

Children & Lifelong Learning Scrutiny Panel	Agenda Item No. 4
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REPORT OF THE DIRECTOR OF CHILDREN'S SERVICES

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Report title:

INTEGRATED CHILDREN WITH DISABILITIES SERVICE AND AIMING HIGH FOR DISABLED CHILDREN

1. PURPOSE

To consider and comment on a report on the Integrated Children with Disabilities project, including the government's Aiming High programme for disabled children.

2. RECOMMENDATIONS

To consider and comment on the proposals to deliver this programme.

LINKS TO CORPORATE PLAN, SUSTAINABLE COMMUNITY STRATEGY AND LOCAL AREA AGREEMENT

The development of the integrated service for children with disabilities directly links with national indicator NI 54 within the local area agreement: services for disabled children, measured by an annual survey as an assessment of parents of disabled children's general experience of services.

The provision of an integrated children with disabilities service, the improvement of services and the improvement of health of children with disabilities is central to a number of strategic priorities including Public Service Agreement 12 (health and wellbeing), NI 54 (services for disabled children), NHS England: Operating Framework 2008/09, Aiming High for Disabled Children: Better Support for Families (2007), Children's Plan: Building Brighter Futures 2007, National Service Framework for Children and Maternity Services: Disabled children and young people and those with complex health needs (Standard 8) 2004, Our Health, Our Care, Our Say 2006 and Healthy Lives, Brighter Futures, the strategy for children and young people's health 2009.

3. BACKGROUND: DEVELOPING AN INTEGRATED SERVICE FOR CHILDREN WITH DISABILITIES

Context:

- 3.1 The Disability Discrimination Act defines disability as "a physical or mental impairment which has a substantial long-term adverse effect on his or her ability to carry out normal day to day activities". This definition is generally recognised as the most appropriate for services to adopt. However, it is necessary nevertheless for services to define eligibility criteria and pathways to access services, so that disabled children and young people, parents and carers have a clear

understanding of what services are available and how to access readily those services which meet their assessed need.

3.2 Integrating services for disabled children provided by health, and the different divisions within children's services (Learning and Skills, Social Care, Family and Communities) is part of the 'Every Child Matters' agenda to ensure that children and families receive a co-ordinated assessment of need and appropriate services to meet those needs. Avoiding duplication of assessment and providing clear pathways for children and families to access universal, targeted and specialist services are key elements of integrated service delivery. For disabled children, this means ensuring that they and their carers are provided with support to remain at home; to be able to access universal services such as community leisure facilities and extended schools; that there are targeted services specifically designed to meet moderate levels of need and that there are highly specialist and well coordinated services to meet complex needs of children with profound disabilities.

3.3 The aim of the project is therefore to develop and implement an integrated service for children with disabilities across health, social care and education services by May 2009 and comprises the following key elements: -

- To integrate processes, policies and procedures
- To introduce a single assessment and referral process
- To provide improved service pathways
- To increase the amount of preventative services
- To create an accurate database of all children with a disability
- To develop joint planning processes
- To develop short break provision taking into account the Department for Children Schools and Families and Department of Health Aiming High implementation guidance
- To provide quality information to children and young people, parents and carers on all of the services available to them
- To ensure that children with disabilities are high on both operational and strategic agendas across children's services and organisations
- To increase the engagement and involvement of children and young people, their parents and carers

3.4 However, the project originating in early 2007, following a recommendation in the Joint Area Review, has been subject to considerable delay due to difficulties in retaining dedicated project management which the complex change programme requires. Peterborough City Council and the Primary Care Trust jointly appointed a project manager in March 2007 to move forward the integration of services for children with disabilities. However, the post holder subsequently left at the beginning of May 07. A second project manager took up post in October 2007 and left in April 2008 for promotion in another authority. A third project manager took up the role in May 2008, seconded for one year from a primary care trust within another area. However, sadly she became unexpectedly ill in December 2008 and is unable to return to work within the period of secondment. Alternative arrangements are therefore being urgently sought. These changes in personnel have led to fragmented development of the service and although some progress has been made towards integration, there has been inevitable delay.

Disabled children: data

3.5 There is no single data source to reliably identify the number of disabled children in Peterborough. Data is collated from health, early years, and special educational needs data sources. It is estimated therefore that there are just over 1,800 disabled children and young people in Peterborough as follows: -

Age band	Number
0-5	605
5-16	1,017
Post-16	229
Total	1,851

Total 0-19 population	40,386
% with disability	4.6%

- 3.6 However, eligibility for the Aiming High Short Breaks programme described later in this report, is targeted at those children and young people who are in receipt of higher level disability living allowance (DDA) and/or mobility allowance. Nationally this would equate to 1.2% of the 0-19 population; information from the Department for Work and Pensions (DWP) states that 764 children and young people are in receipt of DDA in Peterborough and therefore this equates to 1.9% of the 0-19 population.

