

Parliamentary hearings on services for disabled children

Full report

October 2006



The Report is published by an Ad Hoc Parliamentary Committee –
The Parliamentary Hearings on Services for Disabled children.
Following publication, the Committee will disband.

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Acknowledgements

The hearings panel thank Victoria Silver, who acted as Clerk to the hearings, working closely alongside Ewan Russell, Parliamentary Assistant to Rt Hon Tom Clarke MP. We also thank Steve Broach, who worked closely with the review members on the drafting of the report, and Kate Williams, who supervised the data analysis process.

We are grateful for the support of the representatives from the consortium of charities working with disabled children that co-ordinated these hearings – Francine Bates for Contact a Family, Christine Lenehan for the Council for Disabled Children, David Congdon for Mencap and Brian Lamb OBE for the Special Education Consortium.

The hearings were supported by *Children Now* magazine, who publicised the hearings and produced a flyer to promote the written submissions process – we are extremely grateful for this assistance. Finally, we would like to thank IDA for their excellent work to analyse the data from our written submissions, and Expression for their prompt turn-around of the design and print for our report.

Disabled children have huge potential. The role of services for disabled children is to help children achieve that potential, and to allow their families to lead ordinary lives.

Recent years have seen Government develop a comprehensive package of policy in relation to disabled children. Yet our parliamentary hearings have taken evidence that highlights the struggle facing many families with disabled children to access even a basic level of services and support.

Our hearings also took evidence of outstanding examples of good practice in providing support to families with disabled children, including the Spark centre in Tower Hamlets and the Salford Early Support programme, which we both had the opportunity to visit as part of these hearings. We applaud the professionals and support staff who work with passion and dedication to deliver these services to disabled children.

We also applaud the government for focussing on disabled children's services in the current children's policy review, and thank Ministers Ed Balls MP and Lord Adonis for inviting parliamentarians to contribute to this review through our hearings. This has been a groundbreaking exercise in consultation with parliamentarians and stakeholders and we believe that our hearings have added real value to the government's review.

We would like to thank the hundreds of disabled children and young people, parents, professionals and organisations who submitted evidence to our hearings, alongside our fellow parliamentarians who made valuable contributions from their constituency experience.

This report reflects all the evidence we received, and demonstrates a compelling cross-party consensus that services for disabled children matter, that families for disabled children should be a policy priority for government and that significant additional funding is needed from the Comprehensive Spending Review 2007 to ensure that every disabled child gets the support they need and deserve.

Rt Hon Tom Clarke MP, Chair

Joan Humble MP, Vice-Chair

Introduction

This report results from an innovative exercise in consultation carried out alongside a government review process. HM Treasury (HMT) and the Department for Education and Skills (DfES) jointly announced in July 2006 a review of children's services, designed to make recommendations to the 2007 Comprehensive Spending Review. One of the three strands of this review is focussing specifically on services for disabled children.

In order to allow parliamentarians and other stakeholders to influence the review, Ed Balls MP, Economic Secretary at HMT, and Lord Andrew Adonis, Parliamentary Under-Secretary at DfES, jointly wrote to Rt Hon Tom Clarke MP and Joan Humble MP, inviting them to establish a cross-party panel of MPs chaired by Tom Clarke MP to hold hearings on services for disabled children. Members of the hearings panel are listed in the appendix to this report. This report and its recommendations represents the consensus view of all the MPs who were members of the hearings panel.

The panel held three public hearings, following the life cycle of a disabled child and focussing on:

- early years services
- family support and children's services
- transition to adulthood.

In addition, a written submissions process was established, allowing disabled children and young people, parents, professionals and other stakeholders to input into the hearings. 258 submissions were received by the time the data was analysed, and 308 submissions were received in total. Of the submissions sent for data analysis, 145 were from parents, 105 were from professionals and eight were from disabled children and young people.

Tom Clarke MP and Joan Humble MP also visited services and families in Manchester and Tower Hamlets and met with the Salford Early Support team to further inform the hearings process.

The hearings were supported by four national organisations working with disabled children and their families – Contact a Family, Council for Disabled Children, Mencap and the Special Education Consortium – and by Children Now magazine. The process of the hearings was informal, consensual and cross-party in nature. We were delighted that eight government Ministers contributed to the hearings process, which demonstrates the level of engagement across government in our work. A full list of participants in our three hearings sessions is in the appendix.

Ed Balls MP stated that the hearings were a way that 'experts, parliamentarians and families can discuss with ministers at the beginning of our work and identify the issues we should think about'. We hope that Ministers will agree that the hearings process was indeed a useful dialogue, and urge them to take note of this report in determining the content of their policy review.

Where unattributed quotations appear within the text of the report, they are taken from written submissions from parents to our hearings. Other quotations are attributed to individuals or organisations who made written or oral submissions.

Context

This section covers:

- the changing population of disabled children
- what services do disabled children and their families need?
- the consequences of getting services right – or wrong
- the current policy context.

The changing population of disabled children

In 2006, the population of disabled children looks dramatically different to thirty years ago. It is now acknowledged that 7% and not 3% of all children have a disability or long-term condition, a total of 770,000 children and young people in the UK.

The hearings panel took evidence from both official sources and practitioners, which made it clear that services are faced with far higher numbers of children with complex needs that they have ever previously experienced. As a consequence, many children are not getting the support they need.

Current provision has not kept up with modern developments and a generation of children have been enabled to survive but not helped to live and achieve their potential. CHOICES for Families of Children with Arthritis

Demand for our services has increased dramatically over the last few years – and the demographic evidence (to include survival at birth, autism rates etc.) is that this trend will continue. Children's services manager

The charity SENSE told us that, 'the number of complex babies and young children whose families contact SENSE for advice and support has risen over recent years. Extreme prematurity and birth trauma, as well as improved diagnosis of genetic and syndromic conditions, either at birth or later on during school life, are the reported causes of this change.' Two groups identified as presenting an increasing challenge are children with autism and children with complex health needs. Both these groups require significant specialist input to be included in society and achieve their full potential.

The rising incidence of autism and children with behaviour that challenges is real and needs to be met by planned development in all service areas underpinned by new resources. Children's services manager

Current funding levels for services for disabled children and their families are set demonstrably too low. They have not kept pace with growing numbers of children with autism and those with other complex medical and behavioural difficulties. TreeHouse (autism education charity)

More children with very profound problems are being kept alive through medical advances, and yet services aren't there to match the need for support.

Research has shown a 77% increase in the number of children who are oxygen/ventilator dependent (from 135 children in 1997 to 241 in 2000).¹ In two years there was a 60% increase (to 887 children) in the number of children who are tube-fed.² In 1998/9 there were an estimated 6,000 technology dependent children.³ From 1984–89 to 1990–94 the survival rate of low birth weight babies increased from 27% to 42%. Of the babies born at less than 1500 grams, up to 50% show later cognitive impairment.⁴

Other groups of disabled children are also increasing in number. There are more children requiring rehabilitation following acquired brain injury. ICAN highlighted a report by the Basic Skills Agency in 2002, which showed a significant drop in the speaking and listening skills of British primary school children. This shows how important it is to deliver a spectrum of support to disabled children to reflect the level of need of each child.

What services do disabled children and their families need?

A strong legal right to services is needed. By 'services' I mean mainstream and specialist – anything that enables the child to live a 'normal' life.

Disabled children are not a homogeneous population. Every disabled child will need his or her own package of services to ensure that they achieve the Every Child Matters outcomes. Disabled children have the right under disability discrimination legislation to access all the services that other children use. This means everything from GP surgeries through playschemes to mainstream education. In addition, many disabled children will need input from a range of specialist services, such as equipment services, therapists and specialist teachers, if they are to achieve their full potential.

It is essential that service providers are flexible and child-centred in their approach to providing services for disabled children and their families. A mixture of accessible mainstream services and specialist services should be available to every family, with the precise mix determined by each individual child's needs.

I have a son with severe/multiple disabilities who goes to a wonderful special school. I have a daughter with severe physical disabilities who goes to a wonderful mainstream school. I think that both are equally valuable and support choice for children and parents between special schools and mainstream schools.

The consequences of getting services right – or wrong

Each child has the right to a specifically tailored programme of help and each parent should have the right to sleep at night knowing that the right provision will be in place quickly for their child.

Parents and families hugely value the services they receive to support their disabled children.

¹ Ludvisgen, A. and Morrison, J. (2003) *Breathing Space: community support for children on long-term ventilation*, Barnardos.

² Townsley, R. and Robinson, C. (2001) *Food for Thought*, Norah Fry Research Centre.

³ Glendinning, C. et al (1999) *The community-based care of technology dependent children in the UK*, National Primary Care Research and Development Centre.

⁴ Marlow, N. et al (2005) 'Neurological and developmental disability at six years of age following extremely preterm birth', *New England Journal of Medicine*, 352, pp. 9–19.

I would like to commend all teachers, support workers and therapists working in the field of special needs for their kindness, empathy and positive attitudes.

I am fortunate to finally receive respite. What a wonderful relief. One night a week we can be a normal family. Go to the cinema, pub or for a meal or just be. No strict routine, no bathtime, no struggle to medicate, no getting up four or five times in the night. Bliss.

However, evidence to our hearings made clear that the failure to consistently deliver appropriate services at the right time was causing huge distress to disabled children and their families.

Our family are facing break up as a result of the lack of support from services.

Reflecting on this distress, Professor Sir Al Aynsley-Green, Children's Commissioner for England, told us that 'the plight of children and families with disabilities is nothing short of a national scandal'.

In written and oral evidence, the anger of families who felt that they had been totally let down by the system came through strongly.

At the moment disabled children don't count. All that happens is government fights every step that parents try to make and tries to cut to the bone services for disabled children year on year.

Parent and former professional working with disabled children

Written evidence to the hearings spoke of inappropriate education placements leading to school exclusions; withdrawal of respite services leading to family breakdown; and the lack of appropriate childcare places preventing parents from accessing work. In a Contact a Family parent survey in 2003, 76% reported stress or depression and 72% reported tiredness or lack of sleep.

Parents made clear that they cannot afford to wait for pilots and pathfinders to develop appropriate services for their children and families.

Whilst new initiatives are being researched and set up, families are sadly receiving less support and input from the professionals in managing the day to day challenges of supporting a disabled child or young person.

Parents also told us how fragile their position is in relation to the services they receive.

After a six year wait for access to respite care (due to demand) we currently have one night per month support; this is under threat.

One family who submitted evidence received services through a voluntary agency commissioned to provide support workers, play workers and volunteers and provided play schemes every holiday. However, when the service level agreement with the voluntary agency ended, the service went back into the statutory sector and the level of service drastically decreased. In particular, holiday playschemes providing essential short breaks for parents and carers were ended without consultation.

Parents criticised the lack of training and expertise in disability amongst professionals working with children and felt that short-term cost implications were a greater priority than the needs of the child in determining the levels of service received. Moreover, some parents identified the potential cost savings of investing in services for disabled children.

Disabled children are being short changed and often underestimated. Many could work and make a worthwhile contribution to society if better school/college provision was made. The more effort put in as children, the more rewards can be reaped as adults.

Basically, if you lot get it right then these children could be useful, productive adults for this country!

The current policy context

The whole subject of Every Child Matters is a sham. Every child matters if they are normal, as a parent, carer and mother I have had to fight for everything my daughter gets.

Every child matters – that means that every disabled child matters too.

Ed Balls MP, introducing the first session of the hearings

Disabled children and their families have been the subject of significant policy developments in recent years. The Every Child Matters agenda, seeking to co-ordinate services to deliver the five key outcomes for every child, has the potential to particularly benefit disabled children, who use a large number of different services. The Children's National Service Framework, setting standards for health and social care services and for the interface between these services and education, has a specific module on disabled children and children with complex health needs. A new strategy for special education was put in place by *Removing Barriers to Achievement*, and the Prime Minister's Strategy Unit makes recommendations covering early years and transition in their *Improving life chances of disabled people* review. Important new disability equality duties were introduced by recent amendments to the Disability Discrimination Act requiring public services to ensure equal treatment for disabled children and adults.

During our session on early years services, Beverley Hughes MP, Minister for Children, told us that 'I think we've been trying really hard to make sure in all of the general change that we're trying to effect in children services, that the needs of disabled children and their families are there as a very visible strand that both we at central government and local authorities and local agencies have to take into account.' The Minister particularly highlighted the ten-year childcare strategy and the recent Childcare Act as policy initiatives which had prioritised disabled children.

Despite this welcome policy focus, we took evidence of significant barriers that remain to delivery of improved services for disabled children and families. Firstly, even following Every Child Matters, some service providers continue to think in service silos. There is the potential that

these silos will be reinforced by policy initiatives which are seen to come from a particular direction. As one health professional starkly told us:

*NSF (National Service Framework) – Health
ECM (Every Child Matters) – Local Authority
Removing Barriers to Achievement – Education
No joint ownership*

Many submissions also spoke of the need to adequately fund these policy initiatives, to prevent local agencies being set targets to deliver services that are not backed up by resources.

