

# **Aiming high for disabled children: better support for families**

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May 2007



**HM TREASURY**

department for  
**education and skills**





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# Aiming high for disabled children: better support for families

May 2007

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# FOREWORD BY THE ECONOMIC SECRETARY TO THE TREASURY AND THE PARLIAMENTARY UNDER- SECRETARY OF STATE FOR SCHOOLS

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We are really pleased to be publishing this report, which marks the culmination of our Disabled Children Review. The Government believes that every child matters, and this Review will take us closer to achieving our aim of ensuring that every disabled child can have the best possible start in life, and the support they and their families need to make equality of opportunity a reality, allowing each and every child to fulfil their potential.

We believe that we have reached a set of actions and proposals that will make a real difference to all disabled children and their families, and create a local and national focus on promoting the life chances of disabled children and their families. We could not have reached this point without the guidance, expertise and commitment shown by the parents and children who shared their experiences with us and gave us their frank views; the professionals and charities who supported us in developing this report; and the MPs and peers who took part in the parliamentary hearings and generously offered their time and expertise.

Our task now is to turn this report into reality and build on this progress over the next Comprehensive Spending Review and beyond. Our long-term goal is to transform the life chances of disabled children. That will take time, but today's report is a significant step along the way.



Ed Balls, MP  
Economic Secretary  
to HM Treasury



Lord Andrew Adonis  
Parliamentary Under-Secretary of State  
for Schools



# EXECUTIVE SUMMARY

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The Government wants all children to have the best start in life and the ongoing support that they and their families need to fulfil their potential. Disabled children are less likely to achieve as much in a range of areas as their non-disabled peers. Improving their outcomes, allowing them to benefit from equality of opportunity, and increasing their involvement and inclusion in society will help them to achieve more as individuals. It will also reduce social inequality, and allow communities to benefit from the contribution that disabled children and their families can make, harnessing their talent and fostering tolerance and understanding of diversity.

The Government has done much to improve outcomes for disabled children and their families. They should be benefiting more than others from the Government's *Every Child Matters* programme coordinated package of support, given that they often need access to a wide range of services. However, the Government recognises the need to do more. Building on progress to date, and underpinned by £340 million of investment over the CSR period, the Government will take action in three priority areas to improve outcomes for disabled children:

- access and empowerment;
- responsive services and timely support; and
- improving quality and capacity.

## Access and empowerment

Engagement of disabled children and young people in shaping services at a local level results in the provision of more appropriate services, and can help services work more efficiently and effectively, allowing for more flexible and tailored provision. Increased transparency about entitlements and services available, and increased information at a local level, should lead to greater equity in access to provision, and make it easier to benchmark local performance.

To empower disabled children, young people and their parents, the Government will set a clear standard or core offer, and give disabled children and their parents the option to be fully involved in local service development and in designing their packages of care.

**Empowering disabled children, young people and their families.**

- a “core offer“ will encompass minimum standards on information, transparency, participation, assessment and feedback, to make it clear what entitlements and services disabled children, young people and their families can expect. Through providing greater transparency, it will be easier to benchmark provision across the country;
- piloting Individual Budgets will give families and disabled young people real choice and control to design flexible packages of services which respond to their needs; and
- spreading good practice on engagement such as parents’ forums across the country, underpinned by £5 million of investment over the CSR period, will give parents of disabled children a voice in local empowerment mechanisms, foster better relationships between service providers and parents, and allow parents to contribute their expertise to help shape services.

**Responsive services and timely support**

Disabled children and their families should be able to benefit from services which are easily accessible at key transition points in their life, designed around the child and family, and delivered in a coordinated and timely manner. Where this is the case, disabled children, young people and their families will be supported to play a full role in the society of which they are part, and will benefit from equality of opportunity compared to their peers.

To ensure that all disabled children and their families can benefit from responsive, flexible services as soon as they need them, and are included in universal services, the Government will make disabled children a priority at both a local and national level, improve benchmarking of early intervention practices and set up a Transition Support Programme at the critical transition to adulthood.

**Promoting more responsive services and timely support**

- the Government believes that disabled children should be considered both a local and national priority. To ensure that commissioners and providers have sufficient incentives to focus on the needs of disabled children, Government will develop a national disabled children indicator as part of the new set of priority PSAs to be agreed across Government at the Comprehensive Spending Review;
- to prevent interventions coming too late at important stages of a disabled child's life or development, the Government will provide specific resource for evaluation and benchmarking good practice on early intervention for disabled children and their families as part of the work of the new Centre for Excellence for Children and Family Services;
- to develop a clearer picture of the disabled children population at a local level so that disabled children's needs are planned for, Local Authorities and PCTs will improve their data collection for this group, and national and local agencies will work together to develop more coordinated data sets;
- the Government will continue to roll out the Early Support Programme to cover all disabled children aged 0-5 to promote wraparound, timely provision for young disabled children and their families; and
- disabled young people may face more challenges than most in the critical transition to adulthood. The Government will provide £19 million over the CSR period for a Transition Support Programme to help disabled young people and their families benefit from intensive, coordinated support and person centred planning.

**Improving quality and capacity**

Certain services were highlighted throughout the Review as particularly vital to improving outcomes for disabled children, young people and their families. To respond to these needs, Government will make provision over the CSR to boost provision of these services for disabled children.

### **Boosting provision of vital public services**

- a specific grant of £280m over the CSR period to deliver a step change in the provision of short breaks for disabled children. Government will also go further and provide additional funding through the NHS settlement to provide short breaks for disabled children with complex healthcare needs;
- accessible childcare is vital to help parents work, and to improve children's development. The Government will set up a childcare accessibility project, underpinned by £35m over the CSR through the General Sure Start Grant;
- to maximise mobility, help children access schools, leisure and other services, and promote independent living, the Government will deliver a radical reform of community equipment and wheelchair provision, with full consideration and provision for the needs of children, through the DH community equipment and wheelchair review. Subject to the outcomes of the CSR, the NHS will provide additional resource for 2010-11 to increase the stock of wheelchairs and improve provision of community equipment for disabled children; and
- to make universal services more accessible for disabled children, such as positive activities for young people, the Government will commission the Children's Workforce Development Council to research the skills and behaviours required by the workforce and to identify gaps.

### **Responding to stakeholders**

The Review has sought to engage closely with professionals, parents, the voluntary sector, disabled children and young people. Consultation included responses to the Children and Young People Review Call for evidence last summer, joint HM Treasury and Department for Education and Skills seminars in July and October 2006, engagement with the disabled children pathfinder Children's Trusts, and visits to Local Authorities, Primary Care Trusts and voluntary sector organisations. A series of Parliamentary Hearings held in July 2006 have also supported the Review, with 3 hearings and hundreds of written submissions. The Government would like to thank all of those who contributed and shared their expertise and experiences.

# INTRODUCTION

## THE DISABLED CHILDREN REVIEW

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**1.1** The Government's aim is to ensure that every child, irrespective of race, gender, background or circumstances gets the best start in life and the ongoing support that they and their families need to allow them to fulfil their potential. This Review has looked at what more can be done to improve the outcomes of disabled children and young people (0-19) and their families, examining the role that public services can play to make this aim a reality.

**1.2** In line with the Government's report, *Improving the life chances of disabled people*,<sup>1</sup> the Review has worked towards the best ways of creating equality for all disabled children. Improving their educational, social and emotional development, and their opportunities for independent living, choice and control, is a key part of this process. Government wants to ensure that disabled children and their families are enabled and empowered to make a full contribution to the society of which they are a part.

**1.3** Disabled children and their families face a unique and often challenging set of circumstances that demand a unique and sometimes specialised response from both the universal and targeted services that support them. It is essential that they are able to influence the design and delivery of services which should be responsive to their needs.

**1.4** To foster a responsive level of appropriate support for disabled children and their families, the Review has looked at the most effective means of providing disabled children and their families with greater transparency about their entitlements, both locally and nationally. The Review has also considered how evidence on effective practice and support for disabled children can be better evaluated and disseminated.

**1.5** Underpinning better support and improved provision of specific services for disabled children and families is the need for:

- clear entitlements that are well understood, with minimum standards as part of a "core offer", which allow for local flexibility and innovation, but will ensure disabled children are not disadvantaged by how well local areas are accommodating both national standards and local priorities;
- disabled children, young people and their families to feel empowered and supported in the choices they make;
- coordinated planning and commissioning to ensure best use of finite resources across traditional health, social services and education boundaries; and
- focused, effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their siblings, to help to improve outcomes for all.

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<sup>1</sup> *Improving the life chances of disabled people*, Prime Ministers Strategy Unit, 2005

**Box 1.1: The Review of Children and Young People<sup>2</sup>**

In July 2005, the Government announced that a second Comprehensive Spending Review (CSR) would be undertaken, reporting in 2007. It will set the departmental spending plans and priorities for the years 2008-09, 2009-10 and 2010-11. Budget 2006 announced that the 2007 CSR would be informed by a series of policy reviews, one of which was a review of children and young people, building on the Government's strategy to improve their outcomes.

A discussion paper, setting out the evidence and analysis that has been gathered to inform the Review of Children and Young People was published in January 2007. It also provided a discussion of the issues and challenges raised by that evidence. The Review has drawn on a number of sources of evidence, including:

- research studies and evaluations of interventions to support children, young people and families;
- consultation with groups of young people, particularly those who have difficulty accessing services;
- consultation events with parents, practitioners, commissioners of services from public agencies or the third sector, academics and others with relevant expertise;
- smaller workshops, meetings and visits to experts or projects in relevant fields;
- a public Call for Evidence to support the Review's analysis – the Review's discussion paper provides details of those organisations and individuals that responded; and
- some new research commissioned to support the Review, which is also set out in more detail in the Review's discussion paper.

The Review of children and young people consists of four strands, including this strand on disabled children.

## ENGAGING CHILDREN, FAMILIES AND THEIR SUPPORTERS

**1.6** The Review has taken evidence that engaging disabled children and their families in the shaping of services, and in designing packages of care helps deliver improved outcomes that meet families needs. Therefore the Review has sought to engage closely with disabled children and young people, parents and their supporters, including professionals and the voluntary sector. The Review has consulted through responses to the Children and Young People Review Call for evidence last summer, joint HM Treasury and Department for Education and Skills seminars in July and October 2006, engagement with the disabled children pathfinder Children's Trusts, and visits to Local Authorities, Primary Care Trusts and voluntary sector organisations. A series of Parliamentary Hearings held in July 2006 have also supported the Review, with three hearings and hundreds of written submissions (see box 1.2 below). The Review would like to thank all of those who contributed and shared their expertise and experiences.

<sup>2</sup> *Policy review of children and young people – A discussion paper*, HM Treasury and Department for Education and Skills, January 2007. *Aiming high for children: supporting families*, HM Treasury, Department for Education and Skills, March 2007.

**Box 1.2 Parliamentary Hearings and report**

A series of Parliamentary Hearings, supported by a consortium of charities working with disabled children and their families, were held to seek the views of disabled children, parents and professionals. The hearings followed the life cycle of a disabled child, covering the early years, family support and transition to adulthood.

MPs heard frank accounts from disabled young people, parents and professionals on areas of good practice, but also further challenges to the Government to improve services for disabled children and their families. Parliamentarians also contributed their constituency experiences. Hundreds of disabled children and young people, parents, professionals and organisations submitted written evidence, all of which informed the Parliamentary Hearings Report, published in October 2006.

Priority recommendations from the report included:

- significant additional resources targeted at disabled children and their families to be made available to planners and commissioners of universal and specialist services;
- additional funding linked to the development of minimum standards, or a 'core offer' for disabled children and families which would create a universal entitlement to a minimum level of service; and
- ministers should ensure that services for disabled children are part of every Local Area Agreement, and national Public Service Agreement targets should be developed for disabled children.

A link to the Parliamentary Hearings Report can be found on the Every Disabled Child Matters website, [www.edcm.org.uk](http://www.edcm.org.uk)

**1.7** These submissions and recommendations were helpful in informing the conclusions of the Review. This report sets out the Government's response.

## **Fulfilling the potential of every disabled child**

**1.8** Since 1997, Government has placed children at the centre of efforts to create a fairer and more just society. The *Every Child Matters* agenda has transformed the Government's approach to children and families. Public services are now focussed on ensuring that children are healthy, stay safe, enjoy and achieve, make a positive contribution, and achieve economic wellbeing.

**1.9** To deliver these outcomes, the Government has put in place a package of reforms that promote better coordination of and integration of services for all children. Sure Start children's centres provide wrap around support for the youngest children, ensuring every child has the best start in life. Directors of Children's Services are now accountable for the well being of every child in their area. Local Strategic Partnerships are also bringing together different parts of the public, private, community and voluntary sectors at a local level: allowing different initiatives and services to support one another so they can work more effectively together to meet the needs of their local communities. The 570,000 disabled children in England, around 100,000 of whom have complex care needs, need support from a wide range of services, and so should be benefiting even more than most from these reforms.

**1.10** It has traditionally been the case that disabled children are likely to have poorer outcomes across a range of indicators compared to their non-disabled peers, including lower educational attainment, poorer access to health services and therefore poorer

health outcomes, more difficult transitions to adulthood, and poorer employment outcomes<sup>3</sup>. Families of disabled children are less likely to have one or both parents in work, and are more likely to suffer from family break up. Siblings of disabled children may also be more likely to suffer from emotional and behavioural problems, for example through sleep deprivation.