4. THE PROJECT

- 4.1 On 17th September 2008, the Children's Trust Partnership Board mandated the development of the children with disabilities integration project in its current form. It was agreed that the project would be delivered through a shadow management board jointly chaired by Brenda Town, Assistant Director Community Health Services and Maureen Phillips, Assistant Director Family and Communities, and supported by the dedicated project manager. The model which was agreed was for there to be two phases towards a fully integrated service for children with disabilities, the first phase being: -

- To agree a continuum of service delivery
- To set up shadow integrated management arrangements
- To pilot pooled budgets
- To identify the minimum key deliverables that need to be developed to underpin integration

- 4.2 Within the project, there are 18 key deliverables, listed at **appendix 1** (including certain aspects of Aiming High known at the time) which were being actively progressed up to end December 08 when the project manager unfortunately departed on long term sick leave. The model identifies the need for a shadow integrated children with disabilities management board that would include health, education and social care. This board provides governance, setting strategic direction, performance management and accountability for an integrated service across health, education and social care, effectively jointly managing the services and paving the way for formal integration arrangements by May 2009. The shadow management board and its responsibilities are represented diagrammatically at **appendix 2**.

- 4.3 The integrated management board is also responsible for engaging wider stakeholders in development of the service. It therefore has an extended membership which includes co-opted members, the voluntary sector and parent representation with the extended board meeting at key milestones within the project.

- 4.4 Although all key deliverables were on target up to 31st December, there is currently risk to the project if alternative project management arrangements cannot be secured. To date, the following actions have been completed on target: -

- Agreement to common vision, values and principles;

- Establishment of the integrated management board which meets monthly;
- Review of residential respite provision;
- Development of the Aiming High parents' forum;

The following deliverables which are crucial to integration are work in progress and partially completed:-

- Developing thresholds, triggers and pathways and eligibility criteria;
- Identifying all budgets and parts of budgets for children with disabilities

The complexity of budgets for disabled children within health has also resulted in substantial delay in moving forward with pooled budgets and developing further integration plans. However, the project aims remain undiminished and every effort is being made to bring it back on track with the urgent appointment of an interim project manager who will be replaced by the permanent appointment of a service manager for the new service within 6 months.

5. AIMING HIGH FOR DISABLED CHILDREN

5.1 'Aiming High for Disabled Children' published by the Department for Children Schools and Families (DCSF) and the Department of Health (DH) in July 2008 comprises a range of measures to transform services for disabled children and their families and expects PCTs and local authorities to jointly prepare for, plan and build capacity to deliver this transformation programme. PCTs and local authorities are expected to offer a significantly greater volume of short break provision set against a 2007-08 baseline, reflecting the additional funding levels available from the government to both organisations. Local authorities will have substantial additional ring-fenced funding allocated in April 2009 and 2010. There is an expectation that the PCT funding will be matched funding, focusing on commitments to palliative care, short breaks, community equipment and wheelchair services¹. However, growth funding within the PCT baseline allocations has not been specifically ring-fenced and to date, the NHS Peterborough contribution has not been identified.

5.2 The local authority ring-fenced element is set out in the table below. The tapered funding, increasing in year 2 recognises the extent to which the commissioning and delivery arrangements will develop in detail during 2009/10 with a view to full implementation in 2010/11.

DCSF Short Break Funding for Peterborough City Council 2009-2011

	Revenue	Capital	Total
2009/10	£186,800	£ 92,300	£279,100
2010/11	£602,500	£215,300	£817,800
Total	£789,300	£307,600	£1, 096,900

5.3 The government has set out clear expectations in the form of '9 readiness criteria' for local area preparations during 2008-09. Underpinning these 9 criteria are 46 progress

¹ **Healthy Lives, Brighter Futures.** *The strategy for children and young people's health. A commitment from The Children's Plan. DCSF and DH February 2009 (Chapter 6 Services for children with acute or additional health needs)*

indicators that both the Local Authority and PCT must meet by March 2009. Officers within the Commissioning and Performance and Family and Communities Divisions are therefore working together to ensure that the city council is ready to receive the grant, despite the significant loss of capacity at a crucial point in the preparations. The readiness criteria are as follows: -

- A strategic vision for delivering short breaks services
- Clear proposals for increasing short breaks services
- Robust data on need
- Input of parents and carers
- Dedicated service management
- Management capacity for Aiming High implementation beyond April 2009
- Identification of capital projects
- Commissioning arrangements
- A workforce strategy to develop the workforce

The proposals

5.4 There are three key elements to the proposals to deliver Aiming High, all of which are based on key information from consultation with parents and which will be presented to those parents attending the Parents' Forums during March 09 for further debate. These are: -

- Better information to assist families in accessing universal services, including better support to enable parents to participate in decisions about developing services;
- A targeted short breaks 'offer' for children and young people attending special school and those claiming higher rate and/or mobility DLA;
- Improvements in overnight short break services and care support within the home, including use of direct payments.