The NSF is a great document to read, but the resources are not attached to put it into practice. NSF (National Service Framework)

This government has produced fantastic documentation around disability, the Improving Life Chances document is wonderful but words are not enough, they have to be supported with funding.

The DDA (Disability Discrimination Act), SENDIST (Special Educational Needs Tribunal) etc are all worth nothing if not resourced, and people not given adequate training.

There has been a number of initiatives to improve services for disabled children over the past few years and in theory services should becoming more responsive and innovative. However, because of lack of funding in some of the statutory services they are struggling to meet the demand to provide even basic services. Voluntary sector professional

Stakeholders also felt that government could do more to co-ordinate policy and ensure that agencies treat disabled children as a delivery priority.

Professionals are being directed different ways from government, causing conflict at service delivery level. Education professional

The Children's NSF and all the government guidelines do not appear to have brought about any improvements. In fact, the contrary is the case. We have meetings in excess, with goalposts changing all the time. No real plans have been followed through. Health professional

This lack of determination to push through improvements stems from the highest level; there is a woeful lack of collaborative policy and working between government departments. Until there is pressure and endorsement from the government, then services for disabled children will continue to under perform and fail these young people. Whizz-Kidz

Commenting on Every Child Matters, ICAN told us that 'Many local authority children's services departments and PCTS are paralysed by restructuring. Every Child Matters progress is being held up by both the local turbulence from PCT and LA change and through an overload of centrally run ECM programmes. This is of concern for all children, but the particular concern for children with a disability is that limited budgets and time constraints mean that ... they are, sometimes consciously, being excluded from work intended to achieve the ECM outcomes'.

ICAN called for Every Child Matters to be reinvigorated as a programme of implementation, with a public recommitment to the Every Child Matters outcomes as the minimum standard for every child. Although this extends beyond our narrow remit to examine services for disabled children, we would support this submission.

Professor Sir Al Aynsley-Green, Children's Commissioner for England, summed up the evidence that while the right policy is in place, delivery is lacking.

We know what has to be done, it is there in black and white. Where are the political courage and the resources to make it real?

We hope that both political courage and resources flow from government as a result of our hearings and the review process into which they are feeding.

Pervasive themes

This section covers:

- poverty
- social exclusion
- inequality
- the lack of data
- the voice of children and parents.

Poverty

It's clear that the Government cannot achieve its objectives around eradicating child poverty unless poverty is eradicated in families with disabled children. Contact a Family

Working in a family with disabled children is much harder for mothers and this is why families are much more likely to live in poverty. Ed Balls MP

I have given up a £25k per year job and now find myself in serious poverty. If my daughter went into residential care it would cost the local authority £135k per year minimum. We shouldn't have to live like this.

The government has pledged to eradicate child poverty by 2020 and reduce it by 50% by 2010. As Department for Work and Pensions Minister Jim Murphy MP accepted from the outset in his evidence to our review, it will be impossible for government to meet its targets on child poverty without addressing the specific issues facing families with disabled children. One professional summarised the challenge:

Undoubtedly families with disabled children have greater expenses and fewer earning opportunities.

The additional costs of caring for a disabled child are well recognised.

Everything costs so much. You mention disability and you can add a zero or two to the price. Don't even think about a holiday!

In a Contact a Family/Family Fund survey from 2004, only 6% of families with disabled children reported that they were 'comfortably off' with, 92.8% reporting some form of financial difficulty.⁵

Examples of additional costs ranged from a family whose daughter needed five nappies each day, but only received three per day from social services, to a family trapped in a small flat with two children who had spent their equity on their child's therapeutic treatments. For families who need to adapt their home, improvements to the Disability Facilities Grant are welcome – yet the maximum grant of £25,000 still does not reflect the actual cost of significant adaptations to a family home.

However, families with disabled children are struggling not just to obtain additional equipment or adapt accommodation, but to meet basic living costs. The Family Fund told us that they receive many applications from

⁵ Harrison, J. and Woolley, M. (2004), *Debt and Disability*, Family Fund/Contact a Family.

families for grants to cover basic essentials such as cookers, fuel bills, transport, clothing and bedding. As the Family Fund stated ‘support should be available to families to meet their basic needs, without having to apply for charitable funding’.

Barriers to work – childcare

As our report is intended to feed into a Treasury/DfES review, our examination of poverty in families with disabled children focussed on childcare, as a DfES policy area. Alongside additional costs, the major cause of poverty in families with disabled children is barriers to work for parents. Working Families told us that ‘Too often an assumption is made by social care services that the parent will be the carer and can pick up any additional hours that social services can’t provide. This is indicative of a failure to properly assess the needs of the family, including the need for parents to work.’

Parents echoed this complaint:

I can in fact only work on a very ad hoc basis due to all the appointments and other commitments I now have for my daughter and I am not sure how much longer my employer will need me as I cannot work in school holidays at all.

The major barrier to work for parents with disabled children is access to affordable and appropriate childcare.

With no childcare available through the holidays, and lots of meetings with school, doctors etc. many of us find we can simply not go out to work.

We aren’t providing childcare so that families can work – because the demand would be so great and budgets are limited. Children’s services manager

The Daycare Trust highlighted a report by the National Audit Office from 2004, which showed that although many childcare settings describe themselves as accessible, many are also only able to offer one place to a disabled child.⁶ A recent Daycare Trust survey of parents with disabled children found that 64% would use childcare if it was available, but 69% said it was difficult to find childcare to meet their children’s needs. One parent interviewed stated, ‘None of the 57 registered carers I called when my partner left were qualified or willing to take on a child with my daughter’s disability’.

The Daycare Trust also provided an example of the benefits the Sitter Service in Scotland had provided for families with disabled children, offering both respite care and more regular childcare. The evaluation of the service highlighted particular benefits to families with disabled children.⁷

Contact a Family submitted five reasons why the national childcare strategy is failing to deliver more appropriate and affordable childcare for disabled children.

- There is a lack of inspection of the supply of childcare places for disabled children.

⁶ National Audit Office (2004), *Early Years: Progress in Developing High Quality Childcare and Early Education Accessible to All*.

⁷ Wilson et. al., (2003), *The Sitter Service in Scotland: A Study of the Costs and Benefits – Final Report*.

- There is no funding stream to increase the volume of childcare for disabled children.
- There is a lack of coordination between national and local childcare strategies and other legislation and initiatives aimed at supporting disabled children and their families.
- Local authorities are not planning childcare based on the increased numbers of disabled children.
- Families with disabled children are not being consulted about their childcare needs.

Following the Comprehensive Spending Review, additional supply-side funding should be invested in childcare providers, to make the childcare costs for disabled and non-disabled children equal on the point of entry. Governments in the other UK nations should also investigate establishing a Sitter Service along the model evaluated as successful in Scotland, with a clear priority to increase the availability of childcare for parents with disabled children.

Ensuring an increased supply of appropriate and affordable childcare for disabled children may require a flexible approach from Government. For example, the restrictions on allowing childcare payments via Working Tax Credit or employer vouchers to be made to family members could be waived for families with disabled children. A family member may best understand the particular needs of a disabled child, and should be able to be recompensed for their childcare.

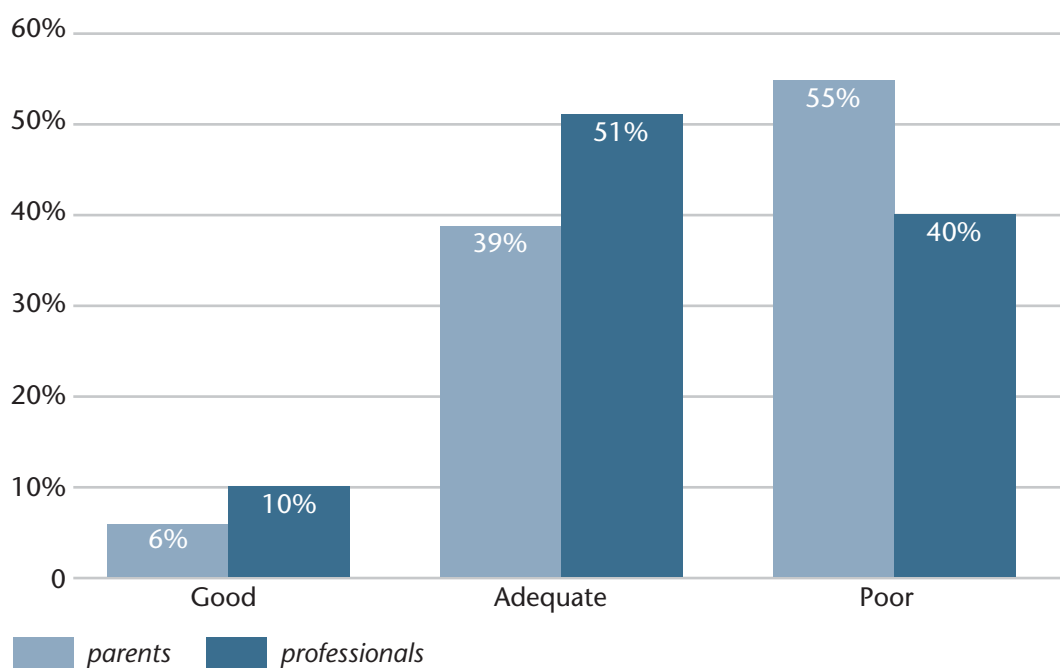
Parents of disabled children also need to be supported to find and retain work. Government should re-examine relaxing the 16-hour rule preventing parents who work less than 16 hours per week from accessing childcare assistance via Working Tax Credit. Regulations on flexible working should be strengthened to give a right to work flexibly (unless there is a clear business case against it), rather than simply a right to ask.

Recommendation

Governments in the other UK nations should investigate establishing a Sitter Service along the model evaluated as successful in Scotland, with a clear priority to increase the availability of childcare for parents with disabled children.

Benefits

With families struggling to access work as a consequence of the lack of affordable and appropriate childcare, many rely on benefits for financial support. Yet as one education professional stated, 'The experience of families suggests Poor Law principles still drive (benefits levels)'. Half of all written submissions to our hearings described benefit levels for disabled children and their families as poor.



Source: written submissions to parliamentary hearings

Particular concerns around benefits centred on Disability Living Allowance (DLA), for which the application forms were described in one written submission as ‘a parent’s dread’. DLA forms could be further simplified and Government could consider awarding DLA for longer periods, without the need for further forms, for children with long-term conditions where variation in the level of need is likely to be marginal.

Further anger was reserved for Carer’s Allowance, the rate of which was described as an ‘insult’ to carers.

£40+ per week Carers Allowance is unbelievable. My son’s provision at age 16 was in a residential setting which cost £2,200 per week. Some difference!

Carers allowance at £46 approx a week is demeaning. We as full time carers save the Government millions of pounds a year.

I received £46.95 per week to stay at home looking after my child. When I got a little part-time job I lost this, and my child tax credits. It was costing me to work. I kept the job to save my sanity this year, but next year I won’t be able to afford to.

The hearings panel received numerous submissions and suggestions to ensure that the government’s child poverty targets for disabled children and their families are met. Many of these involved amending benefits to recognising the full additional costs associated with caring for a disabled child, for instance the childcare element of the Working Tax Credit (WTC) and Carer’s Allowance. Similarly, Government should give serious consideration to extending winter fuel grants to parents of disabled children on benefits, particularly those with disabled children under five who are at home all day and hence are incurring significant additional heating costs.

In addition, Government should consider how best to remove disincentives to work and study from the benefits system, for example the rule which bars Carers Allowance recipients from returning to ‘full time’ study even if they are still caring for over 35 hours a week. The cut off for Carers’ Allowance should be tapered so that there is no disincentive for parents to work. At present, the whole allowance (£46.95 per week) is lost once a parent earns above £84 per week. This creates a disincentive to work more hours if the salary is between £84 and £130.95 per week.

We received submissions from a number of stakeholders calling for Government to establish a minimum income standard which includes targeted support to meet the extra, essential costs of caring for a disabled child. We would urge Government to consider how these costs can be met for all families, whether by a minimum income standard or other mechanism, to help lift families with disabled children out of poverty.

Recommendations

The childcare element of the Working Tax Credit (WTC) should recognise the additional costs of securing childcare for a disabled child.

DLA forms should be further simplified and Government should consider awarding DLA for longer periods, without the need for further forms, for children with long-term conditions where variation in the level of need is likely to be marginal. Government should also consider waiving the 90 day eligibility period where children have additional time-limited care or mobility needs as a result of medical intervention.