**1.11** A lack of appropriate and timely support for disabled children to allow them to fulfil their potential not only affects disabled children and their families, it also prevents communities benefiting from the contribution that disabled children can make. Their talent will be wasted, and society will lack the tolerance and understanding of diversity that inclusion and support for disabled children and their families brings.

## Progress to date

**1.12** There is a significant programme of work underway to improve outcomes for disabled children and their families, across all aspects of their lives. Government has instituted policy reform as part of the following strategies and frameworks:

- the Prime Minister's Strategy Unit report *Improving the life chances of disabled people*, set the Government the challenging goal of achieving substantial equality for disabled people by 2025. The report highlighted a number of changes that must be made in order to achieve this goal. In relation to disabled children and young people it focused on improved early support for families with young children and facilitating a smooth transition to adulthood. This Review builds on the work already underway to meet these recommendations;
- at school, children with Special Educational Needs (SEN) (including most disabled children) are benefiting from DfES' long-term strategy *Removing Barriers to Achievement*.<sup>4</sup> This includes action to improve SEN provision in mainstream schools and to encourage joint working between mainstream and special schools. Ofsted has found that pupils with even the most severe and complex needs are able to make outstanding progress in all types of settings;<sup>5</sup>
- the *National Service Framework for Children, Young People and Maternity Services* is benefiting disabled children and their families through setting standards for the first time in children's health and social care services health support. There are specific standards to address the requirements of children and young people who are disabled and/or have complex health needs and their families (standard 8), and to address the needs of children and young people who are ill (standard 6);
- the recent independent report on palliative care needs *Palliative Care Services for Children and Young People in England* which has highlighted the needs of children with life-limiting or life-threatening conditions. Most children with palliative care needs are disabled, and some children with a disability have palliative care needs. Improvements arising from this Review will benefit children with palliative care needs as they will benefit all other

<sup>3</sup> Policy review of children and young people – A discussion paper, HM Treasury and Department for Education and Skills, January 2007.

<sup>4</sup> *Removing barriers to achievement: The government's strategy for SEN*, Department for Education and Skills, Feb 2004.

<sup>5</sup> *Inclusion; does it matter where pupils are taught?* Ofsted, 2006.

disabled children. The Government is currently considering the recommendations from the palliative care review; and

- strengthened local arrangements to safeguard children, including the establishment of Local Safeguarding Children Boards (LSCB) in 2006. LSCBs bring together a wide range of local partners across sectors, to consider how best to safeguard and promote the welfare of all children in the local area

**1.13** This work is supported and underpinned by legislative and policy actions taken by Government in recent years, including:

- the Children Act 1989, under which disabled children are defined as “Children in Need”. Under the Act, Local Authorities have a general duty to “safeguard and promote the welfare of children in their area who are in need... To promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children’s needs”;
- the Disability Equality Duty, introduced into legislation in 2005, which requires organisations across the public sector (including schools and hospitals, local and central government) to be proactive in ensuring that disabled people are treated fairly and are included in all aspects of policy development from the outset;
- the Childcare Act 2006 which requires Local Authorities to have particular regard to the needs of disabled children as part of their new duties to assess the childcare needs of families and to secure sufficient childcare to children up to and including age 14 (18 for disabled children); and
- a requirement on most public bodies to have a Disability Equality Scheme setting out how they will meet their responsibility to promote disability equality.

**1.14** Disabled children and their families are also benefiting from more flexible support. Many local areas are encouraging parents and young people to be engaged in the design and delivery of services, or using direct payment to develop a package of social care support which fits around their needs, such as provision of short breaks services in a home setting for those who want them.

**1.15** From birth to transition to adulthood, local areas are both establishing and developing new ways of encouraging coordinated provision designed around the child and family. This includes the Early Support Programme, which provides coordinated support for disabled children aged 0-5, and person centred planning at transition to adulthood.

## Remaining challenges

**1.16** The Review has found many examples of good practice, where services for disabled children are fully meeting their needs, and those of their family. For example, in some areas, coordinated working, innovative practice in service delivery, and the involvement of disabled children, young people and their parents is fostering services that are more responsive and flexible to disabled children and their families needs, and families have told the Review that these are making a real difference to their lives.

**1.17** However, as outlined in the interim discussion paper,<sup>6</sup> good practice is not uniform across the country. Challenges remain:

- existing data does not present a full picture of the quality of provision in different areas. However, there is evidence that across local authorities, disabled children and families are offered different levels and standards of care, and that those most in need are not always the most likely to get support. Parents and young people in some areas feel that they are not sufficiently empowered, informed, or involved;
- research for the Review also showed that much provision is targeted on high need, high cost interventions, with a lack of focus on intervening early in a child's life, at a key transition point, or change in their condition. Local areas rightly prioritise those in greatest need, however a lack of early support is sometimes exacerbating the numbers of disabled children and families who reach crisis point and need more complex interventions; and
- despite strong examples of successful coordination in the planning and provision of innovative services, for example through the Early Support Programme which is encouraging multi-agency working, there is more that needs to be done to tackle remaining coordination problems. This includes differing eligibility criteria, differing referral systems and cultures, and differing and inconsistent data about the disabled children population across agencies.

**1.18** This Review considers and sets out the further actions that will be taken to improve outcomes and equality of opportunity for disabled children and their families to address these issues. It aims to facilitate and better support improved outcomes for disabled children in the following areas:

- **empowerment** - offering parents and their disabled children choice and the power to take decisions about their own care and influence local priorities, to improve service quality and responsiveness;
- **responsiveness** - prioritising disabled children at a local and national level, with early interventions, coordinated and timely support, to bring up standards of provision across the country, make it easier for families to access holistic support, and prevent conditions deteriorating; and
- **service quality and capacity** - boosting provision of services which are vital for improving outcomes for disabled children and their families. The Review focuses mainly on specialist services such as short breaks, equipment and therapists, but also tackles barriers to accessing universal services such as childcare.

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<sup>6</sup> *Policy Review of children and young people – A discussion paper*, HM Treasury and Department for Education and Skills, January 2007.

## INTRODUCTION

**2.1** Developing an approach that is more focused on service users leads to good service management and design and contributes to high-quality service provision. Involvement of children and their parents in planning services results in the provision of more appropriate services.<sup>1</sup> Clarity over which services and support mechanisms are available, and consultation and involvement of service users to establish their views, preferences, and needs can help services work more efficiently and effectively, allowing for more flexible and tailored provision.

**2.2** Local Authorities engage and respond to the views of disabled children and their families to differing degrees, and many young people and their families feel they are not sufficiently empowered. Survey data shows that disabled children and their parents are being involved in a range of decisions concerning their own care and in social service development. However, it also shows that participation varies considerably across areas with not all Local Authorities inviting participation.<sup>2,3</sup> Disabled children and young people are also often excluded from wider consultations around local policy and planning within their neighbourhoods and communities.

### Box 2.1: Empowerment

The concept of empowerment is intimately linked to the principle of **rights and responsibilities** for individuals. In this context, empowerment means:

- a *right* for citizens to ‘opt-in’ to networks of support to help influence and shape the services on offer. This creates a duty for service commissioners and providers to reach out to vulnerable groups and empower them in making their views known and heard; and
- recognition that with rights come *responsibilities* for citizens: to engage constructively with service providers in shaping service provision where possible, and understand competing priorities and local constraints.

**2.3** Despite the principles of Every Child Matters, parents of disabled children feel there is a lack of information, too much duplication of assessments and services, and that access is difficult.<sup>4</sup> Empowerment requires information: information for Local Authorities about their populations, and information for service users about the services available to them, and opportunities for consultation.

**2.4** Empowering disabled young people and their families means:

- **improved provision of information and greater transparency in decision making.** Allowing more informed decisions, greater understanding of entitlements, and the process for accessing services;

<sup>1</sup> *National Service Framework for Children, Young People and Maternity Services*, Department of Health.

<sup>2</sup> *Participation of Disabled Children and Young People in decision-making within Social Service Departments in England*, Franklin and Sloper, Social Policy Research Unit, York

<sup>3</sup> *Consulting with disabled children and young people*, Joseph Rowntree Foundation, 2001

<sup>4</sup> *Children's Services CSCI findings 2004-2007*, Commission for Social Care Inspection, March 2007.

- **putting families in control of the design and delivery of their care package and services.** Disabled young people and their parents are often experts on their impairment, and when packages of care are designed in partnership and aim to promote choice and control, they are more likely to be appropriate to their needs, and less likely to leave gaps in provision or to waste resources through inappropriate provision; and
- **supporting disabled children and young people and their parents to shape services.** This can also mean them playing a part in local mechanisms to facilitate citizen pressure to hold front-line services to account, linked to the new Local Government White Paper “*Community Call for Action*”.<sup>5</sup>

## INFORMATION AND TRANSPARENCY

**2.5** Increased transparency about individual entitlements, and increased availability of information at a local level should lead to greater equity in access to provision between families in the same area, through a clearer understanding of their entitlements and how they can access services. There is evidence that different areas make different levels of care available and that those most in need are not always most likely to get support.<sup>6</sup> At a national level, increased transparency about eligibility criteria and levels of provision will give Government and parents a better picture of the levels of variation in provision across local areas. More easily comparable data will make it easier to benchmark local performance and consider what action needs to be taken to improve services. Within health services, the notion of entitlement to a particular service or intervention is less meaningful. Health services are determined by the individual health needs of the child or young person. However, these services still need clear standards about the process for assessing needs and its timeliness.

**2.6** Empowering disabled children and their families through increased transparency and provision of information will reduce frustration at the uncertainty over the level and timing of support that will be provided, helping families plan and adapt to the level of support they can expect to receive. Directly involving disabled people in designing information can also improve the quality of information and satisfaction with services.<sup>7</sup>

### Further action

#### Core offer for children

**2.7** The Aiming High for Children report<sup>8</sup> proposed a “Parents’ Charter”, setting out the minimum level of support parents should expect from local children’s services. Given the importance of social care and health services for families with disabled children, the Government will establish a “core offer” for disabled children and their families. This core offer will help parents and young people better understand their entitlements within local areas, increase transparency about variation in provision across areas, and underpin and support standards such as the National Service Framework Standard 8 for disabled children.<sup>9</sup>

<sup>5</sup> *Strong and Prosperous Communities, the Local Government White Paper*, Department for Communities and Local Government, 2006

<sup>6</sup> *Services for disabled children*, National Audit Office Report, 2003.

<sup>7</sup> *Five principles for producing better information for disabled people*, Office for Disability Issues, February 2007.

<sup>8</sup> *Aiming high for children: Supporting families* HM Treasury and Department for Education and Skills, March 2007

<sup>9</sup> *National Service Framework for children, young people and maternity services, standard 8*, Department of Health, 2004.

**2.8** The core offer for disabled children will encompass the following elements:

- **Information:** disabled children and their families able to access appropriate information at every stage of a child's life;
- **Transparency:** levels of support for disabled children and their parents determined on a fair, understandable and transparent basis, with social care services eligibility criteria defined according to need and published by local authorities; clear information published and made available by Primary Care Trusts to families about how to access health care and support available for children with disabilities and complex health needs in the local area;
- **Participation:** disabled children and their families have the option to be fully involved in the way services are planned, commissioned and delivered in their area, increasing their choice and control, which may include access to a supported parents' forum. This participation will help to make sure that the *Community Call for Action* will deliver for all citizens, linked to the new duty on best value authorities to inform, consult and involve representatives of local people in their activities;
- **Assessment:** disabled children and their families to benefit from integration of assessment processes, with shared information, shared basic assessments including through the Common Assessment Framework, providing a gateway to more specialist assessments where necessary, and more high-level multi-agency assessments provided in the same place at the same time. As children and young people develop there will be a need for ongoing and differential assessment, but this should be provided in a coherent, coordinated way. Parents and young people will be told at assessment when they will get a response setting out what support they will be provided with; and
- **Feedback:** a clear and published complaints procedure for all families who are not happy with the services they are receiving (including through the *Community Call for Action* as set out in the Local Government White Paper).

**2.9** Delivery against this commitment will be measured through the revised Local Government performance framework to be determined at the time of the Comprehensive Spending Review, and reinforced through Comprehensive Area Assessments, which will take an area based view on delivery of local priorities. Information on the offer should be distributed through local services, such as council offices, libraries and local voluntary sector groups, the Early Support Programme and the Transition Support Programme at a local level.

**2.10** This core offer will take the form of a policy statement which will be developed by the Department for Education and Skills and Department of Health, with support from key stakeholders, and underpinned by guidance for each of the above elements in time for the Comprehensive Spending Review this Autumn. It is expected that Local Authorities and their partners consider the core offer policy statement in their local planning and provision of services, and ensure that it is published and accessible to the local community.

## PUTTING FAMILIES IN CONTROL OF CARE PACKAGES

### Direct payments

**2.11** Direct payments are cash payments made in lieu of social service provision to individuals who have been assessed as needing services. They can be made to disabled people aged 16 or over, to people with parental responsibility for disabled children, and to carers aged 16 or over in respect of carer services. Since the Health and Social Care Act 2001, families assessed as eligible for social care services, including families with disabled children, must be offered the option of direct payments.