Associated with these recommendations is the review of current residential respite care provision in Peterborough and considerations of re-commissioning some services to provide greater choice and flexibility and better value for money. This includes the proposals within the medium term financial plan (MTFP) to investigate the possibility of developing a highly specialist service linked to the excellent special school provision within Peterborough, to reduce the need for out of city placements.

5.5 Important considerations in developing the commissioning strategy are therefore as follows: -

- Providing a balance between support to access universal services and providing more targeted and specialist services;
- Extending the range of short breaks available to provide choice and to have access to regular local services in addition to overnight breaks;
- Developing the market for short break provision to include independent sector providers;
- Securing a sufficient and well trained workforce including the development of short break carers and staff to carry out their recruitment, training and support;
- Developing a 'core offer' and a 'full service offer'.

- 5.6 The core offer involves publishing eligibility criteria and being transparent about how decisions are made to allocate services according to need; this is essentially the work that is being undertaken in the integrated children with disabilities project. The full service offer involves expanding existing short break provision using Aiming High funding, and the guidance associated with allocation of the grant makes it quite clear that both capital and revenue grants must be spent on developing a broader range of services with the aim of 'securing short breaks for severely disabled children'.
- 5.7 The focus of the commissioning strategy is therefore to build on existing services to expand on what is on offer, providing greater flexibility and choice and to bridge gaps in existing services identified by parents and carers. Whilst there is sufficient information available to identify investment priorities for 2009/10, further consultation will be required to support the detail and the higher level of investment in 2010/11. The strategy will therefore be refined over the coming months, but will comprise the following elements for which investment will commence from 1st April 2009: -
- i Increasing information, advice and guidance to parents
 - ii Supporting access to universal provision through: -
 - a. Additional care support to access mainstream facilities;
 - b. Developing extended services and holiday schemes to increase access to disabled children;
 - c. Grants to voluntary sector providers to improve access for disabled children;
 - iii Improving transport access to overnight short breaks and universal leisure activities/extended services;
 - iv Increasing direct payments and providing appropriate support to parents to use the scheme;
 - v Increased domiciliary care services;
 - vi Improving the availability of aids and equipment to support short breaks;
 - vii Increasing occupational therapy capacity to provide appropriate assessment for short break provision;
 - viii Reviewing the capacity of the short breaks fostering service following the residential respite review;
 - ix Prioritising allocation of capital to enable disabled children to access mainstream play, leisure and sports facilities.
- 5.8 It is recognised that management capacity is required to deliver this extensive programme. A grant of £40,000 was provided in 08/09 to support preparation, although this falls considerably short of the additional capacity needed. A full time post, principally providing commissioning capacity and funded from the grant will therefore be required to deliver this programme, in addition to the management capacity identified for the delivery of the integrated service.

6. IMPLICATIONS

Aiming High is a key government initiative, the implementation of which is being monitored by central government. It is crucial that the city council delivers this programme to improve services to disabled children and their families. Identification of the PCT element of the funding and a lead commissioner within the PCT to take this forward with the city council are also crucial to delivery of the LAA against NI 54.

7. CONSULTATION

Consultation with parents and carers took place in January 09 with regard to transition and the residential respite review. The proposals also draw on consultation which took place with parents, children and young people in the 'visioning day' which took place in February 2008. Further consultation with parents will take place on 12th and 20th March in parents' forum meetings organised by the Peterborough Voluntary Sector Forum. A stakeholder event of service providers is similarly organised for March 09 to confirm the commissioning strategy and arrangements for further engagement of service providers in developing services to add capacity to those already provided.

8. EXPECTED OUTCOMES

That panel will review and comment on the proposals set out within this paper prior to the lead member's endorsement of the Aiming High strategy.

9. NEXT STEPS

Following the lead member's agreement, the Aiming High strategy will be submitted to Government Office on 31st March to satisfy the 'readiness criteria' requirements.