Government should give serious consideration to extending winter fuel grants to parents of disabled children on benefits, particularly those with disabled children under five who are at home all day.

Social exclusion

Disabilism is ingrained in society. Disabled children do not have equal value. Society has low expectations of their lives, and they and their families remain segregated despite the closure of the institutions.

There is a lack of understanding by the people that control public spending, they appear to feel that disabled children are taking funding away from normal children and that disabled children are not equal members of society.

Disabled children and their families want to live ordinary lives as part of their communities. Yet too many families told us that they feel excluded from society, and too many disabled children are not able to access the same opportunities as their siblings and friends.

For every opportunity a non-disabled child has, there should be an equivalent offered for the disabled child.

Don't try to hide our children away. They have a right to have fun like every other child, in the same places as every other child: parks, swimming pools, leisure centres.

Schools need to facilitate and encourage friendships. Our learning disabled daughter has gone all through secondary school without ever being invited out or to a party.

Attitudes to parents also serve to exclude – parents are made to feel guilty for seeking support, or even for the existence of their disabled child.

As a parent you are often made to feel inadequate in asking for help and then guilty for asking for the help. You often have to beg for every little bit of help.

There seems to be a general consensus amongst the professionals, that our children have behavioural problems that can be 'cured' by teaching us how to be parents. There is no regard that our children have a lifetime and complex disability.

Some groups of families with disabled children experience even higher rates of social exclusion. The prevalence of learning disability in South Asians aged 5–32 is three times higher than in other communities.⁸ Yet services regularly struggle to meet the needs of families from black and minority ethnic communities. Information about local services e.g. childcare, welfare rights, leisure and short breaks do not reach families from minority ethnic communities. Research found that in comparison with white families that BME families were less likely to be receiving DLA and where they were in receipt of the benefit, they were less likely to be awarded the higher rates.⁹

Submissions to our hearings from parents supported this academic evidence.

Including parents from ethnic minorities is essential yet incredibly difficult so culturally specific services are vital as well.

I just never thought the service was for me or my family.

To combat the exclusion of families with a disabled child from Black and Minority Ethnic (BME) communities, regional structures should support local agencies in developing culturally sensitive services and information.

Mencap highlighted the social exclusion of families who have children with profound and multiple learning disabilities. The vast majority of community facilities lack a Changing Places toilet (toilets with a changing bench, hoist and enough space for two carers and a wheelchair). This means that families are unable to enjoy a family day out at shopping centres or family attractions. Local authorities and service providers should develop more Changing Places toilets in community facilities as part of their new duties to promote disability equality.

⁸ Azmi, S. et al (1996) *Improving services for Asian people with learning difficulties*, Hetser Research Centre.

⁹ Chamba, R. et al (1999) *On the edge: minority ethnic families caring for a severely disabled child*, The Policy Press.

Professionals and parents called for more training on disability in professional education. Disability awareness training is needed to end the stigma and negativity associated with disabled children. Government and service providers should ensure that all professionals working with children have received disability equality training. In addition, professionals need the right level skills and competencies to ensure they are able to welcome disabled children into their services and meet their needs. We support submissions calling for the Children's Workforce Development Council to ensure that all training for the children's workforce carries a disability impact statement.

The lack of sufficient appropriate services for all disabled children contributes directly to their social exclusion. The Royal College of Speech and Language Therapists told us that speech and language therapy is essential for children with communication impairments, as 'without shared communication, there is automatic exclusion and isolation'.

Barnardo's Policy and Research Unit highlighted to us how the education system is failing to deliver social inclusion for disabled children growing up. Disabled people are twice as likely as non-disabled people to have no qualification whatsoever, and only 50% of disabled people of working age are in employment compared to 69% of non-disabled people. (Labour Force Survey, Winter 2001/2)

Ending social exclusion for families with disabled children will require changes in social attitudes. To ensure this happens, SEN and disability issues should be prioritised within the citizenship curriculum. Equally important is ensuring that services are set up to meet the needs of disabled children and families. The new disability equality duties coming into force from December 2006 are a potential lever to make this happen. All public bodies developing a Disability Equality Scheme should ensure that a disability impact scheme on universal and specialist children's services is part of the core scheme.

Inequality

What would happen if every parent of a disabled child tried to get help – the system would collapse!

Services for disabled children are entirely inequitable. Government funding and strict rules about enforcing equal opportunities would be the only way forward.

There is no excuse in 2006 for there not to be equality of care across the country. It is not as if there is a lottery about who gets the children.

An overriding theme of the evidence received by our hearings was inequality in service delivery. This inequality is present both within and between geographical areas. Many submissions told us that only those parents who are able to fight sustained battles with agencies can access services.

Services are good for parents who are willing and able to shout loudly, fight and pay independently for services, assessments or legal support. This means that the system is inherently discriminatory against the most socially and economically disadvantaged.

In both health and social care, those parents who are willing to fight hard for their children mostly get what they need. For the rest, it's not available.
Education professional

Parent Partnership services do support many parents, but often disadvantaged families miss out. Education professional

Evidence from professionals and parents highlighted the impact of a child with complex needs on the ability of agencies to deliver services to other children.

Huge care packages for children with complex and unstable health needs affect what we can provide for other families: our eligibility criteria is drawn tighter and tighter and preventative services become a thing of the past. Children's services manager

When families beg for help, they are told that others will suffer if they get help.

Even those families able to fight for services have highly unequal service outcomes dependent on their location.

I am fighting to keep a piece of equipment that our son needed when we lived elsewhere but 'magically' did not need when we moved to another area – this decision was made with no assessment of his needs.

My local authority does not employ any specialist occupational therapists to work with disabled children. The adjacent LA does! Social care professional

In some areas children receive excellent services, in others none at all. This is purely down to funding disparity, geographical boundaries and personalities of individual members of staff. Education professional

One family told us that they received services from a voluntary sector organisation, including access to playschemes and family events. However, this service was only available in the part of the borough where they lived, and they had been advised to move to that area to access the service. This example typified the trend coming through the evidence that those families with the most resources were able to find ways to access services – with less well-resourced families missing out, regardless of their level of need.

The lack of strategic planning by local agencies was blamed in submissions for inequalities in service delivery.

In our area the local authority has no specific strategy for children with autism. Consequently resources and services are patchy and excellence is limited by funding. Professional

Recommendation

To address service inequalities, as part of their children and young people's plans, local authorities should develop a needs analysis and commission a range of services to meet the level of need in their population of disabled children and give families meaningful choice. Clear information then should be made available to families, outlining the minimum service standards they can expect and how to complain if these standards are not being met.

The lack of data

If numbers of disabled children aren't known, how can a budget be worked out correctly?

Our local CDC (Child Development Centre) doesn't know how many children they have with Down Syndrome in their area – so how on earth can anyone plan anything?

I assume that these numbers are available to the powers that be, so that sensible planning/funding of the services are made. Please don't tell me that my assumption is wrong.

There are fundamental gaps in the data on disabled children that should be available to public services. The hearings were not informed of a single local authority that could accurately state their population of disabled children. Without this data, it is obvious that planning and commissioning of services cannot take place on any informed basis. Furthermore, a DfES research report in 2004 identified the lack of comprehensive national data sets as the major barrier to accurate cost benefit analyses of services for disabled children.¹⁰ Without such cost benefit analyses, it remains difficult to demonstrate the impact of additional investment in certain types of services.

One professional suggested that the 2011 census may offer an important opportunity to gather more precise data on children with disabilities. We would suggest that the situation is far too urgent to wait another five years for accurate data.

Good practice cited by the National Autistic Society is the Irish National Intellectual Disability Database, established in 1995 to provide comprehensive information for decision making in relation to planning, funding and management of services for people with a learning disability. Consistency in categories and methodology enables data to be analysed at a local, regional and national level. Reports calculate how the number of people requiring services changes every four years, in, for example, education, employment or residential care.

¹⁰ Papps, I. & Dyson, A. (2004), *The Costs and Benefits of Earlier Identification and Effective Intervention*, DfES Research Report 505.

Recommendation

We recommend that there should be a single multi-agency database in all local areas. This should:

- hold data on all disabled children in the area, based on an agreed definition of disability shared across all agencies
- inform the local needs analysis and children and young people's plan
- inform commissioning agendas
- be used to plan services to anticipate future need.

The voice of children and parents

I get very stressed because I have NO say in many social services/NHS meetings which take place with regards to my son.

Parents, carers and young people need to be consulted when developing services. At present an anonymous panel will determine what they think your needs are – which may well be incorrect.

What happens is we are 'consulted' at the end of the process, not when the blank sheet of paper is sitting in front of the powers that be – it's too late to have any influence.

Involving children and parents in improving services

The final theme pervading the evidence received during our hearings was the need for disabled children and parents to influence the way that services are planned, commissioned and delivered. Al Aynsley-Green highlighted the need to create structures so that all children, including disabled children who require different communication approaches, can influence services. The organisation Kids called for the involvement of disabled children, young people and their families in planning services to be 'actively sought, welcomed and implemented – no more "consultations" that lead nowhere'.

The importance of involving children, not just parents, in service development was well recognised.

Service development is influenced largely by what our parents say rather than the children and young people, many of whom have no verbal communication and have learning disabilities. However, with time (and dare I say resources) there is no reason why we could not consult effectively with the children and young people. Children's services manager

Parents highlighted the benefits to service providers of engaging children and parents.

Rather than local government officers making decisions and assuming they know what families of disabled children and young people want and need to make their lives better, it would be good for parents/carers/stakeholders to feed into the process of putting together a comprehensive package of support with the knowledge that they are being listened to.

I have only ever seen service provision dramatically increase if parents and children apply lots of pressure as a united front.

Examples of current good practice in involving disabled children came through to our hearings.

We deliver a participation project which encourages young people to get involved in their community and speak out. Advocacy, self esteem and confidence building are a priority. Professional

Contact a Family highlighted a recent evaluation of parents' involvement in the emerging children's trusts, which showed how much parents value a participation worker to help them with the administration necessary for their involvement.

One professional submission called for 'A local/regional identified person who can take forward the issues that are highlighted by families and services in the area.' Parent Partnership services are already tasked with ensuring that individual families get the education services they need, and that parents are involved in planning processes. We want to see Local Authorities properly resourcing parent partnership services and giving these services sufficient independence to play this dual role.

A service I found really helpful was parent partnership – because they help deal with other professionals on your behalf.

Local authorities should properly resource parent partnership services so that they can provide hands-on support to parents seeking services, and also support parents to engage in planning processes. Local agencies should also demonstrate how disabled children and parents are influencing strategic planning processes, for instance the development of children and young people's plans.

Recommendation

All agencies should ensure that disabled children and their families have meaningful input into the way that services are planned, commissioned and delivered.

Independent advocacy for children and families

The case for embracing advocacy might be seen as visionary: but in a practical sense it is more vital in today's complex world, particularly in respect of disabled children and their parents, than it has ever been.

Tom Clarke MP

Independent advocacy is recognised as having the potential to make a significant contribution to safeguarding disabled children.

The Children's Society

The Prime Minister's Strategy Unit report *Improving life chances of disabled people* recognises the particular importance of advocacy in ensuring that disabled young people have more choice and control in their lives

(recommendation 6.2). Disabled children and young people are particularly vulnerable to abuse and there is evidence that existing child protection procedures and processes do not effectively safeguard them.¹¹

There was significant demand in submissions to our hearings for additional advocacy and support services for both disabled children and parents. Ivan Lewis MP, Minister for Care Services, in our session on transition to adulthood, highlighted the role of the voluntary sector in delivering advocacy for families. Working Families identified a need for advocacy services to assist parents in negotiations with employers over flexible working.

The Government has developed national standards for advocacy practice for children. Standard 3 states that advocacy agencies should give particular attention to the communication needs of disabled children and young people, including those who are very young and those with multiple and learning disabilities.¹² However research has found that only 5% of advocacy services targeted disabled children and young people and few advocates have experience of working with disabled children and young people, particularly those who have communication impairments.¹³ The Children's Society with CROA (Children's Rights Officers & Advocates) conducted a survey of advocacy providers in 2004/5 which found that less than 15% of disabled looked-after children had received an advocacy service in the past year.

Recommendation

Government should issue clear guidance on the use and commissioning of children's advocacy and parent support services. Government should target resources at independent providers of advocacy support to parents and disabled children, to ensure that disabled children stay safe and to help every family have an equal chance of accessing services.

¹¹ NSPCC (2003) *It doesn't happen to disabled children: Report of a National Working Group on Child Protection and Disability*.

¹² Department of Health (2002) *National Standards for the Provision of Children's Advocacy Services*.

¹³ Oliver, C. (2004) *Advocacy for children and young people: a review*, Institute of Education, University of London.