**2.12** Direct payments create more flexibility and choice in the provision of social services, and allow people to make their own decisions about how care is delivered. If packages of care are designed by users, they are more likely to be responsive and appropriate, with resources less likely to be wasted on inappropriate provision. Some parents described direct payments as having positively “transformed their lives”, however other service users in the review’s consultation felt that the additional responsibility of managing a budget for services was too much of a burden, particularly given their existing care responsibilities. One survey of direct payments found that parents appreciated the flexibility, freedom, choice and control that direct payments offered, but found that managing the payments could be time consuming, and that there could be difficulties in finding suitable people to employ.<sup>10</sup> Parents in the survey also felt that they could make sure that their child was happy with their carers if they chose them themselves with direct payments. Young people have also benefited from receiving direct payments, choosing who provides them with assistance and what activities they engage in.<sup>11</sup>

### Current situation

**2.13** Figures from the Commission for Social Care Inspection (CSCI) show that in 2005 there were over 2,700 families with disabled children and over 300 disabled young people aged 16-17 receiving direct payments, indicating low levels of take up. To promote further take-up of direct payments for families with disabled children, information for Local Authorities and parents has been placed on the Every Child Matters website and an updated version of *A Parent’s Guide to Direct Payments*<sup>12</sup> was published in summer 2006.

**2.14** The Department of Health (DH) has developed a self-assessment tool for councils to review their direct payment systems in collaboration with partners. The focus is on identifying where local barriers exist to identify solutions to promote uptake of direct payments.

### Benefits of Individual Budgets

**2.15** Individual budgets build on some of the successful features of direct payments and apply the same principles of choice and control. There are, however, some key differences. Individual budgets include a number of income streams rather than simply social care services in order to give the individual a more joined-up package of support. Most importantly, individual budgets put people in the centre of the planning process, and recognise that they are best placed to understand their own needs and how to meet them.

<sup>10</sup> *The use of Direct Payments in Essex by families with disabled children*, Kay Poutney, Research Team, Essex Social Care, October 2003.

<sup>11</sup> *Direct Payments for Young Disabled People*, Joseph Rowntree Foundation Findings Ref 553, Abbot D, 2003, [www.jrf.org.uk/knowledge/findings/socialcare/553.asp](http://www.jrf.org.uk/knowledge/findings/socialcare/553.asp)

<sup>12</sup> *A Parent’s guide to direct payments*, *Every Child Matter*, Department for Education and Skills and Council for Disabled Children

**2.16** Unlike direct payments, individual budgets can be held and managed by a broker (to help service users manage the budget and reduce the associated responsibility for arranging their own care). By facilitating the provision of a holistic package of support designed around the child and family, individual budgets can also help encourage coordinated provision of services, and avoid duplication in provision.

**2.17** The *Improving life chances for disabled people*<sup>13</sup> report recommended that the individual budgets approach should, in principle, be extended to families with disabled children. It states, “*The mechanisms, costs and benefits will need to be investigated through pilots coordinated with those for adults. The design and timing of these pilots will also need to be carefully coordinated with the roll-out of wider changes to the landscape of children’s services*”.

**Current situation**

**2.18** The Council for Disabled Children was recently commissioned by the Department for Education and Skills (DfES) to produce a scoping report covering the following issues relating to Individual Budgets:

- the implications of introducing individual budgets for Local Authorities and other stakeholders;
- the relevant evidence collated from various stakeholders;
- possible models to be used in the introduction of individual budgets; and
- the views of disabled children, young people and their families.

**2.19** DfES is intending to carry out a scoping exercise taking account of the CDC report and the recommendations in this Review, with the aim of:

- looking at the financial level of these individual budgets and the different income streams that would need to come together;
- looking at what added value individual budgets bring to current practice; and
- demand for individual budgets and/or direct payments .

**2.20** The scoping exercise will then be evaluated in order to inform the development of the concept of individual budgets for disabled children and their families more widely. It is envisaged that work will initially concentrate on older children and the preparation required to facilitate their successful transition to adult individual budgets.

**2.21** One of the key elements of individual budgets is to bring together a variety of income streams in an integrated manner, to improve choice and control for the individual, and to facilitate coordinated provision of services. The majority of income streams being used by the individual budget pilot sites are only available to young people and adults over the age of 16. The largest potential source of income is the Social Care budget. Other budgets that could be included are the Integrated Community Equipment Services budget, and the Disabled Facilities Grant could be available for children under 16.

**2.22** A number of Local Authorities and health providers are already creatively using aligned budgets or pooled budgets to transfer money to the local authority to part fund a package of care where the individual has specific health needs. However, more

<sup>13</sup> *Improving life chances for disabled people*, Prime Minister’s Strategy Unit, January 2005.

specific guidance would help enable this to become national practice rather than limited to those authorities where good joint working partnerships are in operation.

### Further action

**2.23** To increase flexibility and choice in the provision of services, the Government will pilot Individual Budgets for disabled children and young people, building on the current scoping exercise, with full evaluation over the CSR period. This will involve as many funding streams as possible at a local level, and where there are legislative or systematic barriers, the pilot will consider how best to promote the principles behind individual budgets of greater choice and involvement in decision making by disabled young people and their families.

**2.24** Government also recommends that some health funding streams, where there is already the potential and legal provision of pooled budgets, and where needs are predictable and specific to an individual, should be included in these pilots. On this basis, Government proposes including health funding streams for short breaks, equipment and wheelchairs. This will facilitate provision of a holistic package of support for the child and family, and help further coordinated provision from the family's perspective, complementing work at the local service provision level to improve joint commissioning (see Chapter 3 section on coordination).

## PARENTS, CHILDREN AND YOUNG PEOPLE SHAPING SERVICES

**2.25** Despite policy and guidance which makes clear that service commissioners and providers should be fully involving parents in the design and delivery of services, and some areas with good practice in involving and consulting, participation for disabled children, young people and their families is variable across the country. One study found that where parents were 'active agents' rather than 'passive recipients', this can lead to lower levels of stress for families and better outcomes for both parents and children.<sup>14</sup>

### Local empowerment mechanisms

**2.26** *Strong and Prosperous Communities: The Local Government White Paper*<sup>15</sup>, sets out how the Government intends to strengthen the role of local government, and increase local flexibility, to deliver better outcomes across communities. The Government will create mechanisms for more citizen pressure and greater dynamism at a neighbourhood level, so that front-line services are more accountable to citizens.

**2.27** The White Paper announced a new best value duty to involve local people in the design, delivery and assessment of local services and policies. Building on this commitment, a "Community Call for Action" will be extended across all public services to enable people to hold local bodies to account if services fail to meet their needs. Central government will also work with local government and community organisations to identify and promote good practice in local charters, neighbourhood planning, citizenship learning and participatory budgeting.

**2.28** To help achieve this aim Local Authorities need to consider how best to engage 'hard to reach' groups when deciding how to meet this duty. Any guidance that may be

<sup>14</sup> *Positively Parents: Caring for a Severely Disabled Child*, Beresford, B, SPRU, York. 1994.

<sup>15</sup> *Strong and Prosperous Communities: The Local Government White Paper*, DCLG, 2006

issued to support the implementation of the new best value duty will emphasise the need to take appropriate steps to engage these groups.

**2.29** The Government recognises that given that some parents of disabled children may have substantial caring responsibilities, they may need additional support to express their views at a local level. Some areas already have well established arrangements in place for parents and carers of disabled children to participate and express their views, but others are still developing. A range of mechanisms need to be developed to support parents and carers, building on existing arrangements for parents of disabled children, linking where appropriate with other sources of support such as Parent Partnership Services and Local Involvement Networks, to avoid duplication .

### Parents' forums

#### Box 2.2 Exemplification standards for Parent Partnership Services

The minimum standards for Parent Partnership Services (PPS) in the Special Educational Needs (SEN) Code of Practice include '...that parents' views are heard and understood, and inform and influence the development of local SEN policy and practice...'

In addition, the draft exemplification materials on the forthcoming guidance '*Informing and shaping local policy and practice*' expect parents and carers to be routinely consulted about SEN policy as a minimum, with PPS providing training and support to enable parents to subsequently participate in:

- discussions to inform policy development,
- review and evaluation of SEN;
- Parent Partnership Services; and
- children's services policy.

This will lead to full participation by parents in shaping policy development and practice.

**2.30** All local services are now expected to consult with parents and involve them in the planning and development of services, however the concept of 'parent participation' means different things to different people. Having a facilitated forum, training in the most effective ways to voice views, or a parent support officer or disability champion can all help bring a representative group of parents together to participate in designing appropriate provision and communicate any local challenges.

**2.31** There is no 'one size fits all' solution to parent's forums. They vary depending on many local factors. The structure that will work best in any area will depend on what parents want to achieve, the number of people involved and how they want to work. A forum can:

- be professionally led, an independent organisation, or a regular meeting run by parents;
- provide the opportunity for parents to raise individual issues regarding the provision of services for their children;
- allow parents to feed back views to service providers or commissioners, and develop partnerships with statutory and voluntary organisations;
- send newsletters to keep parents in touch; and
- deliver training workshops.

**2.32** Evidence submitted to the Review and from fieldwork has found that the benefits of parents' forums include an increased feeling of control for parents over their child's wellbeing leading to lower levels of stress for families, better use of services and increased parental understanding of how services work, which often leads to better working relationships with professionals. Parents can also make an impact by asking the questions which no one else would think to ask, and benefit from making new contacts with other parents facing similar issues and supportive professionals. Professionals in turn will benefit from better relationships with parents, gaining a new perspective on the services that they are providing by finding out what parents and disabled children and young people really want.

**Current picture** **2.33** There is currently support and guidance from the voluntary sector in meeting the information and support needs of both parents and professionals. For example, the charity Contact a Family offers:

- information about parent participation in a user friendly format aimed at both parents and professionals;
- key principles to ensure successful parent participation, drawn from their own parent participation work in different areas of the UK;
- examples of different models of participation, their strengths, weaknesses, in what circumstances they might work well and how they could be replicated;
- a range of printed resources on parent participation, some written for parents, some for parent groups and some for professionals;
- tailor made training for both parents and professionals designed to meet the different needs of each group we work with; and
- free e-newsletters for anyone interested in parent participation issues.

#### **Box 2.3 Cornwall Parent Carers Council**

Parents from the Parents Carer Council in Cornwall, in conjunction with the local voluntary befriending organisation, Face2Face, are in close consultation with the Local Family Services social services department. As a result, direct payments and other flexible solutions are being used to ensure that the most flexible, efficient packages of care are made available, and the best use is made of resources available to help families and children, helping to tackle their greatest challenges – be that inclusive childcare or flexible short break provision for families.

Parents are also helping shape services through designing and delivering training to childcare settings in providing for disabled children and their families. The dual benefits of transferring skills to the universal workforce, and allowing parents a platform to share their expertise and regain their confidence, was proving hugely beneficial to both promoting inclusive childcare settings, breaking down attitudinal barriers and improving the trust in universal settings for parents of disabled children.

**2.34** A great deal of existing legislation and guidance on health, education, social care and early years mentions the need for user participation. The Disability Equality Duty promotes the participation of disabled people and this should include children and young people. However, evidence suggests that parents' forums are not yet established in every Local Authority, and in certain areas where the service provision is not very good, statutory bodies have few incentives to increase the voice of service users and the impact of parent forums.

**2.35** A stronger local voice, which sets out Government policy on the future development of the user involvement system in health and social care, was published in July 2006. This included the replacement of Patients' Forums with Local Involvement Networks (LINKs), as well as simplifying and strengthening Section 11 of the Health and Social Care Act 2001, which sets out NHS bodies' duties to involve and consult patients and the public.

**Local Involvement Networks (LINKs)** **2.36** LINKs will strengthen the voice of local people in the health and social care system. By providing flexible ways for a much larger number of people to engage with their local health as well as social care organisations, LINKs will help shape services and priorities in ways that best suit communities and the people in them. They will promote public accountability in health and social care through open and transparent communication with commissioners and providers. This will include people who find it hard to be heard, such as disabled children and their families, and people with learning disabilities and mental health problems, including severely disabled people who wish to live independently.

**Involving children and young people** **2.37** Parent forums give an opportunity to parents of disabled children to express their views on the services they receive. However, the views of disabled children and young people should be taken into consideration as well, independent of the views of their parents. Consultation with disabled children and young people should generate useful advice on how to improve services, help to inform evaluation of specific services and lead to increased participation of disabled children and young people in society.

**2.38** Research suggests that, while in general children are increasingly involved in decision-making, growth is slower for involving disabled children directly in decisions about their own care or in service planning more generally. One study found that when children did participate in consultation exercises, they viewed it as a very positive experience, and the case studies showed some examples of children influencing decisions made in their reviews and of changes to service provision as a direct result of the views children expressed.<sup>16</sup>

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<sup>16</sup> Supporting the participation of disabled children and young people in decision making, Franklin and Sloper, 2007.

### Box 2.4 City Equals – Involving disabled children

Based in Sunderland, City Equals is run by nine young people aged between 13 and 25. They coordinate a group with varying disabilities working towards representing young people with disabilities across the City. The Group has been running since April 2003.

City Equals has been involved in a wide range of national and local consultations, including work on the *Youth Matters Green Paper*, the local Strategic Partnership review of transition services, Sunderland's anti-bullying charter and the State of the City Debate. The work with the Strategic Partnership on transition has been taken forward and is directly influencing transition reviews. Work by the group with local hospitals has convinced health professionals to change their practice by talking straight to disabled young people instead of consulting through parents and carers.

As part of National Youth Work Week, the group held an open day for parents and carers with the theme of 'Mental Health and Emotional Wellbeing'. The group did a display highlighting some of the issues faced by young people with disabilities. One young member said 'We decided to have a parents evening to show what we did and why we should be proud of holding our heads up.'