BACKGROUND DOCUMENTS

Aiming High for Disabled Children: Short Breaks Implementation Guide. DCSF and DH July 2008

Healthy Lives, Brighter Futures. The strategy for children and young people's health. A commitment from The Children's Plan. DCSF and DH February 2009 (Chapter 6 Services for children with acute or additional health needs)

APPENDIX 1:

KEY DELIVERABLES

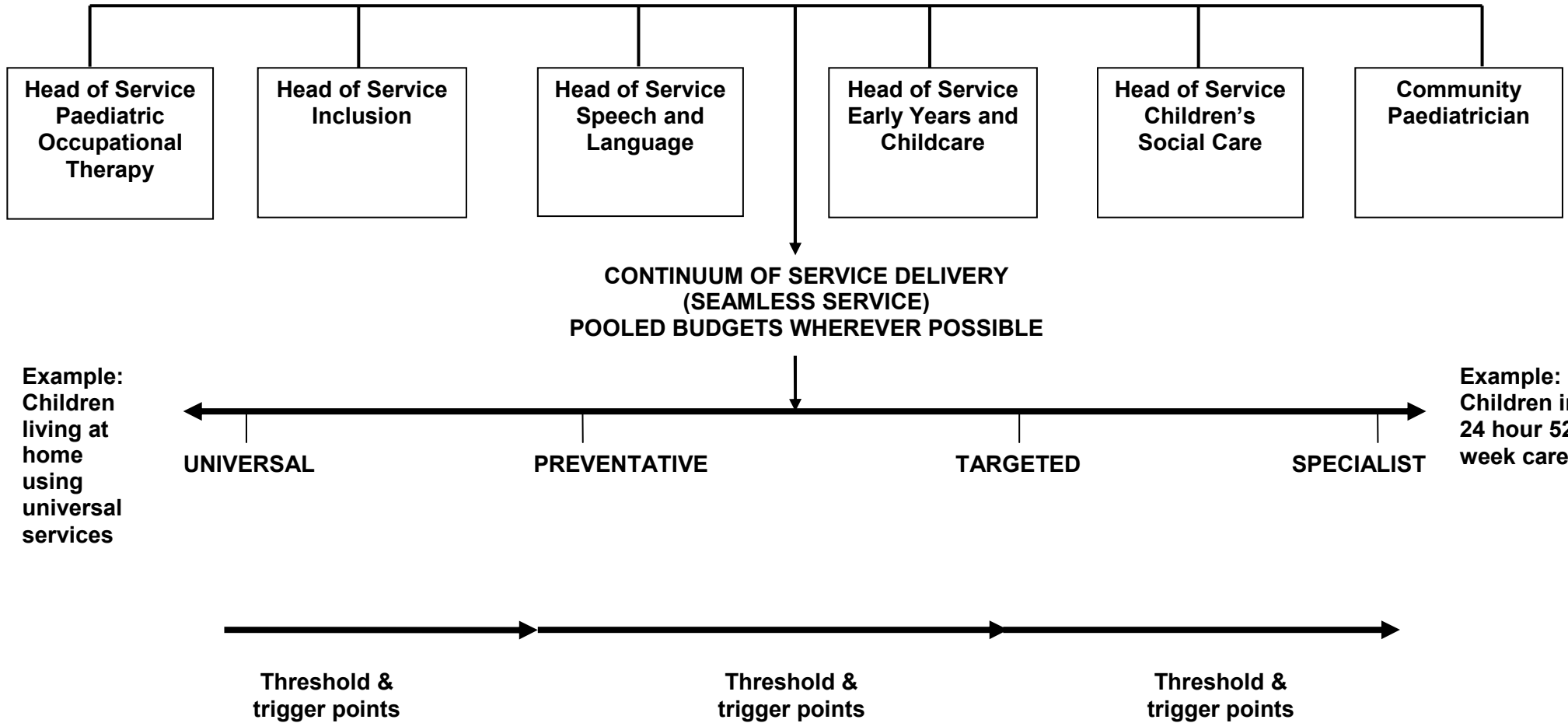
The key 18 deliverables for the children with disabilities integration project are:

- Arrangements for an integrated management board and governance
- Developing integrated performance and information management
- An agreed and consistent full definition of disability
- Agreed threshold/trigger points, pathways and eligibility criteria
- Identifying all budgets (and parts of budgets) associated with children with disabilities across health, (PCT, Acute and CAMH) education and social care with a view to developing pooled budgets and integrating relevant services
- Integrated financial and business planning processes across the PCT and City Council
- Joint commissioning arrangements
- Single/integrated assessment processes
- Commonly agreed care plans used by all relevant agencies
- Shared database or compatible/accessible database which share information
- Development of Aiming High short breaks implementation plan
- Commissioning of Aiming High Short breaks
- Improving support to transition
- Engagement of children, young people and their families
- Workforce development
- Communication and marketing plan
- Developing an integrated equipment service supported by pooled budgets
- Service re-design

CHILDREN WITH DISABILITIES INTEGRATED SHADOW MANAGEMENT BOARD

Joint Chair

Assistant Director Family and Communities and Assistant Director Children's Community Health Services



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