Early Years

This section covers:

- diagnosis
- parenting support
- early intervention
- Early Support.

Early years services for disabled children are widely recognised to have improved in recent years. Over two-thirds (69%) of parents who were able to provide examples of services that they were happy with mentioned early years services in their submissions to the hearings, with many mentioning the Early Support programme (see below). However, challenges to providing consistently high quality early years services remain.

Diagnosis and assessment

Despite improvements in diagnostic services, too many families are still struggling to get a confirmed diagnosis of their child's disability.

My son took years to get final diagnosis, we fought and fought to get things sorted out in school, no one would listen until it was too late, and now he has been home for three years, when he should have been able to go to school and be with his peers.

In our experience diagnosis has been deliberately withheld and private diagnosis ignored so as to avoid the cost of services.

Why does it take three years to get a diagnosis of autism in some parts of the country and in others it's within six weeks?

Just as critical for families is the delivery of appropriate information at the point of diagnosis. One family who recently received a diagnosis for their child was given nothing but a photocopied excerpt from a medical textbook by their paediatrician.

This did nothing to answer our many questions, in fact it raised some more (such as mention of 'survival', an issue we never even dreamt we would have to be thinking about).

Health agencies should ensure that diagnostic services are available at a local and/or regional level to deliver prompt and accurate diagnoses for every disabled child. The Early Support model (see below) should be used and extended to ensure that all parents receiving a diagnosis should receive appropriate information related to their child's condition, including contact details for support organisations.

The Early Support programme has introduced a single family-focussed assessment framework. This has significantly reduced the number of assessments needed for a young disabled child, speeding up the process and ensuring interventions are delivered most efficiently.

Recommendation

Government should extend the single assessment framework beyond the remit of the Early Support programme, including extending the model up the age range to transition to adulthood.

Parenting support

Parents are the most important link in the system – with well-informed parents, children should access the services when they need to, not when they are desperate. Health professional

I feel sick when I think there are parents trying to negotiate this without use of the internet – or single parents with no time to research.

Parents of disabled children need support to help them understand and meet their child's needs. However, too many parents receive no support at all, while others feel that rather than support, public agencies are suspicious and doubt their ability to care for their children.

I have recently been accused by social services of suffering from Munchausen Syndrome and fabricating my youngest child's symptoms even though my three other children already have an ASD diagnosis, as does her father.

One parent told us of her frustration that rather than concentrating on caring for her son,

I am practically full-time learning how the 'system' works and researching and implementing all my own early interventions – even after pouring hours over months into trying to locate suitable education for my son. So far I have plenty of people telling me what to do, but no-one helping me to do any of it.

However, good practice does exist in this area. Schemes such as the National Autistic Society's Early Bird Plus programme provide an opportunity for both a parent and a professional who works closely with a child (such as key worker or teacher) to train in autism following diagnosis, thereby maximising consistency for the child.

To provide effective support to every parent, local authorities should make available a range of services, including training and support to ensure that parents can support their child's needs and access local services. In addition, local children's safeguarding boards should ensure that staff are trained to differentiate between parents who need support to manage their disabled child and situations where disabled children may be at risk of abuse.

Early intervention

I believe there would be less need for respite and certainly less need for residential placements if children had access to early and appropriate treatment.

Government has now recognised the crucial importance of early intervention in improving outcomes for a range of children – including disabled children. Early intervention is emphasised in Standard 1 of the National Service Framework (NSF) for Children, Young People and Maternity Services, which states ‘The health and well-being of all children is promoted and delivered through a co-ordinated programme of action, including prevention and early intervention, wherever possible, to ensure long term gain.’

Gordon Marsden MP highlighted in his written submission that early identification of learning difficulties such as dyslexia, with appropriate support, can reduce the cost of specialised intervention and support at later stages. The review whole-heartedly endorses this observation. Barnado’s highlighted that the early lessons from the National Evaluation of Sure Start (NESS) shows that high quality early education makes a real difference to the lives of children, particularly those growing up in disadvantage. The Challenging Behaviour Foundation stated to us that children with severe learning disabilities need specialist intervention early, before learned behaviours become entrenched.

The only economic analysis of autism in the UK to date highlighted that, from an annual total cost of autism of at least £1 billion, only 7% was spent on education. The authors concluded that ‘evidence suggests that even moderate increases in educational provision could potentially result in major savings in later living costs.’¹⁴

However, many young disabled children are being excluded from early childhood services because they are being denied the right equipment or because staff lack training and expertise to deliver interventions. One parent described early intervention as ‘more an aim than an achievement – and yet it could be pivotal in the development of a disabled child.’ To ensure best outcomes, the universal offer of 15 hours per week free education for all three year olds should be extended to 30 hours per week for children identified as having a learning disability.

Professionals want to deliver early intervention, yet one health professional told us that disabled children under his care have been waiting over five months after diagnosis for therapeutic interventions. This professional stated, ‘This is not acceptable for the parents who want to get underway with therapy and also need maximum support at this time. These first few months can affect the parents’ psychological state for many years to come.’

There are significant gaps in the evidence base around early intervention. Government has commissioned a feasibility study into the development of a National Centre of Excellence in Early Intervention.¹⁵ This feasibility study reached positive conclusions and we urge the government to respond to these conclusions as part of the current policy review.

However, some early intervention services, such as the Portage service, already have a significant body of evidence demonstrating their efficacy, and families with disabled children should have an entitlement to access these evidence-based services. ICAN provided an example of the

¹⁴ Knapp M. and Jarbrink, K (2001) ‘The economic impact of autism in Britain’ *Autism* vol 5(1), pp. 7–22.

¹⁵ Available at www.surestart.gov.uk/doc/P0002061.doc.

independent evaluation of their Early Years Centres, which showed significant improvements in language and behaviour compared with a control group attending other services. Follow-up research has demonstrated the cost effectiveness of the Centres. We commend this type of evaluation of intervention services, and urge service providers and government agencies to do more to evaluate outcomes and cost effectiveness of different types of early interventions.

Specialist early interventions are also needed for low birth-weight babies. In New Zealand all babies born under 1500 grams, or born before 32 weeks, are offered, on discharge from hospital, a specialist adviser visit once a week for four months either at home or at a clinic. By 12 months many of these families were found to need no further specialist intervention but were able to access mainstream services.¹⁶ To mainstream this practice, all babies born under 1500 grams and before 27 weeks should be offered a minimum of one specialist adviser visit per week for the first six months post discharge.

Recommendation

Government should commit to funding the National Centre of Excellence in Early Intervention, to pilot and deliver new approaches in early intervention and commit to the roll-out and mainstreaming of the Early Support programme, which will require further focussed resources.

Early Support

Since Early Support got involved with us there has been a dramatic change in our family. My daughter is no longer a jigsaw puzzle with twenty-one different pieces. My daughter is Alicia and twenty-one different people are there at the end of a phone through one person.

Sharon Kelly, parent, giving evidence to first session

Evidence to our hearings made clear that one of the government's great success stories in relation to disabled children is the Early Support programme. Early Support is currently operating in 45 local authorities and aims to ensure that services for young disabled children are co-ordinated and that families receive information and support at the right time. The Special Educational Consortium highlighted a forthcoming evaluation of Early Support by Manchester University, which is expected to reach positive conclusions.

Our hearings heard substantial testimony to the benefits of the Early Support approach.

The Government's development of the Early Support Programme is excellent, and is benefiting many families. Health professional

New initiatives such as Early Support promote early interviews & family friendly access to multi agency frontline support and services. In (authority)

¹⁶ Carpenter, B (ed) (2005) *Early childhood intervention; international perspectives, national initiatives and regional practice*, West Midlands SEN Regional Partnership.

NO pre-school age children require a statement to receive extra support and resources. Head of pre-school specialist support services

An important element of Early Support is the allocation of key workers to specific families. We heard testimony from parents about the transformative effects of key workers on their lives. Sharon Kelly, a parent from Salford, told us that prior to the appointment of her key worker, she had spent forty-seven and half hours per week dealing with professionals. Sharon stated, 'I've discovered that I don't have to go out to all these appointments I can have a multi-agency meeting where everybody comes to us.'

The Early Support programme is funded until 2007. After this point, the work of the pilot schemes should be mainstreamed into children's services. Beverley Hughes MP, Minister for Children, speaking at our first session, stated that 'the key task now is to make sure that we mainstream Early Support into the routine way in which children centres and other children services work right across the board.'

Mainstreaming Early Support is welcome if it means that all families with young disabled children are able to access the Early Support information resources and can access key workers to co-ordinate services. However, some submissions to our hearings expressed concern about the end of dedicated funding.

I have had feedback that people are so frustrated that there will be no further funding for it so many programmes have stopped. It was supposed to be supported by mainstreaming but realistically that won't happen.

The Special Educational Consortium told us that 'there is concern that without ring-fenced funding, there is significant risk that funding for Early Support will be allocated to other local priorities and the focus will be dissipated.'

The Special Educational Consortium highlighted the danger that if funding for the central Early Support team is withdrawn, its role in developing a training programme, ensuring co-ordination, sharing learning and maintaining quality will be lost. Government should consider extending the funding for the central Early Support team, to maintain local focus as the programme is rolled out to every local authority.

The success of Early Support was highlighted by submissions which pointed out that services up the age range could benefit from the principles of coordination that worked so well in the programme.

The Early Support programme is proving a good example of joined-up thinking and working, and as this rolls forward families will expect this for the whole of their child's life. Professional

Government and local agencies should explore how the principles of Early Support, in particular key working, can be embedded into practice at all ages.

This section covers:

- universal services
- specialist services
- short break provision
- direct payments/individual budgets
- multi-agency commissioning and working.

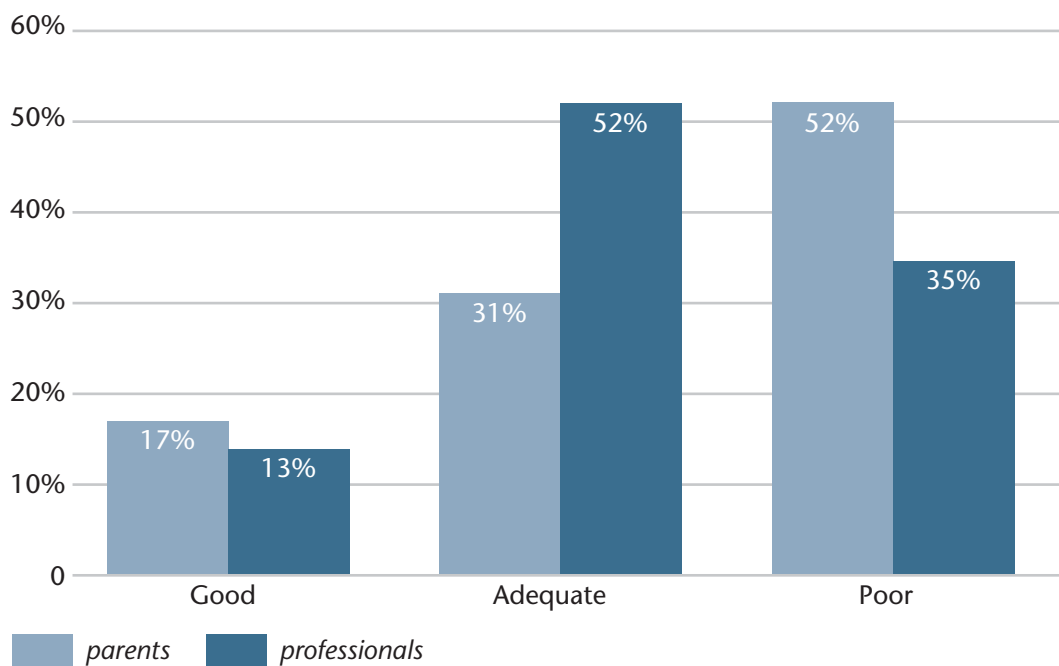
As disabled children reach school age, families who may have had to fight for a diagnosis and to access early interventions face a new battle – to get the right services for their child and the support they need for their family to function.

Wouldn't it be nice to be asked 'What would you like? What would make family life normal?' Parents of disabled children don't ask for anything that other families don't get – it's just that when you've got a disabled child, the structure isn't there, the system isn't in place.

