

You can use the search form to find a range of resources that can help you to improve your provision for disabled young people in transition to adulthood.

## Preparing for Adulthood (PfA)

A 2 year programme funded by the Department for Education as part of the delivery support for 'Support and aspiration: A new approach to special educational needs and disability' green paper. It provides knowledge and support to all local authorities and their partners, including families and young people, so they can ensure young people with SEN and disabilities achieve paid work, independent living, good health and community inclusion as they move into adulthood.

## Preparing for Adulthood (2012), PfA resource list

Created for the PfA 'How are you doing?' events which took place in June and July, 2012. Resources are listed under: Paid employment; Independent living; Good health; Community inclusion.

Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. and Cusworth, L. (2011) Transition to adult services for disabled young people and those with complex health needs, Research Works, 2011-02, Social Policy Research Unit, University of York, York

This research aimed to provide evidence of what works well in developing and implementing multi-agency coordinated transition services for disabled children and those with complex health needs and their families. It also assessed the costs of the services.

## **Commitment 6: We work with key partners to strengthen integration between health, social care and education services, and with services provided by wider partners**

Statutory drivers

### ***Health and Social Care Act 2012***

Duty to encourage integrated working:

- between commissioners of health services and commissioners of social care services
- in particular to provide advice, assistance or other support for the purpose of encouraging use of flexibilities under NHS Act 2006

Power to include in the JHWS a statement of views on how the commissioning of health and social care services, and wider health-related services, could be more closely integrated – i.e. the ability for the JHWS to look more broadly than health and social care in relation to closer integration of commissioning

Disabled children and young people access services across multiple agencies, and therefore are disproportionately affected by poor integration between health and social care services and a lack of coordinated commissioning. Health and Wellbeing Boards must work with key partners to meet the needs of disabled children and young people, including: education providers and schools; safeguarding boards, local children's trust arrangements; learning disability partnership boards; and others. Health and Wellbeing Boards should make recommendations to ensure that disabled children and young people experience seamless integration between the services they access.

In particular, Health and Wellbeing Boards should consider how they engage with education services, including schools and colleges, because of the significance of joined up-working between health, education and social care to disabled children and young people's outcomes.

To promote integrated commissioning Health and Wellbeing Boards will also need to consider how specialised health services commissioned by NHS England are joined up with locally commissioned services and ensure they are taken into account by their JSNA and JHWS.

## How to meet your Charter commitments

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- Details of the way in which the HWB is informed by those with expertise in education, and children's health and social care
- Details of the way the HWB engages with wider partners such as housing, transport, safeguarding and the youth justice system
- Details of steps taken to encourage integrated working between health, social care, education and wider partners in order to improve the services accessed by disabled children, young people and their families

## Key resources for meeting this Charter commitment

[Together for disabled children \(2009\), Facilitating integrated practice between children's services and health](#)

This report contains examples of innovative working practice where services are integrated with health.

[Council for Disabled Children \(2006\), Pathways to success: Good practice guide for children's services in the development of services for disabled children - evidence from the pathfinder children's trusts](#)

This project ran from April 2004 to March 2006 and set out to work alongside the pathfinder children's trusts in developing new ways of working and to capture the learning from their work. The work covered: strategic planning; commissioning services, pooling budgets; joint working and co-location; assessment process and information sharing.

[East Midlands, Everybody's learning \(2012\), Assured safeguarding: GP and Health Leader edition](#)

Resource to help commissioners and health providers reassure themselves they are doing everything possible to ensure that children within the services for which they are responsible are as safe as possible.

[Ofsted \(2012\), Improving outcomes for disabled children by integrating early support and prevention services: Luton Borough Council](#)

Luton's services for disabled children and their families bring together practice across health, social care and education services, alongside innovative short break and early support provision. The development of an extensive range of integrated early support and prevention services is improving outcomes for disabled children and preventing situations deteriorating so that child protection or looked after services become necessary.

## **Commitment 7: We provide cohesive governance and leadership across the disabled children and young people's agenda by linking effectively with key partners**

Statutory drivers

### ***Health and Social Care Act 2012***

Power to encourage close working (in relation to wider determinants of health):

- between itself and commissioners of health-related services
- between commissioners of health services or social care services and commissioners of health-related services

Power to appoint additional members to the board as deemed appropriate

Power for HWB to request information for the purposes of enabling or assisting its performance of functions from:

- the local authority
- certain members or those they represent with a duty to provide

### ***Children Act 2004***

Requirement for each local authority to have a children's trust board which must include representatives of the local authority and each of the children's trust 'relevant partners'

Local safeguarding children's boards put on statutory footing

### ***Children and Families Bill 2012-13 (currently in Parliament)***

(Clause 25) Local authorities must promote the integration of special education, health and care provision.