The group recently went to Birmingham and delivered a workshop at a national conference organised by *Young People Now* on how to involve disabled young people in shaping services.

City Equals is committed to involving the widest range of disabled young people. The group have been awarded funding to acquire Photo symbols; this enabled one young person to receive training needed to ensure his peers understand the concept of using pictures instead of words.

**2.39** Equality 2025 is a new UK advisory network established by Government to advise on matters relating to disability. Equality 2025 members are all disabled people, and include two young people. As part of its remit, Equality 2025 will be developing a strategy for engagement with disabled children and young people and those with parental responsibility. The aim is to engage and empower children and young people, and those with parental responsibilities, across the United Kingdom. This will be achieved by building on existing networks of disabled children and young people, working closely with the Council for Disabled Children.

## Further action

**2.40** The Government expects all local areas to build on good practice in engaging parents of disabled children, such as parents' forums with the support of staff who have skills to support participation, to engage, support, and train parents to influence the design and delivery of services. Underpinned by £5 million of investment over the CSR period, this support should build on models from the voluntary sector and Parent Partnership Services, with organisations bidding for resources to support effective parent participation projects.

**2.41** The Government also expects all Local Authorities, Primary Care Trusts, and schools to engage parents and disabled children and young people in the design and delivery of services appropriate to their needs, building on existing good practice. Most public bodies should be doing this as part of the responsibilities they now have to promote disability equality under the Disability Discrimination Act 1995, building on existing good practice. Actions being taken should be reflected in their Disability Equality Schemes and the actions of individual organisations should be coordinated in Children and Young People's Plans and Children's Trust arrangements as appropriate.

**2.42** Providing a mechanism through which to engage disabled children and their parents will help ensure that the *Community Call for Action* will deliver for all citizens.



# 3

## RESPONSIVE SERVICES AND TIMELY SUPPORT

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### INTRODUCTION

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**3.1** Responsive services should be easily accessible for all disabled children and their families who need them, designed around the child and family, and delivered in a coordinated and timely manner. Where this is the case, disabled children, young people and their families will be supported to play a full role in the society of which they are part, and will benefit from equality of opportunity. Responsive services will facilitate improved educational, social and emotional development, improved independent living, choice and control.

**3.2** Local flexibility in the design and provision of services is to be encouraged, allowing Local Authorities and Primary Care Trusts (PCTs) to focus resources where there is most need and to allow them to respond to the local priorities as voiced by their population.

**3.3** As set out in the Children and Young People Review discussion paper,<sup>1</sup> there is evidence that different Local Authorities and PCTs make different levels of care available, and that those most in need are not always most likely to get support.

**3.4** Variation in how well local areas are accommodating both national standards and local priorities should not disadvantage disabled children in fulfilling their potential. Minimum standards will mitigate against this, which is why this Review recommends a core offer for disabled children and their families (see chapter 2). Building on this offer, this chapter sets out proposals to ensure greater responsiveness.

**3.5** Local Authorities and PCTs rightly prioritise those in greatest need. However, a lack of early support and intervention may be exacerbating the numbers of disabled children who reach crisis point and need more complex interventions. This increases problems for the child and family and is more costly than early intervention.

**3.6** Disabled young people may face additional challenges in the transition to adulthood. Support at transition to adulthood is vital to enable disabled young people to gain independence, choice and control over the assistance they need, and to achieve their aspirations. However, not all disabled young people are getting the coordinated, intensive support that they need.

**3.7** There is much good practice in providing responsive services, for example:

- the *Every Child Matters: Change for Children* programme, with long term investment by the Government, bringing together more opportunities and services into single settings like children's centres and schools;
- extended schools guidance, which makes it clear that children with special educational needs or disabilities must be able to access all services. It explains how special schools in particular often act as a hub for delivery of health, social care and respite services for children and parents. There is a range of specialist health and social care services that children, young people and adults need to access at different times in their lives which support both their general well being and their ability to learn; and

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<sup>1</sup> *Policy review of children and young people – A discussion paper*, HM Treasury and Department for Education and Skills, Jan 2007.

- the Early Support Programme which aims to achieve coordinated, family-focused services for young disabled children and their families across England. It focuses on better joint assessments, coordination of service provision, better information, the introduction of a lead professional or key worker, and the development of family-held, standard material to monitor children's development which can be shared across agencies.

**3.8** Building on arrangements which are already working well in some local areas to promote responsive, high quality provision, this chapter examines:

- how to develop a better understanding of the disabled children population, to help with more efficient planning, commissioning and provision of services;
- the role of the new performance management framework being implemented as part of the Comprehensive Spending Review in prioritising disabled children, including national indicators in the Public Service Agreements and how these are implemented on the ground through Local Area Agreements;
- incentives to provide support and interventions early in a child's life, or at key transition stages, including better evidence on which early interventions are most effective;
- incentives to coordinate packages of care, with planning around the child and family and joined up assessments; and
- support to ensure a smooth transition to adulthood, reducing uncertainty, increasing awareness of options available, breaking down physical and attitudinal barriers to further education, employment and/or independent living.

## **DEVELOPING A BETTER UNDERSTANDING OF THE DISABLED CHILDREN POPULATION**

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**3.9** A clearer picture of the disabled children population and disabled children's needs at a local level is essential for effective planning, commissioning and provision of services.

**3.10** The Review's fieldwork suggests that although some Local Authorities are developing a good understanding of their local population, and undertaking thorough needs assessments to help plan and predict the services and interventions disabled children and their families will need, others still do not have a proper understanding of the profile or even the size of their disabled children population.

**3.11** Good quality, consistent, and up-to-date information is essential to the provision of services to all those in need, including disabled children. Collection and appropriate use of such information facilitates the operation of mutually aware, child-centred services working together to ensure the best possible outcomes for children, and especially for those with additional needs. Some Local Authorities (such as Halton – see box 3.1 below) demonstrate this very well, but where the range and quality of information is lacking disabled children and their families inevitably lose out.

**Box 3.1: Good quality data to promote integrated, timely support**

There are a number of Local Authorities who have developed methods of collecting data for disabled children and their families in a successful way. Halton, for example, use a single data set, which includes all health, social services and education data available on their vulnerable children population to improve communication, eligibility assessment and commissioning of services. The work of the Halton Children and Young People Strategic Partnership is firmly based on the operation of a Children and Young People Database, which is a key element of partnership working.

At its core, the Local Authority maintains pupil-centred data relating to pupil service, early years, grants and benefits (Free School Meals), e-Common Assessment Framework, Special Educational Needs and Admissions. However, beyond its core, it utilises information from a very wide range of organisations and information sources which affect the lives of children, including Youth Offending Teams, Colleges, Looked-After Children, the Traveller Service, exclusions, PCT 0-3 year olds, Connexions (including children not in education, employment or training), non-Halton schools, academic performance, and many more.

**Current situation** **3.12** Statutory definitions relating to disability include “Children in Need”, for social service purposes, Special Educational Needs (SEN) for education purposes, Hospital Episode Statistics for hospital admissions, and the Disability Discrimination Act definition.

**Remaining challenges** **3.13** Volume 6 of the regulations and guidance on the Children’s Act 1989 encourages Local Authorities to develop their own more positive working definitions of disability, and whilst some local areas are doing this and collecting data on their population in a proactive way, this hampers comparisons across the country on a like for like basis. There is no single definition of disability, as the current statistical definitions are rightly used to serve particular service needs, for example the clinical needs of the health definition. In addition, there are barriers to the Department of Health and PCTs using the Disability Discrimination Act definition of disability given that it may be too general a definition to help with planning and provision of medical services and interventions.

**3.14** There is also a lack of longitudinal data at a national level, which exacerbates problems around planning for the population. There is ongoing work across government on improving the level and quality of data on the number and population of disabled children.

**Further action**

**3.15** There is an inconsistent picture of data collection on disabled children at the local level. Whilst some Local Authorities and PCTs are collecting good data, other areas lack the data they need to underpin their planning and equality duties and ensure that progress is being made by disabled children and their families.

**3.16** To allow Local Authorities and PCTs to plan and provide for their population, Government will look to all Local Authorities and PCTs to collect data on:

- the number of disabled children in their area, where possible classified by type of disability; and
- the percentage of this disabled children population accessing both universal and specialist services, such as short breaks or therapy services.

**3.17** Over time this data may be developed into a system of benchmarking which will allow Local Authorities and their partners to compare profiles and degrees of satisfaction with services, both overall and against Local Authorities in similar circumstances (i.e. “statistical neighbours”).

**3.18** This data collection should be based initially on the definition of disability in the Disability Discrimination Act, and all local areas should also use data on the number of disabled children taking up higher rate Disability Living Allowance as a proxy interim measure for the number of severely disabled children. This will be an important first step in helping Local Authorities and PCTs deliver for their populations, however to further help this planning and commissioning process, this process will be reviewed to help encourage more detailed needs assessment and to further support effective partnership working.

**3.19** This work will be underpinned by guidance following the CSR on how Local Authorities should be collecting data on their disabled children population. Local Authorities should consider how to make this information available to citizens and across agencies, and it should be reflected in Children and Young People’s plans by 2010-11.

**3.20** **The Government will also take forward further work to develop more consistent, compatible and comparable data on disability on which to base service planning, commissioning and provision at both a local and national level, to report in 2008-9.** This work will be undertaken across different agencies and departments to reduce duplication and to join up national government and local agencies. The work will be coordinated by the ONS, with input from the Office for Disability Issues (ODI), the Department for Education and Skills (DfES), and the Department of Health (DH), and should be informed by:

- a DfES survey of Local Authorities to determine what data they currently collect on their disabled children population, what definitions they use, and how they use this data;
- a DfES Survey to investigate the reasons underlying the wide local variations in the proportions and classification of children with SEN and/or disabilities, to allow Local Authorities to reflect on their performance and learn from others;
- DfES research project on data collection in children’s services including a schools pilot. This will look at the child or young person’s own attribution of disability in a user-friendly manner, but based on the DDA definition. Different methods of data collection in schools will be evaluated and cost estimates made;
- DfES work on the refreshed Children in Need census for 2008-09;
- ODI work on a proposed longitudinal survey of disabled people;
- DH Child Health Mapping data work on developing a better understanding of disabled children in PCTs;
- DH work on Hospital Episode Statistics and identifying children in the set who have a disability; and

- development of a child health data set to support implementation of the *National Service Framework for Children, Young People and Maternity Services*, (DH, DfES, 2004), which will include developing data collected on disabled children to monitor the achievement and the delivery of NSF standards and quality requirements, to support the audit of service quality and coverage and to inform strategic planning processes and the prioritisation of service development and provision.

## PERFORMANCE MANAGEMENT

**Current situation** 3.21 Nationally, there are a number of requirements that will influence local provision of responsive services for disabled children. These include:

- **legislation** such as the Children Act 1989, the Disability Discrimination Act (DDA) 1995, and the DDA 2005. Under the Children Act 1989, Local Authorities have a general duty to “safeguard and promote the welfare of children in their area who are in need... To promote the upbringing of such children by their families, by providing a range of services appropriate to those children’s needs.” The DDA 1995 makes it unlawful to discriminate against people in respect of their disabilities, and the DDA 2005 extends this to introduce a new duty on public bodies and authorities to have due regard to the need to promote equality of opportunity for all disabled people;
- **guidance**, such as the *National Service Framework for Children, Young People and Maternity Services*, which sets standards for the first time in children’s health and social services. Standard 8 of the National Service Framework relates specifically to children and young people who are disabled and those with complex health needs; and
- **national level performance indicators and targets**, which encourage a focus on the disabled children’s population. For example, the current child poverty PSA target encourages reducing poverty for disabled children and their families, while current targets on raising attainment require a focus on SEN as they are likely to have lower attainment.

3.22 Some local areas are already pioneering the use of local performance indicators to give clear signals to services about what they should achieve, responding to identified local priorities. Some of the indicators which the Review team have seen used at a local level to encourage improved outcomes for disabled children and their families include measuring the proportion of:

- parents/carers of children with severe and complex disabilities with access to information about services;
- children with complex needs receiving multi-agency assessments who access services to meet their identified needs;
- children with complex needs accessing mainstream education, inclusive play and leisure opportunities;
- disabled children participating in person centred transition reviews to enable them to influence their outcomes;
- disabled children accessing more flexible and individual services through direct payments;

- disabled children accessing short break services; and
- disabled children in inclusive settings.

**Remaining challenges** **3.23** Many submissions to the Review have suggested enhancing these measures. There have also been suggestions to strengthen existing legislation to introduce legally enforceable duties on local bodies to assess and provide services. Introducing specific legislation cuts across existing general duties and local flexibility, and would be hard to put in place for all services which disabled children and their families need. Given the varied but often specific needs of disabled children and young people, it would not be possible to provide comprehensive entitlements which meet every individual's needs, for example, not all disabled children will need a wheelchair, or a certain number of hours of short break provision. While some submissions have suggested that service provision for disabled children should be determined and specified nationally, others have emphasised the importance of local areas having the autonomy to set local priorities to allow a continuation of the innovative, flexible provision which currently occurs in areas of good practice.