Gail Hanrahan, parent, giving evidence to third session

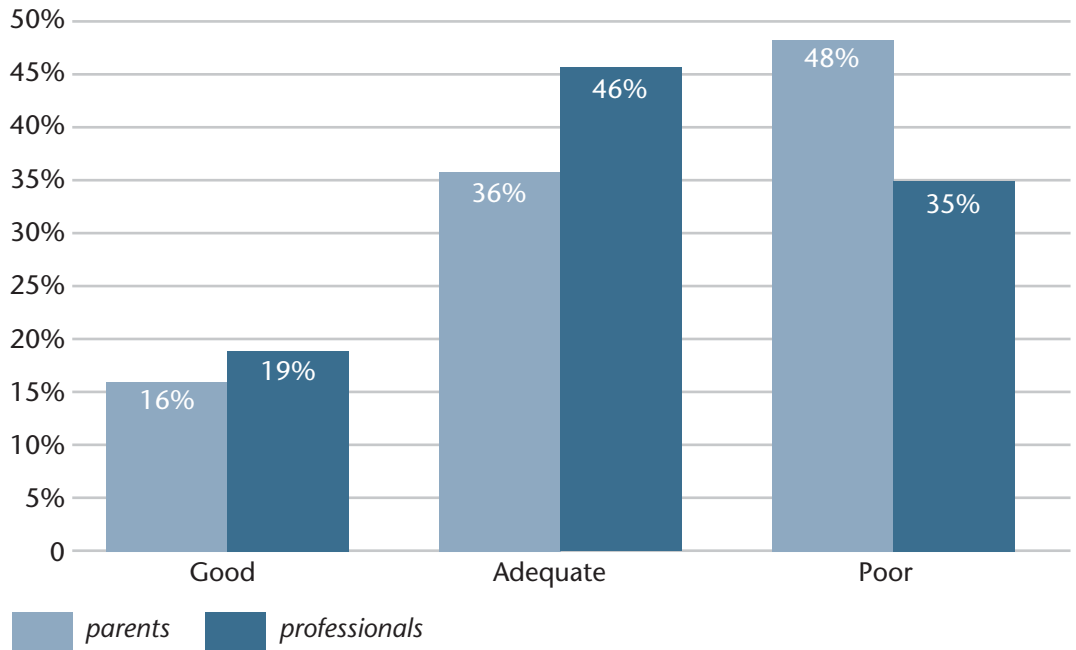
Submissions to our hearings expressed a high level of dissatisfaction with the services that disabled children and their families receive. Parents and professionals described services provided by education, health and social services as follows:

Education



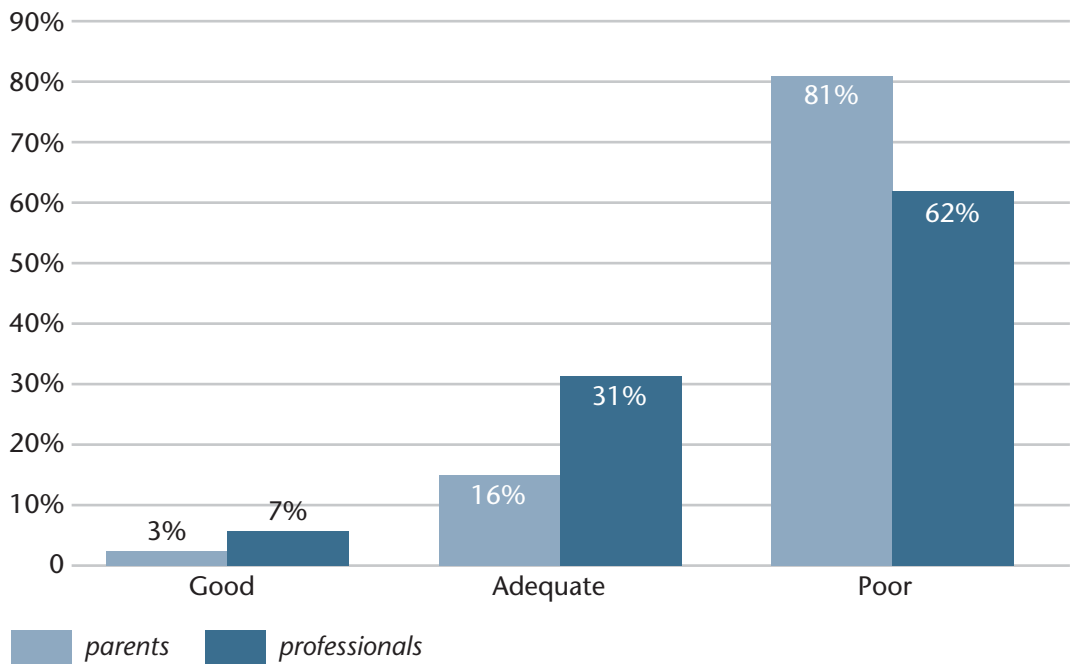
Source: Written submissions to parliamentary hearings

Health



Source: Written submissions to parliamentary hearings

Social care



Source: Written submissions to parliamentary hearings

It can be seen that parents in particular are generally dissatisfied with the state of services their children receive. Four-fifths (81%) of the parents rated social care services for disabled children as poor, while half of the parents rated education services (52%) and health services (48%) as poor.

Universal services

Disabled children and their families have a right to access the same services that are available to other families. All services must commit to meeting their disability equality duties to disabled children. Beverley Hughes MP, Minister for Children outlined the 'architecture' of the 'massive change programme for children services', including extended schools and children's centres. She stated, 'within that architecture we've tried to be very specifically focused on disabled children making sure that local authorities amongst others think specifically about how those changes, those improvements have to be developed in a way that meets the needs of disabled children and families.'

The benefits of disabled children having full access to universal services are manifold – for disabled children and non-disabled children alike.

Our daughter was the first PMLD (Profoundly and Multiply Learning Disabled) child to attend the local leisure centre and activity days run by the youth service. It has been difficult sometimes, but overall the pleasure of seeing her enjoying being with other kids has been fantastic. She clearly loves it and so do I.

Parents provided examples of professionals in universal or mainstream services who had made a real difference to the lives of their family.

Our GP is fabulous and fantastic and it is only with his support that we are able to access the services that our son requires.

We have had continual support from our community nurse. She has visited several schools with us and help in our decision about which would be best for our child.

Childcare, children's centres, extended services, children's information services

Families with disabled children should be able to benefit from all the new services emerging from Sure Start and the government's Every Child Matters programme. Government must ensure that every extended school and children's centre is offering its full range of services to children with all types of disabilities. However, there was substantial evidence that children's centres, extended schools and other universal services are struggling to meet the needs of disabled children. In a survey by Contact a Family in Southwark, only 9% of disabled children with the highest needs used extended school services.

The new Children's Centres do not provide the core services that disabled children need and tend to concentrate on able-bodied children.

Health professional

Access to childcare, extended school activities and leisure, the core offer in Children's Centres needs to be carefully thought through ... Funding does not allow full support for children with more complex disabilities and the workforce is not yet sufficiently competent or trained to provide the appropriate extra support. Head of pre-school specialist support service

Many disabled children, particularly those with more complex needs, are not accessing extended services. Special educational consortium

Parents of disabled children are in particular need of timely and accurate information about the services and support that they can access. Children's Information Services should provide information to all parents on childcare and financial support.

Recommendation

Children's Information Services should receive sufficient resources and training for staff to provide specific advice and guidance to parents of disabled children on appropriate childcare and the financial support to which they are entitled.

Local authority services – play and leisure, housing and transport

All commissioners and providers of services within local authorities need to be considering whether their services are fully accessible for families with disabled children. Although education, health and social care services were prioritised in our evidence, play and leisure, housing and transport also featured as key services in some submissions. All these services will shortly need to comply with new disability equality duties under the revised Disability Discrimination Act.

With regards to play and leisure, parents were clear that this was a priority for their disabled children.

Our children have a right to have fun like every other child, in the same places as every other child: parks, swimming pools, leisure centres.

The charity Kids proposed a new duty on local authorities to ensure that disabled children can experience a full childhood, including access to play, access to out door play and opportunities to take risks. Disability Challengers, a play provider based in Surrey, described a national shortage of leisure opportunities for disabled young people, and linked this to the lack of short break opportunities for their families.

The Audit Commission found a 'national shortage of inclusive and specialist (play) provision' and 'gaps in play and leisure provision within a locality, for children of particular age group or with certain needs'.¹⁷ The Government's review of children's play stated that 'disabled children and young people have significantly worse access to good play opportunities'.¹⁸ In this context, it is essential that the developing local authority play strategies take full account of the need to develop play and leisure services that make sense for disabled children.

Housing was mentioned as a priority in the submission from the Foundation for People with Learning Disabilities, while the College of Occupational Therapists described appropriate housing and access to housing adaptations as 'essential' for families with disabled children. Submissions welcomed the abolition of means testing for the Disabled

¹⁷ Audit Commission (2003) *Services for Disabled Children*.

¹⁸ DCMS, (2003) *Getting Serious About Play: A Review of Children's Play*.

Facilities Grant for housing adaptations, but the College of Occupational therapists stated that the £25,000 limit remains insufficient to fund for most adaptations for disabled children.

The College called for more occupational therapists to be available to give advice about housing options at an early stage of a child's disability or illness. They stated further that it is vital that families are able to work with housing departments to meet their child's needs. Sally Keeble MP highlighted the need for district councils in two-tier authorities to be aware of the needs of disabled children and to have effective protocols for working with other agencies to meet these needs.

Training

A major issue in accessibility of universal services is staff training. Research by the National Autistic Society has shown that fewer than one in five schools has a single teacher who has received more than a day's training in autism.¹⁹

Training for mainstream teachers is very poor Education professional

Beverly Hughes MP, Minister for Children, highlighted the role of the Transformation Fund in developing the capacity of the private and voluntary sector workforce to work with disabled children. Yet as Joan Humble MP stated, 'many of the people who work in nursery settings, in pre-schools settings are frightened of children with disability'.

In some cases, a lack of trained staff is driving children from universal to specialist services, regardless of what may be in the best interests of the child.

Lack of local expertise means that too many children with severe learning disabilities and challenging behaviour are placed in out of area residential schools. Voluntary sector professional

Recommendation

Training and continuing professional development frameworks within the children's workforce must ensure that all professionals have the skills and competencies necessary to deliver services to disabled children.

Universal education services

Far too many LEAs are blatantly failing children and their families and forcing many to go back to SENDIST time and time again for every little thing. LEAs should be policed better and SENDIST should have powers to do something when they see an LEA behaving badly.

The universal service with the greatest entitlement to services for disabled children is education. However, the Special Education Consortium told us that 'the consensus amongst our members is that while there are some

¹⁹ Barnard, J. et. al., (2002), *Autism in Schools: Crisis or Challenge?*, NAS: London.

excellent examples of practice in education services, too many disabled children are currently let down by the education system'. The Consortium cited in evidence of this statement the high rate of exclusion of disabled children and young people, the high and rising number of cases registered with SENDIST (Special Educational Needs and Disability Tribunal) and the volume of calls received to member helplines.²⁰

SEN helplines particularly report large numbers of 'informal' or 'unofficial' exclusions of disabled children, where parents are required to collect children at lunchtime or keep them away from school for a certain number of days – despite the fact that this practice contravenes law and guidance. The Consortium also provided examples of situations where schools had made reasonable adjustments to avoid the need to exclude disabled children with severe behavioural needs, showing that it should be possible to keep all disabled children in school with the right support. To help with this, Government should consider strengthening the guidance to schools to seek a statutory assessment or an early annual review of the statement before excluding a child with special educational needs into a legal duty.

In his written submission, Clive Betts MP pointed out the impact of delays in SENDIST appeals on a child's education, and stated the need for a variety of flexible education placements in every area to maximise choice. In another written submission, Gordon Marsden MP highlighted that many schools lack an understanding of their duties under the Disability Discrimination Acts and are failing to implement these Acts fully. He highlighted the need for social care and out-of-hours family support to be integrated with educational provision to deliver on the Every Child Matters outcomes.

While training is a key issue in all universal services, it is particularly critical in education, where teachers may be faced with a classroom where pupils have a wide range of special educational needs. There was consensus in the submissions that SEN and disability training needs to pervade teacher training and continuing professional development, so that teachers at every stage in their careers can demonstrate appropriate levels of competency. Furthermore, teachers need training to meet the needs of children with specific disabilities and impairments. Autism education charity TreeHouse told us that 'given the specific communication, social and behavioural difficulties of children with autism, generic SEN training is unlikely to provide the specialism required to address their needs'.

Cost concerns continue to prevent schools from properly meeting the needs of their disabled pupils. One Occupational Therapy service told us of a school with three wheelchair users which required adaptations to toilet facilities costing £30,000. Lack of funds has prevented the adaptations from taking place, meaning children are still changed on the floor, undermining the dignity of the children and placing school and health staff at risk through the need to lift the children.

²⁰ A survey by the Audit Commission in 2002 found that children with SEN accounted for the vast majority of all permanent exclusions – almost nine out of ten from primary schools and six out of ten from secondary schools. Audit Commission (2002), *Special Educational Needs: A Mainstream Issue*.

Recommendation

Government should reinforce guidance to schools and LEAs preventing exclusions of children with recognised disabilities and/or special educational needs.