(Clause 26) Local authorities and their partner CCGs must make arrangements for the joint commissioning of education, health and care provision for children and young people with SEN.

(Clause 27) Local authorities must keep under review special education provision and social care provision for children and young people with SEN and consider the extent that it is sufficient to meet their needs.

(Clause 30) Local authorities must publish a Local Offer containing information about services available for children and young people with SEN, including education, health and care provision.

The role of the Health and Wellbeing Board must be understood in relation to new and existing partnerships, including: local children's trust arrangements; local safeguarding children's boards; learning disability partnership boards; and others. A clear local framework on how these partnerships interact needs to be established to avoid the duplication of effort or even

competing for resources.

The JSNAs and JHWS need to be aligned with other arrangements, such as: reviewing and commissioning of SEN services via the High Needs Block<sup>9</sup>; safeguarding arrangements; child poverty strategies; and children and young people's plans if they are still used.

Additionally, the Children and Families Bill currently in Parliament contains clauses for promoting integration between special educational provision, health and social care provision (25), making joint-commissioning arrangements (26), keeping education and care provision under review (27), and producing a local offer (30), for children and young people with SEN. These new duties on local authorities all have a clear relevance to the functions of the Health and Wellbeing Board to encourage integrated working, promote close working and undertake a JSNA and JHWS. This is particularly important as CCGs will be under a new duty to secure specific services in education, health and care plans for children and young people with SEN<sup>10</sup>. Indicative regulations also make clear that local authorities must consult Health and Wellbeing Boards when preparing and reviewing its Local Offer<sup>11</sup>.

## How to meet your Charter commitments

In order to fulfil this commitment, we would expect a HWB to be able to provide the following evidence:

- Information on links to other local integration forums which set strategic direction for disabled children's services, e.g. the local children's trust arrangements, the local safeguarding board, the learning disability partnership board, the school forum, etc.
- Evidence of how the JSNA and JHWS is aligned with other arrangements, such as: reviewing and commissioning of SEN services via the High Needs Block; safeguarding arrangements; child poverty strategies, etc.

## Key resources for meeting this Charter commitment

NHS Confederation (2012), [Children and young people and health and wellbeing boards: putting policies into practice](#)

Developed by the health and wellbeing board learning set for children and young people, part of the National Learning Network for health and wellbeing boards, to give HWB members some ideas of how other boards are organising themselves to deliver coordinated services for children and young people.

9 See Department for Education (2012), [School funding reform 2013-14](#), pp. 16-20

10 See Department for Education website (2013), [Children and young people with special educational needs to benefit from new legal health duty](#)

11 The Special Educational Needs (Local Offer) (England) Regulations 2014: <http://media.education.gov.uk/assets/files/pdf/c/clause%2030%20draft%20regulations%20sen%20local%20offer.pdf>



Children and Young People's Health Outcomes Forum (2012), Health and wellbeing boards and children, young people and families

Poster produced in June 2012 by the health and wellbeing board learning set for children and young people.

Easton, C.; Hetherington, M., Smith, R., Wade, P., Aston, H. and Gee, G. (2012). Local Authorities' Approaches to Children's Trust Arrangements (LGA Research Report)

The Local Government Association commissioned the National Foundation for Educational Research (NFER) to investigate local authorities' approaches to their children's trust arrangements and how they are fulfilling their duty to promote cooperation with partners to improve children and young people's health and wellbeing.

## General resources

### [The Marmot Review \(February 2010\), Fair Society, Healthy Lives: A Strategic Review of Health Inequalities in England Post-2010](#)

Professor Sir Michael Marmot was asked by the then Secretary of State for Health to chair an independent review to propose the most effective evidence-based strategies for reducing health inequalities in England.

### [Kennedy, Prof Sir Ian \(September 2010\) Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs](#)

An independent review of services provided by the NHS to children and young people, concentrating on understanding the role of culture in the NHS. It focuses on areas where there are cultural barriers to change and improvement and makes recommendations.