**3.24** Stakeholders have also suggested using the performance management framework, which has played a fundamental role in driving up public service performance since 1998. The performance management framework is set to evolve in the 2007 Comprehensive Spending Review, with the introduction of a focussed set of Public Service Agreements (PSA) that articulate Government's highest-priority outcomes and typically span several departments, and a comprehensive set of Departmental Strategic Objectives for each department. Genuine focus and rationalisation in the PSA set, with a significant reduction in PSAs and a similar reduction in the number of underpinning indicators set from the centre will enable frontline delivery agents to balance national with local needs, without restricting options to deliver, and will allow greater space for innovative and responsive public services at a local level. In addition, the current Local Area Agreement outcomes framework will be replaced by a new framework for Local Authorities working alone or in partnership with quantitative areas for improvement in both national and local priorities articulated in the Local Area Agreements.

**Box 3.3 The New Performance Management Framework**

Public Service Agreements (PSAs) have played a vital role in galvanising public service delivery and achieving major improvements in outcomes since their introduction in the 1998 Comprehensive Spending Review (CSR). The 2007 CSR will build on the approach driving ambitious improvements in priority areas while developing the supporting performance management framework, to ensure a user-focused, devolved approach to public service delivery. The performance management framework in the CSR07 period will include:

- a comprehensive set of Strategic Objectives for each department;
- a focussed set of PSAs which articulate the Government's highest priority outcomes for the spending period and will typically span several departments;
- a single, cross-departmental Delivery Agreement for each PSA, developed in consultation with front line workers and users, supported by a basket of national, outcome-focused indicators;
- an emphasis on central coordination working in synergy with greater bottom-up accountability, local flexibility and user responsiveness; and
- a premium on the use of high quality, timely data while freeing up the frontline by reducing low value data burdens.

Each department will agree and publish a new, comprehensive set of Strategic Objectives at the CSR. Departments will use these objectives to manage and report on performance and to inform resourcing decisions, ensuring a more holistic, coherent and better aligned framework for performance and financial management across the board.

Alongside Departmental Strategic Objectives, a new set of PSAs will set out the highest priority outcomes for the Government for the CSR 07 period, with less than a third of the number of PSAs than in the current spending review period. Recognising that delivery of the Government's highest priority outcomes requires public services to adopt collaborative approaches across organisational boundaries, both at Whitehall and the frontline, these PSAs will not be constrained by departmental boundaries but will reflect a government wide set of priorities, articulating the most important areas for collective action.

To ensure coherent cross-departmental working as well as buy-in throughout the delivery chain, each cross-cutting PSA will be underpinned by a single, published Delivery Agreement setting out plans for delivery, the role of each organisation in the delivery chain, and how progress towards the outcome will be measured and strengthening accountability at all levels. Departments are working together to draw up Delivery Agreements involving local authorities, frontline professionals, such as teachers and nurses, and service users so that frontline expertise informs the definition, measurement and delivery of priorities.

Delivery Agreements will set out a small basket of national, outcome-focussed indicators that will be used to measure progress on each PSA. Indicators will be selected and developed in consultation with frontline professionals to ensure that they are appropriate and effective. Precise targets and minimum standards will continue to be key levers for improvement but will give more weight to the priorities of individual areas and communities – focusing action where there is most need for improvement.

## Further action

**3.25** The Review has already highlighted the importance of empowering disabled children and young people and their families to help them influence services to make them responsive to their needs, through mechanisms for improving local accountability such as clear complaints procedures when services are not up to scratch. However, not all disabled young people and their families will want this responsibility, and this will be a more powerful tool if it is backed up by other ways of influencing services at the local level. It is important to maintain local flexibility in the design and provision of services, and Government wants to encourage even more responsive services, and greater coordination of provision, encouraging early intervention, supported by underpinning data to help planning and commissioning for the population.

**3.26** The Review has considered the advantages and drawbacks of further legislation. In particular, it considered the challenges of ensuring that legislation is sensitive enough to be able to prescribe provision against a wide variation of need in the disabled children population. As innovation and flexibility are critical to improving the quality of services, and their impact on disabled children, young people and their families, the Government believes that the right approach is to strengthen and sharpen the performance management framework.

**3.27** In order to focus service provision on improving outcomes, performance indicators need to be outcome-focused and meaningful. Difficulties arise when trying to design one performance indicator which would measure overall improvement in disabled children's outcomes. Having a performance indicator which is very specific and focused on one element of service provision can reduce flexibility in responding to the full range of needs for the population. For example, a performance indicator focused purely on short breaks may divert focus from other essential support services for disabled children and their families, such as equipment and inclusion in universal provision.

**3.28** In addition, it is hard to design one indicator measuring improved outcomes for disabled children as a population, given that the population is so diverse. An indicator on improving educational attainment, for example, may not capture improvements in the degree of independent living made by disabled children and young people with learning difficulties, and may not fully capture improved life chances and conditions for children and young people with complex health needs. The Review has therefore explored an indicator using general satisfaction with both universal and specialist services for disabled children as a proxy for measuring improvements in outcomes, and an indicator around the 5 elements of the core offer, i.e. around information, assessment, transparency, feedback and participation.

**3.29** Before reaching a final decision on an indicator as part of the CSR, DfES will carry out a feasibility study on how to measure whether families with disabled children and young people are benefiting from the core offer, including looking at the methodology for data collection from a suitable sample of families with disabled children and young people in all 150 Local Authorities and all PCTs on an annual basis, or a rolling programme of data collection from Local Authorities and PCT areas over a 3 year period. It is anticipated that a robust set of data collected in this way will encourage Local Authorities and PCTs to implement the core offer, address their responsibilities in this area, allow benchmarking across the country and inform parents and young people of the performance in the area in which they live. Over the longer term, the Government

will continue to make sure that any indicator on disabled children is as focused on outcomes as possible.

**3.30** Government will therefore ensure that high priority is given to improving outcomes for disabled children in the forthcoming CSR, with sharper incentives to embed a focus on disabled children at both a local and national level. In particular, Government will develop a national disabled children's indicator as part of the set of priority PSAs to be agreed across Government at the CSR.

**3.31** To ensure that what we see in the best Local Authorities can be replicated across the country, this will be supported by better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing.

## EARLY INTERVENTION

**Current situation** **3.32** There is evidence that poor responsiveness sometimes manifests itself as late intervention. Local Authorities and PCTs currently rightly prioritise those in greatest need. However, a lack of early identification and intervention may be exacerbating the numbers of disabled children and families who reach crisis point and need more complex intervention, which increase problems for the child and family, and are more costly.

**3.33** Early intervention is not just about providing support for disabled children and their families early in childhood. Disabled children and their families need properly coordinated support, delivered as soon as they need it, particularly at key transition points in their lives, and they need services and support to respond quickly when their circumstances or a child's condition changes.

**3.34** Early support for disabled children and their families is essential to prevent problems such as deteriorating health, family stress and breakdown, children potentially being placed in care, and deteriorating emotional and social development for disabled children and their siblings.

### Box 3.4 The Early Support Programme

The Early Support Programme, set up in 2002, is a partnership between the Government and the voluntary sector to improve the quality, consistency and coordination of services for disabled children and their families. Originally piloted from birth to three, it is being rolled out for disabled children in 2007-8 from birth to five across the country. Parents have been at the centre of the process since the beginning, helping to make multi-agency working and improved service provision a reality. The independent evaluation of the programme has found that the Early Support Programme has had positive effects on the quality of service provision, improvements in multi-agency working and a smooth process of referral, identification and initial assessment.

For parents whose experience of early support included multi-agency assessments and review or key working, there were clear advantages to inter-agency working, including a reduced sense of burden from otherwise having to coordinate services themselves, confidence engendered through the routine and predictable ways in which they knew professionals planned together, greater accountability, and increased opportunities for parents to become involved in decision making about their child's future.

### Benefits of early intervention

**3.35** Services can intervene earlier than they sometimes do, and make a difference to disabled children and their families' lives. For example:

- short breaks: families with disabled children often face particularly high stress and breakdown owing to the increased pressures of having a disabled child. A break from caring to be with their partner and/or other children can be the single most important factor in helping their relationship;<sup>2</sup>
- early provision of equipment or wheelchairs: pressure relieving mattresses or special seating may prevent the development of pressure sores, contractures, or skeletal deformity. Once pressure sores develop, the patient can lose dignity, suffer considerable pain, and the NHS may have to pay for district nurses' time or expensive plastic surgery to solve the problem;
- sleep programmes: without early support to help parents manage their children's sleep patterns, parents and siblings may have to function on only a few hours of sleep, not to mention the detrimental effects on the disabled child themselves. Families testimonies include memory lapses, having to give up work, and siblings falling asleep at school or missing school having been awake all night; and
- behavioural management: this will prevent worsening educational outcomes, and reduce stress for parents and siblings.

#### Box 3.5 A parents experience: the consequences of a lack of early intervention to support sleep deprivation<sup>3</sup>

"I get so tired I dream about sleep during the day. Not holidays or having fun, just sleep.

Some nights I get around 5 hours, others as little as 3. I find it hard to get motivated because I often have aching sensation in arms and legs where so tired. When too tired get weepy.

I forget things all the time, as you personally know, and am convinced that my lads probably do use this to their advantage, not that I blame them, I would if I could.

Friendships are few and far between because I have become so lousy at calling people and keeping in touch. I used to be Mrs Efficient And Houseproud, not any more.... real life is here.

I blunder through each day from one thing to the next. I get side-tracked, on route to doing one thing I find myself doing something completely different."

### Remaining challenges

**3.36** There appear to be two underlying reasons why early intervention is not happening on a consistent basis. Firstly, in some circumstances there is a lack of knowledge and understanding of early interventions that can improve outcomes, for example behavioural management and sleep programmes. Comprehensive cost effectiveness studies covering the financial implication of the full range of potential benefits are scarce. Further research into the full economic and social benefits of these early interventions, and the potential to avoid problems later in a child's life or a

<sup>2</sup> No time for us. Relationships between parents who have a Disabled Child: A survey of over 2,000 parents in the UK. Contact a Family 2004.

<sup>3</sup> Handsel Trust Sleep Stories <http://www.handseltrust.org/sleep09.htm>

worsening of their condition will help encourage a shift toward earlier support at key stages of a child and families' life.

**3.37** Secondly, there is the challenge of shifting allocation from crisis provision to early intervention, given finite resources. Local Authorities and PCTs will always rightly prioritise those in greatest need. However, focusing more on early intervention may prevent some disabled children and their families reaching crisis point and developing such high support needs.

### Further action

**3.38** To encourage early intervention to help prevent deteriorating outcomes for disabled children and their families and to promote development, **the Government will provide additional resource over the CSR period to enable the new Centre for Excellence for Children and Family Services to evaluate and benchmark good practice on early intervention policies for disabled children**, including interventions on behavioural management and parenting, sleep, communication, and mobility. Priority must be given to ensuring that findings are disseminated to practitioners and parents in a way that impacts on practice.

## COORDINATING CARE ACROSS SERVICES

### Benefits of coordinated working and provision

**3.39** Good joint commissioning and delivery matters. Its absence puts an extra burden on parents in terms of extra stress and time demands. It can also raise waiting times (for example where children are waiting for separate assessments). Where families have coordinated support, through joint planning, commissioning, assessment and provision, or through a key worker or lead professional, disabled children and their families are more likely to benefit from better coordinated support from accessible, knowledgeable professionals in both universal and specialist services.

**3.40** Many local areas use key workers or teams working around the family and child, which may be part of the Early Support Programme. The philosophy of the Early Support Programme of joint working and shared understandings of goals and approaches across agencies has underpinned its success, reinforcing and enhancing existing good practice, and in other cases enabling previous ineffective structures of joint working to be left behind. Key working is a way of managing the package of support available and ensuring families access the services to which they are entitled, with workers being named individuals who act as a single point of contact for multiple services, empower families and help them navigate the system.

**3.41** Available evidence on key workers suggests that they improve the overall quality of life of families with disabled children. Specifically, they can reduce parental stress and enable families to make better use of other services.<sup>4</sup>

<sup>4</sup> An exploration of different models of multi-agency partnerships and key worker services for disabled children: Effectiveness and Costs Greco et al, 2005.

**Box 3.6 Best practice on coordinated provision**

Wolverhampton is a pathfinder Early Support area, and through the Local Authority's Child Development Service (CDS) it coordinates the "Team Around the Child" programme. The programme involves a single assessment of need; a multi-agency referral panel; a well defined flexible model of early intervention and continuing support; an emphasis on empowering families by listening to their needs; and a training programme for key workers and professionals in the team.

Drawing on funding from the Department of Health as well as from the Early Support Programme, Wolverhampton has set up the Gem centre – a brand new building that co-locates education, care and health services for young children with complex needs. The CDS occupy one wing, while the others house audiology, physiotherapy and paediatrics departments, and Child and Adolescent Mental Health Services. The centre is equipped with state of the art facilities, including purpose built learning aids and computer software, and a "sensory room" with an array of light/sound equipment to explore the coordination of movement, cause and effect.

Staffing is planned around the needs of families, and services are integrated to provide a single experience for children and their parents – so for example, an audiologist might drop into a play session to take a mould of a child's ear, without breaking up the session. Key workers employed by the CDS use the centre as their base, but also work directly with families in their homes.

**Current situation** **3.42** As set out in the Children and Young People Review discussion document,<sup>5</sup> the Call for Evidence acknowledged that the Every Child Matters programme is making progress, with more joint working between different agencies, and some areas using pooled budgets and joint assessments. However, the Review has also found that this joint working is variable, with remaining challenges including differing eligibility criteria, incompatible computer systems, differing referral systems and cultures, and a lack of managerial commitment to joint working.