Universal health services

In health services, similar funding and training issues impact on accessibility, compounded by negative attitudes to disabled children.

There is a lack of understanding in universal services about disabled children ... there is still a belief held by some health professionals that disabled children are not eligible for the universal offer. Social care professional

Disabled children regularly experience 'diagnostic overshadowing', where physical illnesses are missed by physicians because they are wrongly attributed as a symptom of the child's disability. The Royal College of Speech and Language Therapists told us that 'disabled children with more severe communication problems often have underlying health and medical conditions, which go unnoticed and undiagnosed'.

Health service targets may impact on the ability of health professionals to give the time and attention needed by disabled children.

Although we have a good community nurse and paediatrician they are so overwhelmed with clients that they find it difficult to give the service they would wish.

It is essential that health providers fully engage and communicate with the disabled children and young people that they are treating. One professional told us that consultation with disabled young people had shown that they would like more support and explanation and for health staff to talk to them and not their carers. 'Many recounted health care experiences as frightening and that they did not understand what was going on.'

Summing up his contribution to our hearings, Al Aynsley-Green called for a 'cultural transformation in the way people think about services for disabled children'. We echo this sentiment from the Children's Commissioner – we believe that disabled children offer an acid test of whether the Every Child Matters outcomes and universal services really apply to all children.

Specialist services

My disabled daughter challenged services from the moment she was born – but why? Services should be available to meet the child and family's needs.

In addition to services available to all children, disabled children require specialist services to allow them the best chance of reaching their potential. A minority of parents were pleased with the level of specialist support available to their families.

We have seen an enormous increase in family support, childcare, leisure opportunities and respite in this borough.

The charity SENSE told us that, 'high satisfaction levels are expressed by families who are referred on to specialist centres (like Great Ormond Street Hospital, Manchester and Birmingham) where they are able to see specialist staff who *really know* about the cause of their child's condition, and see their child as "whole".'

As with universal services, parents were full of praise for individual specialist professionals.

Our social worker is brilliant.

Our Occupational Therapist has been excellent. She has always supported our son's need efficiently and effectively. We know that when we approach her she acts straight away, is totally honest about the availability of equipment and funds and does all she can to help.

Our son's current teacher at his special school is absolutely fantastic. She values every child for what they can do, and never talks about what they can't do, only what they are working hard on to improve. She works as a 'team' with each child's parents to find the best strategies for teaching that child and for tackling any problems that arise. In all her thinking, she puts the children's needs first, and this, I believe, is the secret of her success. It would be heaven if all professionals were as dedicated and caring as this!

Yet significant weaknesses were identified in the provision of specialist services. As Anne McGuire MP, Minister for Disabled People, noted, 'too often the services that are being provided to disabled people in general and disabled children in particular have been tailored around the providers'. In her written submission, Anne Milton MP noted that disabled children's services remain 'Cinderella services'.

Many parents told us that vital services to support their families, from playschemes to short break services, were being delivered by voluntary agencies, operating on short term contracts with shoestring budgets. The hearings team saw an example of this in operation during our visit to a playscheme in Manchester.

Our organisation provides services consistently described as excellent and which are highly valued by the families and children ... and yet all but one of our services is likely to end come 31 March 2007 due to lack of funding.

Parent group

Voluntary organisations, small and large have to pursue a hand to mouth approach, snatching at funding streams as they appear, and ceasing projects which have proven worth. Children's services manager

Submissions to our hearings told us of the need both to increase the capacity of specialist provision while also ensuring that mainstream services can meet the need of all disabled children.

There aren't enough special needs units in mainstream settings.

Although the teaching staff in special schools are often highly skilled dedicated professionals, the continued teaching of disabled children in a separate system continues to perpetuate their exclusion from society.

My son attends a language unit attached to a mainstream school, at primary school level. It is an excellent unit and offers the best of specialist teaching mixed with inclusion with mainstream children to provide good role models and rewarding friendships. It would be excellent if this format at secondary level could be considered and more provided in the future.

Afasic highlighted the need for specialist intervention for children with speech and language impairments (SLI), and criticised the over-use of poorly-trained or untrained classroom assistants to support children with SLI. ICAN and others called for greater integration of special schools, particularly non-maintained and independent special schools, into mainstream education programmes.

Importantly, the line between specialist and universal services is becoming blurred, as more service providers recognise the need for both inclusion and specialism. A recent report by Ofsted found that the most effective provision for disabled children with a wide range of impairments was resourced units within mainstream schools. Disability Challengers, a Surrey-based service provider of play and youth services, described their 'inverse inclusion' approach, where specialist services established for disabled young people are opened up to non-disabled people to create a 50:50 ratio, creating large numbers of inclusive places. A quarter of children enrolled at TreeHouse school spend part of their school week in local mainstream infant and primary schools. However, TreeHouse told us that 'this relies on heavy resourcing by TreeHouse and exists in spite of, as opposed to because of, current policy on school collaboration and dual placements'.

Recommendation

The review endorses the recent report of the Education and Skills select committee inquiry on SEN, which called for a spectrum of educational provision to be available in every local area, to ensure that all disabled children can attend a school or provision that meets their needs.

Specialist education services

The need for specialist expertise was generally recognised in our evidence. Submissions provided examples of the critical role played by specialist support services. One education professional highlighted their local autism support team, who work with young people with autism who are at risk of exclusion. Intense support and training are invested into the school and the scheme has been successful at reducing the number of children who are excluded. The Royal College of Speech and Language Therapists praised the Medway Communication Team, which operates on a pooled budget between the PCT and the Local Authority to deliver

SLT support to all children with speech and language problems in Medway schools.

In this context, it is worrying that the level of specialist support appears to be falling away rather than increasing. TreeHouse told us that ‘parents complain that support services intended to be provided “at regular intervals” are mostly “regular” in the way that Christmas comes “at regular intervals”.’

In a number of cases, a direct link was made in submissions between cuts in local authority support services and delegation of funding to schools. This is clearly still a contentious issue which Government should examine further.

Centrally funded support services have been pared to support delegation, so schools find LA support limited. Education professional

Delegated funding to schools has led to lost money and lost economies of scale, depriving staff of the opportunity to access specialist training and support services. TreeHouse

Our evidence called for increased accountability regarding SEN money that is delegated to schools.

When money is short, we need to be certain that money allocated for a purpose is being used for that purpose. Education professional

In an environment where the DfES has asked us to delegate an increasing amount of resources to schools each year there is a danger that these resources are not used for the purpose they were given.

Education professional

Giving financial control and greater autonomy to schools should not be tantamount to an abdication of the government’s responsibility to disabled children – and to taxpayers to ensure the money is spent appropriately. TreeHouse

RNID research *At the Heart of Inclusion* (2005) also pointed to the damaging effect of delegation of specialist support services for deaf and hard of hearing children and confirmed the importance of specialist support services for deaf children in mainstream schools. Meanwhile the Special Educational Consortium highlighted a recent report by Ofsted which stated ‘The delegation of funding for support services had a negative effect on the provision for some pupils with SEN. It diminished the capacity of many LEAs to monitor the progress of pupils with SEN and reduced the range and quality of specialist staff available to provide advice and support’.

In the light of this evidence, and to ensure that children’s services departments retain sufficient funding to deliver specialist support services to schools, Government should consider issuing guidance advising local authorities against excessive delegation of funding. In addition, Government should establish minimum standards for SEN support services to ensure that services are available to every school to support inclusion.

The Special Educational Consortium cited evidence from the evaluation of the Behaviour Improvement Programme, which showed that multi-agency Behaviour and Education Support Teams were one of the crucial

elements in the success of the programme.²¹ Government should consider putting in place a package of national support for the Behaviour Support Programme, based on the Early Support model, to ensure successful roll-out of the programme to every local authority.

Overall, our review took evidence from parents that the statutory framework is not delivering appropriate support to every child with SEN. Significant issues with the statutory framework, in particular with the process of issuing statements of SEN, were also identified in the recent report of the Education and Skills Select Committee. Access to statements should not be used as a means of rationing resources, nor should the absence of a statement be used as a reason to deny services. The Select Committee called for consideration by government of a break in the link between assessment of need and provision of SEN support. The Government's response, instead of accepting this recommendation, recommitted to the programme of action set out in the strategy document *Removing Barriers to Achievement*. Parliamentarians will have the opportunity to debate the Government's response shortly.

In the light of this ongoing debate, this review fully endorses the recommendation of the Select Committee that the Government should give clear guidance to local authorities on how and when statements should be issued, and that national minimum standards of provision are needed to prevent 'postcode lotteries' in SEN support.

Equipment services

Equipment services are severely stretched and underfunded. Barnardo's provided evidence that the funding formula for wheelchair services has not been reviewed since 1991, despite significant increases in costs due to improved technology.

We are constantly hearing bad reports about wheelchair services – again an over stretched service with a limited budget. Professional

We live in (local authority) – a city built on seven hills – unless you work in wheelchair services in which case the 'local topography is flat.' By stating that our home city is flat they are justifying the non-provision of a powered chair. I can no longer push his manual chair without significant pain, so we are unable to go out on a regular basis.

Time and again children who need multiple equipment items are subject to scandalous delays because of resistance to the funding of sometimes paltry amounts. Professional

The Family Fund told us that families are increasingly applying to the Fund for items they have been assessed as needing by their health authority and which cannot be provided because of lack of funding or a long waiting list. 'However, the Family Fund is also underfunded and cannot continue to plug gaps in services'.

To address the problems families face in accessing equipment, the forthcoming joint government review of community equipment and wheelchair services must ensure that equipment services are child-centred and delivered appropriately.

²¹ Hallam, S. et. al. (2005), *Research and Evaluation of the Behaviour Improvement Programme*, DfES Research Report 702.

Social care services – eligibility criteria

Extremely strong views were expressed in this area. Social care services were generally felt not to be meeting needs, and to be restricted to crisis intervention largely due to funding constraints. Funding to children's services departments needs to recognise the importance of delivering preventative support services rather than simply adopting crisis management strategies.

Accessing Social Care provision is the area where we struggle most – the service appears to be so underfunded that resources in some areas seem to be almost non-existent, and if they are provided it is often only after a crisis has occurred.

I was informed there is very little help available unless my family are on the brink of 'collapse'.

Eligibility criteria for social care services are tightening. Parents reported losing allocated social workers and being turned away when approaching social services for short breaks or other family support services.

Eligibility criteria set too high only allowing for crisis management and not preventative work. Even the social inclusion worker is only meant to work with statemented children but the LEA is reducing the number of children given an educational statement.

Inadequate funding (for social care) has resulted in targeting resources at the most complex and severely disabled children. The 'thresholds' for accessing this provision have risen and families of children with mild to moderate disabilities, are finding themselves less eligible to access additional support. NHS Trust CAMHS team

We are unable to access any respite services through social services as our child has 'no additional needs'. He has severe total body involvement cerebral palsy, registered blind, no means of communication, doubly incontinent, has asthma and is frequently oxygen dependent. He needs assistance in all activities of daily living. I dread to think how disabled you need to be to qualify for assistance!

Certain groups of children are highly unlikely to access social care services, however much they might benefit an individual child. For example, Afasic told us that 'children with SLI (speech and language impairments) and their families rarely receive support from social services for issues arising from their disability'. Another group regularly denied access to social care services is children with autistic spectrum disorders.

There are a group of children who are labelled as having 'moderate disabilities' that do not fit the criteria for most social work teams. In the last few years this has been heightened with children having diagnosis of ADHD. ASD and Aspergers Syndrome but most often are not eligible to access social services unless it becomes a child protection issue!

Professional

High eligibility criteria for social services support prevents other agencies from accessing additional resources. The Special Educational Consortium

told us that 'tightening eligibility criteria in social care and funding constraints prevent the development of creative packages of support for disabled children and young people with complex needs'.

Following the Children's National Service Framework standards, local authorities should be developing threshold eligibility criteria in partnership with health, education and voluntary sector providers. These should be open, transparent, published and shared with families and providers. Threshold criteria for social care services should be based on the impact of disability on both the child and family, with a view to minimising the impact and to giving children maximum opportunities to participate in family and community activities, as required by the Children Act 1989.

Therapeutic services

Families experienced a similar level of difficulty in accessing specialist therapeutic services. ICAN highlighted a government commitment in a 1997 green paper to deliver speech and language therapy more effectively for those children who need it by 2002. However, ICAN describe current provision of SLT as 'variable', affected by a shortage of therapists, cuts of therapeutic posts to manage budget deficits and turbulence created by NHS restructuring. Other submissions supported this critical analysis across a range of therapeutic services.

In my LA children receive therapy services until they are five years old and then they stop. The health service do not have enough therapists to provide continuity of service after five years, whilst they admit that many children continue to have needs. They simply choose not to prioritise in this way.