### [NHS Confederation - Resources for Health and Wellbeing Boards](#)

The NHS Confederation has been working with each health and wellbeing board learning set in collaboration with the NHS Institute for Innovation and Improvement, Department of Health and Local Government Association to produce publications which summarise their key points of learning and which will be shared with other shadow health and wellbeing boards.

### [NHS Confederation \(2012\), Children and young people's health and wellbeing review of documents](#)

Briefing summarising the key policy documents on children and young people's health and wellbeing that have been published over the last two years."

### [NHS Confederation \(2012\), Support and resources for health and wellbeing boards](#)

Summary of the support available to spread networking and learning opportunities for Health and Wellbeing Boards

### [NHS Confederation \(2012\), National learning network for health and wellbeing board publications 2012](#)

A list of publications produced by The National Learning Network for health and wellbeing boards to share learning and support the establishment of well functioning boards.

### [Local Government Association - Resources for Health and Wellbeing Boards focusing on children, young people and family issues](#)

The Health and Wellbeing Board learning set for children and young people looked at the issues important to the development of Health and Wellbeing Boards. The learning sets are a part of the Department of Health's development and support programme for Health and Wellbeing Boards which is supported by the LGA, NHS Confederation and NHS Institute. Nine learning sets focused on a number of themes including governance, resources and public engagement.

### [Getting the Best Out of Your Health and Wellbeing Board Leadership Development Offer - Health and Wellbeing Board Information Resource](#)

This document brings together information about publications and websites which should be of value to Health and Wellbeing Boards.

## Child and Maternity Health Observatory

ChiMat was established in 2008 as a national public health observatory to provide wide-ranging, authoritative data, evidence and practice related to children's, young people's and maternal health.

## National Voices

The national coalition of health and social care charities in England. They work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

## Regional Voices

Supports the voluntary sector to successfully influence local strategic decision making in health and social care. This group of pages links to a variety of resources to support you develop strategies to influence in your local area.

## About Us



Every Disabled Child Matters is the national campaign to get rights and justice for every disabled child. It is run by four leading organisations working with disabled children and their families: Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium.



The Children's Trust, Tadworth is the leading UK charity for children with acquired brain injury, multiple disabilities and complex health needs. The Trust's services include the UK's largest rehabilitation centre for children and young people with acquired brain injury, nursing care for technology-dependent children, and education for children and young people with profound and multiple learning difficulties and complex health needs.

# Disabled Children's Charter for Health and Wellbeing Boards

The ..... **Health and Wellbeing Board** is committed to improving the quality of life and outcomes experienced by disabled children, young people and their families, including children and young people with special educational needs and health conditions. We will work together in partnership with disabled children and young people, and their families to improve universal and specialised services, and ensure they receive the support they need, when they need it. Disabled children and young people will be supported to fulfil their potential and achieve their aspirations and the needs of the family will be met so that they can lead ordinary lives.

**By [date within 1 year of signing the Charter] our Health and Wellbeing Board will provide evidence that:**

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
2. We **engage directly with disabled children and young people** and their participation is embedded in the work of our Health and Wellbeing Board
3. We **engage directly with parent carers** of disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board
4. 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
5. We **promote early intervention** and support for smooth transitions between children and adult services for disabled children and young people
6. We work with key partners to **strengthen integration** between health, social care and education services, and with services provided by wider partners
7. We provide **cohesive governance** and leadership across the disabled children and young people's agenda by linking effectively with key partners

Signed by ..... Date .....

Position: **Chair of Health and Wellbeing Board.**

For guidance on meeting these commitments, please read the accompanying document: [Why sign the Charter?](#)

**every disabled  
child matters**

**Every Disabled Child Matters (EDCM)** is the campaign to get rights and justice for every disabled child. It has been set up by four leading organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. EDCM is hosted by the National Children's Bureau, Charity registration number: 258825.

**The Children's Trust, Tadworth** is a national charity providing specialist services to disabled children and young people across the UK. These services include rehabilitation and support for children with acquired brain injury, expert nursing care for children with complex health needs, and residential education for pupils with profound and multiple learning difficulties at The School for Profound Education. Charity registration number: 288018. Find out more about the work of The Children's Trust, Tadworth at [www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)

  
**The Children's Trust  
Tadworth**  
For children with multiple disabilities