**3.43** The Early Support Programme is facilitating the development of key worker schemes for disabled children and their families as part of a wider programme of support, including information materials, professional guidance and training. It has been well received as a successful programme and additional funding for 2007-08 will allow the programme to continue to embed its approach across all local authority areas.

**3.44** The *National Service Framework* Standard 8 on disabled children states that the Government expects all Local Authorities and Primary Care Trusts to ensure that "families caring for disabled children have a key worker/care manager to oversee the delivery of services from all agencies involved in the care and support of the family, and to ensure that the family has access to appropriate services".

**DH Commissioning Framework** **3.45** The Department of Health Commissioning Framework for Health and Wellbeing and performance frameworks for the CSR years provide a basis on which to further develop and improve joint commissioning and co-ordination of services. Part of the vision set out in *Our health, our care, our say*<sup>6</sup> is to create services which are flexible, integrated, and responsive to people's needs and wishes. This includes the concept of

<sup>5</sup> *Policy review of children and young people – A discussion paper*, January 2007. HM Treasury and Department for Education and Skills.

<sup>6</sup> *Our health, our care, our say*, DH White Paper, 2005.

PCTs as the local commissioner of health services on behalf of, and engaging with, their local population. To further facilitate cooperation at a local level, PCTs will be required jointly with Local Authorities to undertake a strategic needs assessment to identify local health priorities. PCTs will then be held to account using a new performance framework which DH is developing for the CSR years, which will link to the new PSA performance management framework.

**3.46** Subject to consultation, there is an expectation that all PCTs will undertake a joint strategic needs assessment with local authorities, and publish a prospectus in 2008-9. It is envisaged that the joint strategic needs assessment will provide key analysis to feed into the development of local Sustainable Communities strategies and Local Area Agreements. This joint accountability and objectives identified in the joint strategic needs assessment and Local Area Agreements should encourage PCTs and Local Authorities to work more constructively together.

### Remaining challenges

**3.47** An Audit Commission report from 2003 found that families with disabled children have to struggle through a maze of services to gain access to support.<sup>7</sup> Where it is unclear which agency is responsible for delivering support for a disabled child, and there is a lack of joint responsibility, the disabled child's needs may be left unmet. Poor planning, data collection and commissioning also raise the risks that the population is not adequately supported.

**3.48** The Review found particular problems in coordination around transition to adulthood for disabled young people. Case studies from a recent Audit Commission report<sup>8</sup> found a confused picture about which services were leading on transition and the roles of the professionals involved, with one parent stating: *"The transition process can be quite confusing for parents and young people as a number of new professionals get involved. I have to explain the different workers' roles."*

**3.49** The report found that although there was good progress in some areas to improve coordination between social care, education, health, housing and other services, good practice is not happening everywhere, with inadequate provision, poor coordination of services and a failure to plan with young people and their families resulting in anxiety, delays, multiple assessments and confusion.<sup>9</sup>

### Further action

**3.50** In order to better coordinate service provision and encourage joint assessment and provision, the Government will take action to:

- include within the core offer for disabled children a focus on integrated assessment (see chapter 2); and
- continue to roll out the Early Support Programme to cover all disabled children aged 0-5 and to be embedded in programmes addressing the needs of this age group.

**3.51** The Government also expects that all disabled children should benefit from coordinated service planning and delivery from Local Authorities and their partners, and support to help navigate the system. For example, a team around the child or family

<sup>7</sup> *Services for disabled children: a review of services for disabled children and their families*, Audit Commission, 2003.

<sup>8</sup> *Growing up matters, Better transition planning for young people with complex needs*, Commission for Social Care Inspection, January 2007.

<sup>9</sup> *Ibid.*

approach, building on the Early Support Model across the country and on the best practice of professionals in contact with the child taking a lead role in coordinating their package of care.

**3.52** The Government will also develop a Transition Support Programme (see next section).

## SUPPORT AT TRANSITION

### Why support at transition matters

**3.53** It is accepted that for many disabled young people, having timely, comprehensive information and careers guidance is sufficient to ensure that they reach their goals when making the transition to adulthood.

**3.54** However, for a smaller number of young people, more support is needed to help them to meet their goals and take their place in society. At the moment, the support that young disabled people receive is variable. Services may struggle to provide information at the right time, coordinate their responses with other agencies, and provide appropriate support to young people and their families.

**3.55** Support at transition to adulthood is vital to enable disabled young people to gain independence, choice and control over the assistance they need, and achieve their aspirations. All disabled young people need access to sufficient information and support to ensure that they reach their goals when transferring from child to adult services, enabling them to remain safe, grow up and live the lives they want to live, and to play a full and active role in society.

## Transition

### Current situation

**3.56** The Education Act 1996, SEN regulations and the SEN code of practice set out a statutory transition planning process for young people with SEN statements from Year 9 onwards. The Connexions Service must arrange assessments of young people with learning difficulties and disabilities who are in the last year of compulsory schooling and are intending to go on to Further Education or training. Assessments must also be undertaken when these young people reach year 11 or at the point of leaving school and up to the age of 25. The Learning and Skills Council has to take account of these assessments.

**3.57** *Youth Matters: Next Steps* has set out plans for comprehensive information, advice and guidance for all young people with targeted support for those with complex needs. It also sets out how Local Authorities, working through Children's Trusts, will work with all the relevant agencies to develop a more personalised, integrated and efficient support service for teenagers and ensure that those young people who need integrated support in a number of overlapping areas can have it effectively coordinated and delivered by a lead professional.

**3.58** There is a core standard within the *National Service Framework for Children, Young People and Maternity Services* on 'Growing Up into Adulthood', and within the standard for Disabled Children and Young People and those with Complex Health Needs there is a marker of good practice on multi-agency transition planning. Work has also been carried out on transition under the *Valuing People/Learning Disability strategy* and each Learning Disability Partnership Board should have a "transition champion".

**3.59** The DfES has recognised the challenges that disabled young people at transition face, and has supported, through the Council for Disabled Children, the development of the Transition Information Network. The DfES has also commissioned the Council for Disabled Children to produce good practice guidance on transition which will be published in Summer 2007.

**Extent of provision** **3.60** Children and young people with more complex needs require more carefully prepared and intricate packages of support as they transfer into adulthood. It is recognised that as there is an increasing population of young people who would not previously have survived into adulthood, the transition planning process and the services available beyond this have to develop in order to meet their needs.

**3.61** Despite some good practice, many disabled young people do not end up in education, employment or training, or end up in the wrong provision for them. The Qualifications and Curriculum Authority is currently working to develop a coherent framework of provision for all levels of ability, including at pre-entry level, so that young people can find something suitable and demonstrate their skills to potential employers.

**3.62** There is currently a lack of consistent multi-agency working to ensure that disabled young people are given a real choice about their futures. Parents have reported that if there are no arrangements in place when the young person leaves school, they can find themselves without provision. If arrangements are not made during the autumn term, young people can miss up to a year in education or training if the course or placement they are seeking is full.

**3.63** A Commission for Social Care Inspection report last year stated that ‘peoples’ expectations of social care are changing. In future, people will expect social care that enable them to live independently, that give them choices, that are high quality and that leave them in control. For children, social care must support them and their families to make the most of their educational and life chances’.<sup>10</sup>

**Barriers to enhanced provision** **3.64** Evidence submitted to the Review suggests the following barriers to smooth transition to adult services for children with disabilities:

- a lack of suitable provision for young people on transfer from school. Some disabled young people accept unsuitable and often part time courses in the absence of a full range of suitable options;
- lack of young person and family input into the transition planning process so that the aspirations and ambitions of the young person are often not known and realised, with transition planning meetings sometimes not involving the child and family;
- lack of multi-agency working to support transition and confusion over roles and responsibilities in transition planning;
- a gulf between child and adult services in health and social services;
- the timing of preparation for transition often does not always take into account the complexity of need; and
- the lack of recognition that transition occurs at the appropriate time for the individual rather than at a specific point in time for all young people.

<sup>10</sup> *The state of social care in England 2004/05*, Commission of Social Care Inspection December 2005

**Box 3.7 Examples of best practice for support at transition****Person centred planning**

A joint initiative between the DfES and the Department of Health/Valuing People Support Team to improve the participation of young people and their families in transition review meetings has had a successful pilot across 70 Local Authorities. This is now a national programme involving almost all Local Authorities across England. The project aims to demonstrate how transition review meetings can be far more effective when using person centred planning strategies. With a small level of investment and innovative thinking about transforming processes, the programme has been successful in supporting young people to identify what is important to them and their aspirations for the future, supported by a transition plan.

**Transition Teams:**

Greater collaboration across agencies is required in the field of transition. Transition teams are one way of achieving a change in culture, behaviour, attitudes and priorities towards this group of disabled young people in relation to transition planning.

Examples of existing best practice include Suffolk, where a specific transition team comprising a range of specialists has been set up. In addition, Sandwell and Bolton have also developed specific transition teams. Leicester City have a jointly commissioned transitions development officer shared between the Learning Skills Council, the Learning Disabilities Partnership Board and the Disabled Children's Partnership Board.

**3.65** Research into good practice suggests that:

- the process needs to be individual to the needs and aspirations of the young person;
- the process needs to be spread out over a number of years starting at the transition review following the young person's 14<sup>th</sup> birthday, with reviews held annually;
- statutory processes for transition need to be used consistently; and
- adults' and children's services need to work together to ensure that young people maximise their life chances as they enter young adulthood.

**3.66** Transition planning and transition services need to be seen as a way to enable and support disabled young people to move towards and onto a new stage of life rather than from one service to another. Much good practice exists – but it needs to be pulled together and made consistent.

**3.67** The Government will therefore initiate and develop a **Transition Support Programme, underpinned by £19m of investment over the CSR**, to be piloted initially and then rolled out across the country. This model should be based on the same principles as the early support programme, including transparency, coordination and support for parents, children and professionals. It should be based on the principle of enabling disabled young people to have choice and control over the support needed in their daily lives, and should be embedded as a new model of working for the years ahead.

**3.68** This Transition Support Programme should include:

- a young person's information pack, including information on further education, training opportunities and work options;
- access to an advisor or key worker and advocacy and support;
- consolidation of the person centred planning process from age 14, with increased information for professionals, and coordinated and timely assessments based on the young person's aspirations, at key points to assist in the transition to adulthood, including signposting to future appropriate provision; and
- joint team working across agencies and with adult services to encourage a holistic approach, and choice and control for young people.



# 4

## IMPROVING SERVICE QUALITY AND CAPACITY

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### INTRODUCTION

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**4.1** Respondents to the Review and wider research at a local and national level have highlighted a number of specific services that are particularly important to improving outcomes for disabled children, young people and their families. The specific services highlighted in the Review’s Call for Evidence, the Parliamentary Hearings and report, seminars and visits in terms of both universal and specialist services were:

- **short breaks:** to support disabled children and families, giving families a break from care duties and allowing children to experience new relationships, environments and positive activities;
- **childcare provision:** which can facilitate parental employment, reduce family stress, and increase a child’s social and educational development;
- **provision of appropriate equipment and wheelchairs:** to maximise mobility or communication, make it less physically tiring to care for a disabled child, and prevent deterioration of conditions;
- **therapists:** to manage posture, maximise mobility, provide support and advice on feeding, and improve and enable communication; and
- **training of staff in universal services:** to improve their knowledge and understanding to help make universal services more accessible for disabled children and their families.

### VITAL SERVICES FOR DISABLED CHILDREN

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#### Short breaks

#### Why short breaks matter

**4.2** Families with disabled children often face particularly high levels of stress which may result in family breakdown. For parents and siblings of disabled children, short breaks reduce stress, allow a rest from caring, provide time to carry out tasks and activities that other parents take for granted and allow more time with other children. Disabled children are disproportionately represented within the looked after population, making up 10% of all children in care, and only around 5% of the overall population.<sup>1</sup>

**4.3** The *National Service Framework for Children, Young People and Maternity Services* states that “Good short term break services are associated with reductions in maternal stress and a reduction in marital problems and breakdown”. According to a survey of parents of disabled children, a break from caring to be with their partner and/or other children is the single most important factor in helping their relationship.<sup>2</sup> The survey found that 76 per cent of families had experienced stress or depression and 72 per cent were suffering from lack of sleep. Similarly, the *Breaking Point* report from

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<sup>1</sup> *Children in Need data, DfES, and Family Resource Survey, DWP, 2004-5.*

<sup>2</sup> *No time for us. Relationships between parents who have a Disabled Child: A survey of over 2,000 parents in the UK, Contact a Family 2004.*

Mencap found that 80 per cent of families with children with severe or profound learning disabilities had reached breaking point due to lack of short breaks.<sup>3</sup>

**4.4** Furthermore, short breaks can also have a positive impact on disabled children, as they help to tackle social isolation, provide access to leisure activities, friendship networks, and promote development.

**4.5** A recent report<sup>4</sup> identified the following costs as being potentially preventable from increased short breaks provision:

- the cost to the family from parents not being in work;
- the cost to employers and the health service from parents' stress;
- the cost to schools from educating siblings with emotional and behavioural difficulties;
- the cost of foster care or a residential placement due to family breakdown;
- the cost to social and educational services of caring for a disabled child outside the family home; and
- the cost to the family of separation and marital breakdown.