Education professional

Because the focus for children's services is education-led, the therapeutic health needs of children are taking a very low profile in PCTs.

Health professional

Our service (Occupational therapy) is only able to address a fraction of children's needs to participate in daily life activities due to scarce resources.

PCT occupational therapy team

Again, the shortage of specialist therapy services has a negative impact on the ability of universal services to meet the needs of disabled children. The Special Educational Consortium told us that 'the limited availability of therapeutic services, including SLT, OT and physiotherapy, impacts on the ability of many schools to become fully inclusive'.

Mirroring comments in the section on inequality above, families reported that they had been able to buy specialist support services that would not be available for less well-off families, either directly or through taking legal action.

Physiotherapy was sadly lacking. My son did not walk until he was four. To enable his muscles to develop and for him to walk we employed our own Physio weekly. If we had not take this action I am quite sure my son would not be walking today.

SALT (Speech and Language Therapy), Physio, OT (occupational therapy) – non-existent other than paying privately to receive provision.

We found it impossible to get our child into a school for autistic children without having to resort to legal proceedings.

Specialist health services

Specialist health services for disabled children are frequently overstretched and struggle to meet the demands of children with increasingly complex health needs, rare disorders and palliative care needs. The Association of Children's Hospices (ACH) and the Association for Children with Life-Threatening and Terminal Conditions and their Families (ACT) told us that 'often staff are unable to access the expertise they need to provide high quality care during the terminal phase for children needing palliative care'. RNID stated that many support services for deaf children and parents post-diagnosis are simply not available, let alone co-ordinated. Furthermore, cochlear implants for children are not consistently available or properly co-ordinated, and are vulnerable to a 'postcode lottery' due to poor commissioning practice.

The Rett Syndrome Association described a young girl with Rett syndrome, a rare health condition, who has been crying and screaming in pain since March 2006. A referral to a specialist service has been made but the waiting list for an endoscope will be another six months. In the meantime the girl is suffering on a daily basis. She has hardly attended school and the situation has placed considerable pressure on the family. The family are completing investigations privately at considerable expense. The Association commented 'We wonder if someone who was able to verbalise would have been subjected to the same delay, without appropriate management? Is there discrimination inherent in the system for someone with a profound disability?'

Particular issues were raised around the mental health needs of disabled children. The Royal College of Speech and Language Therapists told us that one third of children with communication problems develop mental illnesses if left untreated.²²

Children who have a learning disability are not often accepted into the Child and Adolescent Mental Health Service (CAMHS) because some of the CAMHS staff do not feel that they are equipped with the skills to work with children who have a learning disability. Health professional

One professional in a sensory support service was worried by the limited CAMHS service offered to blind and deaf children in their area. A social care professional told us that families wanted a specialist CAMHS provision tailored for and accessible by disabled children, especially for those with behavioural problems related to complex mental health needs including autism.

A major issue in health services is the commissioning of specialist services. This is particularly important for children who have continuing care needs. The Children's Trust told us that 'present systems designed to address multi-faceted complex health needs seem extraordinarily complex and present

²² Clegg, Hollis and Rutter (1999), 'Life Sentence', *RCSLT Bulletin*, 571, pp16–18.

too many examples of failure with inadequate clarity about who is responsible for what, resulting in bureaucratic and time-consuming turf wars, sometimes over small amounts of money.' The key solution identified here was joint commissioning of services, using the children's trust model as a basis for developing joint working. To spread risk, commissioning could be done at a regional level, with accountability jointly to new Strategic Health Authorities and regional Government Offices.

Short break provision

Respite for my daughter provides some social life with her peers outside of school and gives me time to spend with other children and recharge my mind and body. I need to be a mum, not just a carer.

It doesn't take a rocket scientist to work out the savings if my authority provided me with one night a week respite – say £500 per week as opposed to £4,000 a week for a residential placement!

You have to be at breaking point for help. My child is severely disabled; she meets all criteria, yet I had to have a breakdown to get help. My children almost ended up in care. That is costly for any council, yet three hours a week help prevented this – what did that cost?

A key service priority for parents with disabled children is a regular, reliable and appropriate short break. Disabled children also benefit from the opportunity to have a break from their family and access new experiences.

Without respite, our son would not have a separate life from us other than when he is at school. It teaches him self reliance within a safe environment. Of course it gives us a life too!

However, the lack of short breaks was the biggest single cause of unhappiness with service provision in submissions to our hearings, mentioned unprompted by three in ten submissions from parents. Examples of high quality respite provision, such as that offered by The Children's Trust at Tadworth, were warmly praised by parents. Yet The Children's Trust's submission described respite care provision in general for disabled children as 'grossly inadequate'. Mencap highlighted that the families with the highest levels of need often have the lowest levels of access to short breaks due to a lack of staff skills, for example in meeting additional health needs.

Particular groups may have even greater need for effective short breaks. One Parent Families highlighted that access to respite care is particularly important for lone parents because of the demands of single-handedly caring for a child with additional needs. The Association of Children's Hospices (ACH) and the Association for Children with Life-Threatening and Terminal Conditions and their Families (ACT) told us that for children with palliative care needs, 'Timely support is essential for all family members to be able to cope with the day-to-day demands of care and to prevent family breakdown.' Yet for this group of children, specialist respite care may not be readily available and general respite care may not be able to deal with the clinical care needs of the child. In response

to this, Tim Loughton MP highlighted the need for flexibility in respite provision, structuring the provision to meet the needs of the family.

Local authorities can also benefit from short break services, by making significant long-term savings to their residential care budgets through providing adequate short break services.

Most out of county placement requests (which cost our county £150,000 – £350,000 per year) are driven by the parents need for adequate respite care. Education professional

There is concern that the level of respite and short break provision for families is falling.

We have recently lost respite due to local hospital's lack of funds to continue a successful service.

Evidence from a recent report by Mencap suggests that a third of families receiving short breaks have suffered a reduction in the level of service they receive in the past year.²³ Contact a Family told us, 'It is our view that the criteria for short breaks are constantly being made harder and harder to meet so that none but the *most* desperate are able to get access to any sort of break now.'

One local voluntary agency told us that their respite facility was empty for 22 weekends a year, despite huge demand from parents for the service. This agency could provide short breaks for double the number of families that they currently support, but the social services department was unable to fund staffing for these additional families.

The consequences of this failure to deliver sufficient short break services are disastrous – both for individual families and for local authority budgets.

If adequate funding were available to provide the level of short break and respite services many families would not reach breaking point, and many children who are placed in residential schools because of family reasons could be educated within their local community. Education professional

To meet need, local authorities should audit their existing short break services and plan to progressively increase the capacity of these services to support additional families.

Recommendations

Families with disabled children should have a statutory minimum entitlement to short break services, set to reflect the level of their child's needs and that of the family.

Local authorities should target funding at providing a flexible menu of short-term breaks, as a proven preventative measure to further costs later. A multi-agency approach should be taken to funding and commissioning short breaks, recognising the potential cost savings to a range of agencies.

²³ Mencap (2006), *Breaking Point – Families Still Need a Break*, Mencap: London.

Direct payments/individual budgets

The use of direct payments as a means to give families control over the services they receive was the subject of great debate in our hearings. The exchange of views between Department of Health Minister Ivan Lewis MP and parent Gail Hanrahan at our session on transition to adulthood was reflected in the hundreds of written submissions we received that mentioned direct payments. While the Minister highlighted the control direct payments had given to a family with a number of severely disabled children, Gail Hanrahan raised the point that direct payments potentially place an additional burden on some families, and that the right services may not be available to buy with direct payments.

The written submissions contained evidence for and against direct payments and their extension into 'individual budgets' as envisaged by the *Improving Life Chances* report.

The introduction of direct payments has been marvellous as my son now mixes with kids his own age, attends gigs, goes to the cinema, and generally organises his own social life.

Direct payments have allowed us to hire (and retain) a very good helper for 12 hours a week, with total flexibility, to do what we need her to do, not what an agency or social services think she should do!

Direct payments seems a very extreme measure when we are already up to our eyeballs with responsibility. We simply haven't the capacity.

Direct Payments are heralded as being the way forward but PAs are hard to recruit and in our area there is no training available for health care needs and families are having to do the training themselves.

To ensure that as many families as possible are able to take control of their own services, Direct Payments support services need to be established in every area, to assist parents in managing payments and all the issues associated with managing care workers. Direct Payment training schemes should also be established to give parents the skills they need in child protection issues and supervision for workers.

A common concern regarding direct payments was that local authorities were using them as a means to shrug off their commissioning responsibilities.

We were asked to consider Direct Payments so that we could purchase the services for our child. Firstly this is often the last thing a depressed family of carers would want piled on top of them, and secondly it appeared this option was only because the local Social Services could not access any services.

A simpler concern about Direct Payments is that there is insufficient funding in the system to deliver payments to every family who are eligible for them. Government must ensure that local authorities receive sufficient funding to offer Direct Payments on a fair and equitable basis to parents.

The money from the direct payments scheme has run out, and some parents now can't access the scheme.

There is also concern about the level of payments, particularly whether the hourly amount is sufficient to pay a carer with the skill and experience to support a child with complex needs. The Rett Syndrome Association also raised concerns over consistency of care, with Direct Payments encouraging a transitory workforce which may be poorly trained.

Anne McGuire MP, Minister for Disabled People, acknowledged the concerns about extending Direct Payments into broader individual budgets.

Some parents of disabled children have said to me that they are not sure if they want to go down the road of individual budgets because they don't want to project manage their children.

However, general support for the principle of Direct Payments, offering families more control over the services they receive, came through in our evidence.

Although we are not awarded the number of hours we need, and Direct Payments are full of pitholes and risk, they have improved our lives.

In the context of conflicting views over direct payments, the work to take forward individual budgets should take careful account of the need to ensure that local authorities continue to plan and commission a range of services for disabled children and families.

Recommendation

Direct Payments and Individual Budgets should be a choice for those parents and young disabled people who want to manage them. However, parents, families and young people should also be able to choose to receive services directly provided or commissioned by local agencies. Sufficient funding should be made available so that all those eligible can receive Direct Payments should they choose. Direct Payment support services should also be established in every area, to assist parents in managing payments and care workers.

Multi-agency commissioning and working

The liaison between agencies seems scanty and non-existent when it could be seamless and powerful.

Multi-agency working was recognised by many submissions to be a major challenge for service providers – and key working was felt to be the most important solution (see below). Parents and professionals recognise the desperate need for greater co-ordination and working across agencies.

These children are complex and therefore solutions are also complex, requiring multi-disciplinary working which is often not available. Health professional

The evidence received for these hearings was universal on the need for greater multi-agency working. However, many submissions recognised the continuing barriers to delivering a successful multi-agency approach.

Government departments should do what they constantly ask us to do – talk to each other and produce one set of guidance for everyone working with children, one set of competences that all staff should have, joint training schemes, pay and service structures that make it easier to work together and provide services. Health professional

In 30 years of health working I have heard that joint funding/pooled budgets/working together is/will/must happen. In reality at the coalface it still is awaited. Health professional

Families with disabled children continue to comment on how compartmentalised services are, how 'service-centred' the system is. Foundation for People with Learning Disabilities

The failure to fully co-ordinate budgets and services has huge negative consequences on families.

Education for our kids is also about the inclusion of non-educational services – physiotherapy, occupational therapy, speech and language therapy, sensory impairment service etc. While these services remain in the remit of health rather than education there will never be adequate provision or meeting of minds between education and health.

During our session, Paul Burstow MP highlighted the frustration felt by families passed around between services as each declines to take up the funding burden or broker a deal with other services. One parent told us that a social services department had put in place an interim care order to remove the child from the family, in the parent's view in order to avoid co-funding a special school place. This care order was overturned by the High Court, who ordered joint funding.

One example cited in evidence concerned a grandparent denied any respite care for the disabled child she was looking after, who was informed that a budget was available for the child to attend residential school at a cost of at least £100,000 – a great deal more than the cost of the respite care that would have allowed the child to stay with the family.

Particular tensions between agencies were identified in evidence. Firstly, the relationship between education and health was described as difficult in several submissions.

Education and Health services often do not work together well and as parents you go back and forward between them both on the issues of who is going to fund things.

The health service can choose which and how many therapists it provides without having to meet the identified health and therapy needs of children.

Until this imbalance is altered and the health service have a mandatory duty to make provision that meets needs this will not alter.

Education professional

Worrying concerns were raised that recent reforms to children's services may have a negative impact on multi-agency working with health.

The SEN branch of (local authority) works very hard to provide successful placements for children locally, however, since it has formed the Children's Services Authority (education and social services) its links with health have been seriously weakened making the service to children poorer.'

Health professional

However, positive examples were forthcoming of where successful multi-agency working had significantly improved services.