**4.6** In addition, there are other non-economic benefits, such as the happiness of the family and social inclusion of the child, which although not measurable in terms of costs are important to the child, family and society, and need to be taken into consideration.

## Childcare

### The importance of childcare

**4.7** Provision of good quality childcare is an entitlement for disabled children, as it is for all children and families. Government wants to ensure that all families have the same access to appropriate childcare provision. The provision of good quality childcare will allow parents to return to work, reducing poverty and increasing employment opportunities if this is what parents choose. Good quality childcare can also improve children's outcomes and general wellbeing.

**4.8** Work carried out on the costs and benefits of childcare for disabled children for the Review estimates that the annual monetary benefits of increased employment for both mothers of disabled children (who are more likely to be the main carers for children) and lone parents of disabled children are significant. As well as facilitating parental employment, childcare will benefit disabled children as it benefits non-disabled children, with the provision of high quality education and care at an early age reducing the risk of developing Special Education Needs at a later stage from 1 in 3 to 1 in 5.<sup>5</sup> There may also be additional benefits to disabled children in terms of helping them feel included in mainstream provision, and facilitating their transition to inclusion in mainstream education provision when they reach school age.

<sup>3</sup> *Breaking Point: Families still need a break*, Mencap, 2006.

<sup>4</sup> *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families*. New Philanthropy Capital, 2007.

<sup>5</sup> *Effective Provision for Pre-School Education Study*, Kathy Sylva et al,

## Equipment and wheelchairs

### The importance of equipment

**4.9** Equipment, from wheelchairs to communications aids, is essential to help disabled children and young people access school, leisure and other services, and to facilitate independent living. Good quality equipment services can also enable independent living in the community at low cost, compared to longer hospital stays. Provision of appropriate equipment maximises physical mobility and communication and makes it less physically and emotionally tiring caring for a disabled child.

**4.10** Well-fitted wheelchairs can also prevent deterioration of conditions and other worsening health conditions, such as potentially expensive operations, or pressure sores, which make up 4.1 per cent of gross annual expenditure.<sup>6</sup>

#### Box 4.1 The benefits of equipment – case study<sup>7</sup>

Pressure-relieving mattresses or special seating may be particularly cost-effective by preventing the development of pressure sores, contractures, or skeletal deformity. Once pressure sores develop, the patient will lose dignity, suffer considerable pain, and the NHS will have to pay for district nurses' time and/or expensive plastic surgery to solve the problem. Apart from the fact that pressure sores cause considerable pain and can be life-threatening, the cost of prevention is small compared to the cost of community nursing time required once sores have developed, or to the £35,000 cost of the in-patient episode that would be needed to treat serious cases.

**4.11** As well as creating problems for children and families, long waiting times also increase complaints and the time and energy which professionals have to spend responding and chasing progress, making the system less efficient. Waiting times can be a major factor in driving up staff costs and in disrupting the processing of applications, and indicates a lack of control in the application, ordering and delivery process.

## The workforce

**4.12** Disabled children and young people and their families can expect to come into contact with the full range of the children's workforce, depending on the complexity of their needs. This continuum extends from universal services such as midwives, health visitors and Sure Start Children's Centre staff, through targeted provision such as Special Educational Needs Coordinators (SENCOs) and speech and language therapists.

<sup>6</sup> *Out and about. Wheelchairs as part of a whole-system approach to independence.* DH publication, October 2006.

<sup>7</sup> *Fully equipped,* Audit Commission, 2002.

**Box 4.2 The importance of the workforce**

Good quality staff can transform a child and family's experience of services. For many people, an outstanding member of staff can make an enormous impact on their lives by providing support, information, empathy and expertise.

One disabled child's parents described the positive impact of a member of staff who made a real difference to their family's life:

Father: "She was the one who got things moving, she'd come round and then she'd chat and we realised that we weren't getting the things we should have been getting. She did a lot of things".

Mother: "She did a lot of things that probably weren't in her job description as such...She helped with a lot of paperwork. A lot of what we've got now is down to her".<sup>8</sup>

**Benefits of therapists** **4.13** Therapy services for disabled children are key to improving their outcomes. Speech and language therapists, occupational therapists, and physiotherapists help to enable and promote communication, improve and manage posture, and maximise mobility. The ability to communicate is fundamental to children's learning and progression. As well as leading to lower attainment, an inability to communicate can find expression in erratic or challenging behaviour. Postural management and other occupational therapy and equipment services for disabled children can prevent deformities (which can start to develop at 3 months old), which may be more life limiting and painful than their original condition, and might impact on digestion and respiration which can lead to costly and painful surgery.<sup>9</sup> In addition, a lack of appropriate equipment, seating, or advice on handling or facilitating communication may have a negative impact on carers, for example a bad back from continually lifting a disabled child in the wrong way.

## FUTURE PROVISION OF SERVICES

### Short Breaks

**Current situation** **4.14** Short break provision can encompass overnight short breaks, sitting schemes, befriending schemes and residential services. The Shared Care Network "Still Waiting" (2006) survey provides the most comprehensive picture of short break provision in the UK, however it is not complete as it does not have any information on disabled children receiving short breaks in residential settings. According to this survey there are 188 family based short break schemes in the UK providing services to an estimated 9,194 disabled children.

**4.15** Following the principles of Every Child Matters, Local Authorities should be assessing local need in order to prioritise the way in which they meet the needs of children in their local area. Alongside this, the Government is increasing funding for short breaks through yearly increases in the Carer's Grant, leading to increases in services for parents of disabled children. The Carers Grant is worth £185m in both 2005-06 and 2006-07, with approximately 20% allocated to children's services, including carers of disabled children. In addition, the Government has recently announced an

<sup>8</sup> *Services for disabled children*, Audit Commission, 2003

<sup>9</sup> *The Chailey Approach to Postural Management*, Pautney, Mulcathy, Clarke and Green – South Downs Health NHS Trust, 2000.

increase of £25m for emergency respite care for 2007-08, some of which will be available for disabled children and their families.

**4.16** Both existing and new resources need to be spent in the most cost effective manner, which combines service quality to both parents and children and measurable outcomes. Currently, there is variation in the ways short breaks are provided, with some Local Authorities demonstrating more flexibility than others in meeting the needs of families with disabled children, and providing more efficient services.

#### **Box 4.3 Efficient and effective short break provision**

Cheviots Children's Disability Service is part of Education Children's Services and Leisure within the London Borough of Enfield. Since the 1980s the Cheviots Management believed that many of the children in residential settings could live at home if there were more opportunities for parents/carers to access a short break. In line with current thinking and legislation they have realized that families with disabled children need more than just overnight breaks. They require services which reflect the changing nature of family life. With this in mind they began to develop a menu of options including holiday playschemes and home care support utilizing existing money that had previously been invested in long-term care.

In the 1990s Cheviots began to work more proactively with parent/carers and partner agencies to collectively develop and improve service delivery. Consulting with parents prompted the development of a home sitting service.

The service aims to provide families with the right level of support at the right time, through playschemes, after-school clubs, homecare, home sitting, weekend care, overnight breaks, direct payments and support for young carers. The array of available services provides a 24/7 delivery model. It is about 'making a difference' and ensuring families do not feel isolated. Sometimes that can be as little as 8 hours a month home sitting, particularly in the case of a young and newly diagnosed disabled child. Sometime it is a more substantial support package with three or more services. It offers families choice, supporting them in leading their lives.

Cheviots success culminated in the award of a Charter Mark in 1993 for excellence in the delivery of public services. Cheviots was one of the first social care agencies to be awarded Charter Mark and presented its model of service delivery at the launch of the following years awards.

**Barriers to enhanced provision** **4.17** There is a need for a better understanding of the current picture of short breaks provision and the need for such services. There is evidence, however, that there are lengthy waiting lists. The Shared Care Network survey shows that over 90 per cent of short break schemes reported having waiting lists, with families commonly waiting up to a year for services.

**4.18** Evidence also suggests that there is a lack of staff in schemes to carry out proactive recruitment, training and support to carers and the necessary development and regulatory work in order to meet the needs of disabled children and their families. There are also capacity difficulties in some areas, with insufficient attention given to ensuring that there is a level playing field between public, private and voluntary sector provision.

### **Further action**

**4.19** Recognising the critical importance and significant benefits of short breaks to disabled children and their families, **Government will provide a specific grant of £280m over the CSR period to deliver a step change in the provision of short breaks. This**

**grant makes provision for an additional 40,000 fortnightly short breaks for severely disabled children by 2010-11.** Pathfinders involving local authorities and providers will develop best practice in building efficient, high quality short break provision based around the needs of disabled children and their families. Provision will then be rolled out across the country by 2010-11.

**4.20** This funding will be underpinned with guidance from the DfES and DH (in partnership with the voluntary sector and the ODI), which will:

- assist local areas in planning more effectively for their population in need of short breaks, with a needs assessment of the local population;
- build and support a diverse and high quality market of public, private and voluntary sector providers;
- ensure provision is commissioned fairly and cost-effectively;
- present solutions to the particular problems faced by groups of children with autistic spectrum disorders, children with complex health needs and children from black and minority ethnic communities; and
- allow disabled children and their families to influence the range of provision, have real choice, and confidence that provision is safe.

**4.21** The NHS CSR settlement will also provide additional funding to provide short breaks for disabled children with complex health care needs.

**4.22** This should be accompanied by evaluation of the efficacy of different types of provision, which will continue to feed into best practice guidance, and data collected on the percentage of the population accessing short breaks at a local level to demonstrate that improvements are being made.

## Childcare

**Current situation** **4.23** Support for parents for childcare is provided through a number of sources, including the childcare element of the working tax credit. Families with disabled children receive an extra (means tested) £2,440 a year as a disability element of the child tax credit, and families with a severely disabled child receive an additional extra £980 a year.

**4.24** In addition, the Sure Start grant includes resources to support the inclusion of all children in early years and childcare settings, including those with Special Educational Needs and disability. This funding can be used to support early intervention, provide training, and fund adaptations to equipment or facilities for childcare providers. In addition, funding from the Dedicated Schools Grant can be used to support the provision of area SEN Coordinators (SENCOs), to provide support to settings in delivering childcare for disabled children with SEN and disabilities.

**Extent of provision** **4.25** Disabled children will also benefit from the free childcare available for all 3-4 year olds, however initial take-up statistics are lower for parents with disabled children or special education needs, with 82 per cent of children aged 3 and 4 with disabilities or SEN having used childcare in a sample week compared to 87 per cent of other children.<sup>10</sup>

<sup>10</sup> *Childcare and Early Years Provision: A Study of Parents' use, views and experiences.* DfES research report 723, Bryson, Kazimirski, Southwood, National Centre for Social Research, 2006.

**4.26** Survey evidence also suggests that families with disabled children are less likely to access childcare than other families. A Sure Start study found that children who had a statement of SEN were less likely than children with non-statemented needs or children without special needs to have received childcare (although part of this may be explained by the older age profile of statemented children).<sup>11</sup>

**4.27** These surveys aside, Government does not currently collect data on the numbers of disabled children accessing childcare. However, the Childcare Act 2006 places a duty on Local Authorities to assess the demand for and supply of childcare in their local area and identify gaps in provision. This is expected to improve the provision of data on the take-up of childcare by disabled children and their families. Under the Section 11 duty in the Childcare Act, Local Authorities will be required to assess the demand (by age and type of childcare) in each sub-local authority area for specialist childcare for disabled children and those with SEN, and the number and nature of places available for children who need special care due to a disability or SEN. Local Authorities will also be required to analyse the gap between demand and supply of childcare for disabled children who need special care, and reflect it at the level of the whole Local Authority area, in their published assessment documents. These documents will be finalised by the end of March 2008, and Local Authorities must keep them under review between assessments (which must take place at least every 3 years).

**4.28** This is the first step towards fulfilling their duty to secure sufficient childcare to enable parents to work or to undertake education or training leading to work (which will come into force in April 2008). In order to meet this duty, Local Authorities must have particular regard to the provision of childcare which is suitable for disabled children. Childcare must be sufficient in terms of the number of places, affordability, and appropriateness, so far as is reasonably practicable.

### Barriers to enhanced provision

**4.29** Existing evidence and testimony from parents, the voluntary sector and professionals suggest that both affordability and accessibility can act as barriers to disabled children accessing childcare. Appropriate childcare places that meet the needs of disabled children may not be available, and where they are, survey evidence suggests that they tend to be more expensive. A recent survey found that 41 per cent of Children's Information Services in England reported insufficient provision of appropriate services for disabled children in their area for 0-13 year olds, and 32 per cent said they were unsure. For 14-18 year olds, 46 per cent reported insufficient provision of appropriate services, and 39 per cent were unsure.<sup>12</sup>

**4.30** The key barriers to disabled children accessing childcare, identified by surveys and qualitative feedback from parents and voluntary sector organisations, include:

- lack of awareness and information, perception and trust of services amongst parents of disabled children;
- attitudinal barriers on behalf of some providers;
- a lack of disability awareness training for the workforce, and specifically, issues with the level of specialist training and expertise in the workforce (for example for children with additional communication need or in behavioural management);

<sup>11</sup> *The use of childcare among families from minority ethnic backgrounds and among families with children with special educational needs.* Sure start, March 2005.

<sup>12</sup> *Childcare costs survey 2007: Childcare costs for disabled children,* Daycare Trust

- the perceived and real cost to providers of securing the right capacity (such as facilities and equipment), and capability (such as staff with the right skills); and
- the cost of providing appropriate transport provision for disabled children and their families, to help them access services.

### Further action

**4.31** High quality childcare for disabled children will improve disabled children's development, and will help their parents rejoin the workforce if they choose. Given that there is survey evidence that families with disabled children find it harder to find appropriate childcare for their disabled children, there is a case for further intervention to encourage better access to childcare for disabled children.

**4.32** The Childcare Act 2006 placed an important new duty on LAs to secure sufficient childcare for working parents, and to pay particular regard to the needs of parents with disabled children. To help improve access to childcare and reduce attitudinal barriers, **Government will set up a childcare accessibility project, initially piloted in 10 Local Authorities, with best practice rolled out to a larger number of Local Authorities.** The project will test out ways of meeting provision for disabled children highlighted in the childcare sufficiency assessments which all Local Authorities will have undertaken by April 2008. **New investment of £35m over the period will complement funding available through the General Sure Start Grant to assist with childcare providers' capital costs associated with the sufficiency duty.**

**4.33** This childcare accessibility project will be evaluated to collect better information on the degree of additional costs of childcare for disabled children, and it should be used to develop best practice on increasing accessibility of childcare which can be shared across the country. Data should also be collated as a result of local authorities' new duties under the Childcare Act to measure the number of disabled children accessing childcare.

**4.34** The review found that the current backdating rules relating to the disabled and severely disabled child elements of Child Tax Credit mean that some families are missing out on the financial support that they are entitled to. Since May 2006, the Tax Credit Office has been using data from the Department for Work and Pensions on disability living allowance to award, and amend awards of the disabled element and the severe disability element of child tax credit, and the severe disability element of working tax credit, simplifying the process for claimants. The Government is now actively examining further options for streamlining the notification procedure between DWP and HMRC, and will also look for other ways in which to further improve the system in the future, in consultation with stakeholders, and will report on progress in this year's Pre-Budget Report.

### Wheelchairs and equipment

**4.35** The last guidance on wheelchairs was issued in 1996, when electrically powered indoor outdoor wheelchairs (EPIOCs) became available for severely disabled people through the NHS. Additional ring fenced funding totalling £50m was available for EPIOCs and vouchers to offer financial aid to users who prefer to contribute to buying an alternative wheelchair of their choice privately, over the initial four year period. From April 2000 the funds were placed in health authority revenue allocations recurrently with annual increases.

**4.36** Target times for the delivery of wheelchairs of 16 days for a powered wheelchair and 4 days for a non-powered wheelchair were introduced following a National Audit Office study which found that waiting times for powered wheelchairs ranged from 13-143 days and for non powered wheelchairs from 3-28 days.

**4.37** Effective joint working between the NHS and Local Authorities is essential to ensure the provision of high quality community equipment services, and parents and the sector have provided much anecdotal evidence that there is often a breakdown in joint working, with children falling between provision and waiting even longer for equipment.

**4.38** The 1999 Health Act signals the Government's view that such joint arrangements should become the norm. The Act gives new powers to health authorities and councils to address these traditional problems by enabling:

- pooled budgets so that staff from either NHS or social services can commission or provide services from the same pool of money and integrated packages; and
- lead commissioners, where one Local Authority takes over entire responsibility for the service.

**4.39** This approach is underpinned by the joint national priorities guidance and new performance frameworks for health and social services.

### Extent of provision and barriers to access

**4.40** Many children and families currently face long waiting lists for both assessment and provision of equipment and wheelchairs. There is also variation in the overall time taken for social services to provide equipment, and for the NHS to provide wheelchairs.<sup>13</sup> Provision may also focus too heavily on clinical need, and may fail to take into account the impact of independent mobility on social, development and educational attainment, or on family's preferences (for example, being able to get to school and sit up and learn in class).

### Further action

**4.41** The DH *Community equipment and wheelchair review* is looking at a radical overhaul for assessment and provision of equipment and wheelchair services for all client groups, including disabled children, to improve the efficiency of provision, and reduce waiting times for assessment and provision of equipment. The review has taken a collaborative approach, involving all stakeholders, to designing a new model for service delivery of community equipment and wheelchairs.

**4.42** The review found that there is a lack of informed and proactive commissioning, no evidence of cost modelling across health and social services, little emphasis on performance managing the service, little evidence of demand forecasting or planning, and some areas still operating legacy budgets. The programme has developed a new retail model for delivery of community equipment services. It puts users and carers at its heart and is supported by an outline business case. Over the next 10 months, the team will work with users and carers councils and their PCT partners, practitioners and other stakeholders to develop the outline model to operational status.

<sup>13</sup> *Fully equipped, the provision of equipment to older or disabled people by the NHS and social services in England and Wales*, Audit Commission, 2000.

**4.43** The Government will therefore continue to scope and ultimately deliver a radical reform of community equipment and wheelchair provision, with full consideration of and provision for the needs of children through the DH Community equipment and wheelchair review, including:

- DH working with DfES to ensure that the demand forecasting tool being developed by the Care Service Efficiency Delivery programme will reflect the differing requirements of children in the provision of community equipment and services, including an understanding of the disabled children population;
- assessment which considers the complete needs of the child, including social and educational needs as well as clinical needs, and the needs of the family and carers;
- the impact of equipment and wheelchairs on children's development, including the detrimental impacts of waiting considerable periods for equipment (such as growing out of equipment);
- the expectation that most parents young disabled people will not be in a position to self-fund; and
- dedicated staff in retail provision centres trained specifically in provision of fitting wheelchairs and equipment for children with complex needs, which takes account the specific safeguarding issues in relation to children.

**4.44** Subject to CSR decisions, the NHS will provide additional resource for 2010-11, once the Community Equipment Review has bedded in, to update the stock of wheelchairs and improve provision of community equipment for disabled children.

## The workforce

**4.45** Evidence provided to the Review shows that the experience of disabled children and their families varies greatly, with some recalling helpful and proactive support from professionals working with them, others reporting gaps, discontinuities and unmet needs in services, and some citing obstructive or insensitive responses from people and services.

**Current situation** **4.46** Workforce issues need to be seen in the context of an increased emphasis on mainstreaming provision of services for disabled children. *Every Child Matters: Change for Children*, and the *National Service Framework for Children, Young People and Maternity Services* all anticipate significant increases in the numbers of children with disabilities and SEN in mainstream provision. The rapid development of the Children's Centre and Extended Schools programmes, together with the development of the Early Years Foundation Stage and the new role of the Early Years Professional, also imply a proactive approach to staff development around disability and Special Educational Needs.

**4.47** In terms of specialist workforce issues, the number of therapists has been increasing since 1997. There are currently 6,623 Speech and Language Therapists working in the NHS, an increase of 36 per cent since 1997. These increases will support service improvements in the Government's core objectives including the National Service Frameworks (NSF). Through the NSF, PCTs and Local Authorities should ensure that the supply of timely therapy services is sufficient to meet the needs of children and young people who require it, based on assessed needs. As can be seen from box 4.4,

many PCTs have developed more effective provision of therapy services through service redesign.

**4.48** In addition, the DfES has decided to focus the opening round of its Inclusion Development Programme (continuing professional development for teachers and others) on speech, language and communication needs and dyslexia. This is in recognition of the fact that communication is essential to children's learning and development.

**Box 4.4 Examples of services redesign: increasing efficiency of therapy services.**

In East Sussex, a drop-in monthly clinic was set up in 2002 to enable immediate access to children and parents without an appointment. The child either receives advice and a repeat check up at a later date or an appointment for a fuller assessment.

Waiting times have decreased from 8 months for assessment, and 12 months for treatment to commence to 1 month for assessment. The number of children taken on to the caseload has decreased by 50% and therefore the overall wait for treatment has also decreased. The feedback from parents was such that drop-in clinics have been set up in all community clinics in this area.

Another innovative good practice initiative involved 4 geographical mini-teams which meet weekly to allocate work load – with some referrals requiring telephone reassurance only, others initial screening. Where 2 localities have high Do Not Attend rates, drop-in clinics have been developed (last 3 years) and the model will be developed in the Children's Centres.

There is a Specialist Support Service to parents/education where there have been detailed assessments and therapy in the past but it is no longer indicated and parents/teachers may need support and advice, supported by an educational psychologist.

At the end of an episode, clear and specific indicators for re-access are given and communicated to several professionals and parents. This prevents ongoing reviews but also prevents children slipping through the net.

**Barriers to accessing services** **4.49** Despite these improvements, parents identified problems in accessing universal services, hindering inclusion of their disabled child in society and placing unnecessary burdens on already stretched specialist services. A lack of skills and training make situations more difficult and upsetting for disabled children and their families, with problems ranging from poor practice in giving news on diagnosis exacerbating stress, to staff unable to offer the care they are engaged to provide for disabled children.

**Box 4.5 Problems in accessing universal services**

"you know perfectly well he's not going to be able to join in with a group because a) they don't know how to deal with him and b) they won't have the staff to deal with him... People are very keen to be seen to be doing inclusion but that doesn't just mean saying "Yes, come along". There's more to it than that."<sup>14</sup>

<sup>14</sup> *Services for Disabled Children*, Audit Commission 2003

**4.50** Specific areas where training and preparation of staff appeared to be lacking across all services include communication and interpersonal skills, communicating directly, expertise in behavioural management (especially with Autistic Spectrum Disorder and challenging behaviour), moving and handling, and personal care. In addition, there is a perception that there is still some way to go in tackling attitudinal barriers (in terms of both leadership and the general children's workforce), which block inclusion in mainstream services such as childcare.

**4.51** The Review also received evidence about long waiting lists and strict eligibility criteria for therapy services as a result of limited budgets and national shortages of trained professionals.<sup>15</sup> For families, staff recruitment and retention problems have a major impact on the quality of the service that they receive. The Audit Commission found that many spoke of the loss of continuity of care resulting from high turnover, with new relationships having to be built from scratch each time a new worker was introduced. One family talked of seeing four speech and language therapists in the space of a year. Sometimes there would be a delay in the arrival of a new worker, setting back any advances that the child had achieved.<sup>16</sup>

### Further action

**4.52** There is currently a lack of a coherent approach to developing the skills and competencies required by those working with disabled children and young people with disabilities, underpinned by a lack of knowledge about current levels of expertise in the workforce. To help make services more accessible for disabled children, all those who work with children, young people and their parents and carers need appropriate training and development provision to ensure that they have an awareness of working with disability and the appropriate skills. This may involve disability awareness training, or may involve more intensive training, such as in communication or behavioural management.

**4.53** As a step to meeting this goal, **the Government will Commission the Children's Workforce Development Council (CWDC) working with Children's Workforce Network (CWN), to research the skills and behaviours required by the workforce to service disabled children effectively and to identify gaps.**

**4.54** The Government recommends that PCTs and Strategic Health Authorities develop better data on the number of disabled children and young people in need of and receiving therapy services to allow them to better plan, commission, and recruit to provide for their population. This should be part of the wider data collection work recommended by the review in chapter 3.

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<sup>15</sup> Submission to the review from the Royal College of Occupational Therapists, 30 August, 2006.

<sup>16</sup> *Services for disabled children*, Audit Commission, 2003

**5.1** This report is a further step along the way to meeting the Government's vision of equality of opportunity for all disabled children and their families. Building on the progress being made in implementing the *National Service Framework for Children, Young People and Maternity Services*, the Special Education Needs (SEN) framework *Removing Barriers to Achievement*, and the *Improving life chances for disabled people report*, it will further improve outcomes in terms of educational attainment, social and emotional development, and a degree of independent living, choice, and control.

**5.2** As part of Budget 2007, the Government announced an early Comprehensive Spending Review (CSR) settlement for the Department of Education and Skills (DfES), informed by the findings of this Review. It will see education spending in England rise by 2.5 per cent a year in real terms on average between 2007-08 and 2010-11. This will allow the DfES to immediately start planning provision for disabled children for the CSR period, underpinned by £340 million of investment to:

- empower disabled children and their families, with a clear and transparent “core offer”, piloting Individual Budgets, and £5 million to support best practice on engagement, such as parent forums;
- encourage more responsive services, with disabled children prioritised at both a local and national level, developing a national indicator on disabled children;
- provide better coordinated support, delivered as soon as disabled children and their families need it, with £19 million for a Transition Support Programme; and
- improve provision of key services, with a grant of £280 million over the CSR to boost provision of short breaks, and a childcare accessibility project underpinned by £35 million of additional resource.

**5.3** HM Treasury and DfES will continue to work with other departments to ensure that the findings and recommendations of the Review are reflected in other departmental priorities, including the Department of Health who have a key role to play in improving disabled children and young people's lives.

**5.4** Any additional costs to Local Authorities arising from new policy initiatives as a result of this review will be funded by the relevant Government Departments as required under the Government's new burden rules.

**5.5** This vision cannot be achieved without the skills and expertise of local public services, voluntary groups, community groups, and the professionals working directly with disabled children and young people and their families. The Government will therefore continue to engage and collaborate with these groups to inform the way the recommendations in this review are implemented and built upon in the future.

**5.6** This document represents the final report and recommendations from the third sub-review of the Policy Review of Children and Young People, to inform the CSR. Further details of the Comprehensive Spending Review can be accessed through the Treasury's website: [www.hm-treasury.gov.uk](http://www.hm-treasury.gov.uk).

**5.7** Government would like to thank all of those who submitted evidence to this review, brought examples of the excellent work that they are doing across the country, and took the time to share their advice and expertise.



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