Integration with Social Care two years ago has been successful and provides a more holistic and consistent approach for the child and family.

Professional from health and social care integrated team

One CAMHS team described their involvement in the pathfinder Children's Trust in their area, developing a Team Around the Child approach. The team stated, 'Although initially very time consuming both families and clinicians have found it very effective, as it has provided a holistic approach to assessing both the child and their family's needs. It has also improved communication between families and agencies.'

Co-location was identified as a potential ingredient in developing better multi-agency working relationships.

I work in a Child Development Centre and when professionals are co-located and know each other I believe we offer much better coordinated, holistic and appropriate services that reduce duplication and are therefore cost effective. Professional

Key working

At the level of individual families, key working schemes received universal support from parents. Key workers were identified as essential in Standard 8 of the National Service Framework, which stated that they should be 'the main point of contact with the family' and should take responsibility for co-ordinating review meetings and liaising with professionals to ensure all agreed support is delivered.

Parents stressed the importance of key workers to co-ordinate services and appointments and avoid endless repetition of information.

A key worker would be ideal. Someone to support the family and provide information as it was requested.

Many disabled children and their parents face a life time of appointments in various settings and repeating their story endlessly. If professionals could work together more and keep the child's needs as the focus of their work, life could improve for many people.

With any disability, it is so frustrating and time consuming to have to

repeat your story time and time and time again. Service plans and care plans should be networked across the board so that professional services can co-ordinate. This would cut down on resources and time.

One parent without a key worker stated that they were required to 'do all the management between lots of different services.' Another parent stated:

I consider that my child's well being is under the care of a 'team' of people ... some of whom never meet each other. A child needs to be seen holistically ... not as a 'movement problem' or a 'speech problem' or a 'learning problem' ... but full team assessments are hard to come by and liaison between professionals is often poor.

Sharon Kelly, stressing the need for key workers, told us

My daughter is quite unique. She's the only child in the world that's suffers with her combinations of conditions. We have twenty one services involved in our family.

Recommendation

Families caring for a disabled child needing support from multiple agencies should be entitled to a key worker to oversee and manage the delivery of support from all agencies. The vital importance of this method is emphasised by the success of the key worker element to Early Support. Key working should be extended up the age range into transition to adulthood.

Multi-agency commissioning

Although key workers are necessary to ensure coherent packages of services for families, a multi-agency approach to commissioning services is equally important. Indeed, key worker services themselves should be jointly commissioned between all the relevant agencies. No amount of co-ordination will hide a failure to increase the supply of services.

There are lots of people currently being paid to integrate services but very little service to integrate.

Professionals were also clear that multi-agency approaches cannot be a figleaf to hide resource shortfalls.

We are working hard to achieve a multi agency team approach to delivering services which will make a huge difference to the experience of children and families but this will have to be achieved by prioritising existing resources, which are already stretched to capacity.

Children's services manager

Adequate time and resources need to be allocated to enable this work to take place. Commissioners need to support the use of resources in this way.

NHS Trust CAMHS team

Following the National Service Framework standards, Government should ensure that, through the development of Children's Trusts, all localities have a multi-agency steering group for disabled children which reports to the local strategic partnership and is involved in the production of the children and young people's plan. The group should include senior managers from all main agencies, adult services and other appropriate representatives.

Government should also consider supporting its policies on the co-ordination of services by establishing a joint appeal process based on SENDIST (special educational needs and disability tribunal) with a mandate to ensure provision assessed as needed is delivered by all agencies.

This section covers:

- transition planning
- employment, education and training
- impact on parents
- future service developments.

The transition to adulthood is an exciting time for all young people. However, for disabled young people it is often a confusing time that comes with the move to adult services. A great deal of work has been taking place around the country to improve the transition experience for disabled young people and their families and we are starting to see a range of good practice emerging. Despite this, for many young people and families, it continues to be a time when young people have few options, become more isolated and families experience a drop in levels of support.

I would like to get a real job again, a real wage with this. I would like to get married and have family in a few years. I want to go to college to learn more about computers in September. I want to pass my driving test.

Ajay Choksi, session on transition to adulthood

It should be a right for every citizen, whatever their challenges, difficulties or disabilities, to know that the system will organise itself to support you to have the best possible chance to get those things if you want in your life, which many other people take for granted.

Ivan Lewis MP, Minister for Care Services, responding to Ajay

I have often heard Transition described by other parents as like 'standing on the edge of a cliff, about to fall into a black hole'. I can now confirm that this is exactly what it feels like!

Gail Hanrahan, session on transition to adulthood

The submissions to our hearings from disabled young people and their parents were full of anger at the sense that services that they may have had to fight for simply disappeared at transition to adulthood.

Disabled children do not go away – their needs are often similar, but even more acute as they grow into young adults and beyond.

Once the disabled person reaches the age of 18 then it seems no one is really interested in them. Disabled children do not grow into non-disabled adults!

I used to have speech therapy and physiotherapy and then it stopped because health services told me once I was 16 I wasn't entitled to it.

Disabled young person

The positive ethos and enthusiasm for looking to the future and encouraging disabled people to pursue their dreams and aspirations that seems to fuel children's services disappears when adult services are reached.

Why invest all of this time and energy into children's services if we are not going to give these children the means by which they can follow these aspirations through when they reach adulthood?

Similar scepticism to the comments on children's policy was expressed by parents about the impact of key policy initiatives for disabled adults.

Valuing People is only paid lip service and quoted in politico gobbledegook that we receive in letters – at the chalk face it is meaningless and worthless.

Disabled young people want the same things as other young people – yet services are not able to support their needs.

Sadly, many students leave college and other than going to another college, doing a bit of voluntary work or going to a local weekly support group there is little for them to do. They are young adults who want what we all take for granted ... a job, a home of their own, a partner, possibly children, friends, a car, nice clothes, foreign holidays. Many are relegated to tedious lives on the fringes of society. Professional

At 16 my eldest daughters social life took off, and yet it looks like Guys will stop all together. Gail Hanrahan, session on transition to adulthood.

Professionals told our hearings that it is possible to deliver high quality services for young people in transition.

When the transitions service works well, it has enabled young people to achieve their aims: the best possible outcome. This is through accurate person centred assessment, an encyclopaedic knowledge of local services and resources, and an excellent personal/worker/relationship with the adult social care team. Social care professional

Local agencies should collaborate to ensure that young people and their families experience continuity in delivery during the transition from child to adult services. However, our evidence is that this is the exception rather than the norm, and that urgent action is needed to ensure that disabled young people's lives are not wasted in the transition to adult services.

Recommendation

Government should make available specific programme funding to encourage the development and dissemination of models of good practice in transition service provision. Local agencies should put in place multi-agency protocols and agreements that set out how they will work together to support young people and their families throughout the transition process.

Transition planning

Education, with health and social care have a statutory duty to develop effective transition plans for disabled young people from the age of 14,

as set out in the SEN Code of Practice. The *Improving life chances of disabled people* report states that ‘Planning for transition should be focussed on individual need’ and that there should be ‘continuous service provision’ and ‘access to a more transparent and appropriate menu of opportunity and choices’. Responding to this, Gail Hanrahan stated

In my experience young people are offered no such menu and the only choice their parents are left with is to accept what is offered, however inappropriate, or like us, go through the gruelling experience of a legal challenge, enduring unnecessary and unjustifiable stress at an already difficult phase in our lives.

Transition planning is not currently giving families confidence that they will continue to receive support as the young person moves into adulthood.

After 19 years of familiarising myself with one system, it is like starting again from scratch with all the same worries, concerns and fears.

Transition is a VERY frightening place to be in.

Transition plans – having just encountered the ‘new improved’ system, it was a total failure, did not happen at all, my son left school with no plan and despite two years of fighting still does not have one.

Local agencies should ensure that young people and their families should have access to good quality local information during transition. Disabled young people should be included in planning that is centred on their own needs. Transition planning must start at 14 to ensure that local services can be identified, particularly for children with complex needs. Where children are educated outside their home authority, particular care must be taken to ensure that transition planning takes place properly.

My son has a hidden disability. Because he attends a school outside of my local authority he was not seen at all for six years by anyone relating to his disability or the impact that may have on his transition in adulthood and adult services.

Young people and parents should be supported to be involved in transition planning. In some areas, young people are not supported to be actively involved in the process. Parents are often not given enough information about the process to enable them to participate fully. Information on the transition process must be available families in user-friendly formats. Transition planning needs to be carried out with a multi agency approach to ensure that young people and families do not have to continuously repeat themselves and receive multiple assessments. To maximise independence and control, Direct Payments and Individual Budgets must be considered as an option for the support package to be received in the transition planning process.

An example submitted to our hearings told of a parent needing support from an advocacy organisation to identify that it was necessary for the young person they cared for to apply for funding from both the Learning and Skills Council and social services to access an appropriate post-16

placement. Yet this is exactly the sort of co-ordination that transition planning is supposed to deliver for families.

Joan Humble MP identified Connexions as the service which should be seeking to co-ordinate the transition process. However, given changes to the remit of the Connexions service, it appears that new service solutions need to be identified to ensure the statutory duties on transition planning are delivered. In 2008 when the funding for Information Advice and Guidance (IAG) is given to local authorities there will be further changes to local Connexions services and in some cases IAG may be commissioned from alternative providers. By 2008, when funding for IAG goes to local authorities, Government should ensure that arrangements/commitments are in place across children's services for IAG providers to have a clear role in the transition process.

Employment, education and training

Disabled young people should be able to access the same range of employment, education and training opportunities available to other young people. However, submissions told us of a shortfall in specialist support to help disabled young people into work or at college.

There is a lack of post 16 opportunities for disabled young people across the country which leaves young people repeating life skills courses year after year that do not help to skill them up for employment. Transition Information Network

Disabled young people with high support needs but with the ability to achieve mainstream qualifications face a catalogue of barriers to obtaining an education equivalent to their non-disabled peers. DARE Foundation

I've got a learning disability I find it difficult to get employers to bother and to get the interview technique. Ajay Choksi, session on transition to adulthood

Mencap highlighted that employment should be a realisable goal for many children with a moderate learning disability, but only one in six adults with a learning disability are in employment (Emerson 2003). A Connexions personal advisor told us that disabled young people miss out on support because the Government's focus is 16–18 year olds who are NEET (Not in Employment, Education or Training). Yet disabled young people are twice as likely to be NEET as other young people (DfES 2004). Funding specialist support services for disabled young people can help government meet its targets in this area. Employers should also ensure that they are meeting their duties under the Disability Discrimination Act not to treat disabled young people less favourably in their interview processes and to make reasonable adjustments to meet their needs.

A case study provided by Gail Hanrahan explained to us the consequences of the failure to provide appropriate support to disabled young people. One young man started at a college of Further Education. The college had insisted they could meet his needs, but he was sent home

after only two hours on the first day. He went back some months later for one day a week only to be expelled a month later. The young man in question is now attending residential school because the family have broken down and his behaviour has deteriorated so much no one (including his family, a single mother with two younger children) can cope with him anymore – despite the family having coped well for the first sixteen years of his life.

In relation to education, parents and disabled young people were clear that an appropriate individualised curriculum needs to be delivered for each disabled young person, with the right balance of academic, vocational and life skills elements. There was a sense that the focus on academic standards in education suppresses movements to improve the curriculum for disabled young people. Further education providers should work with the Learning and Skills Council to ensure that a full range of courses is available to meet the needs and interests of disabled young people and prepare them for the move into employment.

The British Association for Supported Employment (BASE) highlighted ‘widespread anecdotal evidence’ that disabled young people are not getting access to work experience placements whilst at school or in further education. Reasons cited include the lack of suitable placements, a lack of workplace support and transport difficulties. The DARE Foundation commented: ‘Work experience is meant to be compulsory for all school pupils. Employment should be seen as a legitimate goal for young disabled people.’ We endorse these comments and urge education providers to ensure that disabled young people have access to the widest possible range of work experience placements.

Recommendations

Government should re-examine the funding available for adult and community learning, to ensure that all disabled young people can access appropriate courses.

Disabled young people should have full access to individualised learning and vocational pathways into chosen employment and other meaningful occupation opportunities.

Impact on parents

Parents of disabled young people find that the caring responsibilities often get more onerous, rather than easier, as their children get older.

Only recently I've heard from three mothers of disabled young people who will have to give up their jobs despite having managed to work throughout their child's childhood, because the college day is being shortened from 9am–3pm to 10am–3pm, cut to four days a week instead of five and the college holidays are longer than the schools.

Gail Hanrahan, session on transition to adulthood

By the time their child reaches transition, parents tell us that they are worn out by the caring responsibility.

I have had no social life for 12 years, I am unable to leave my daughter with unqualified people.

My child is 14 and I am starting to realise the full horror of the lack of respite at age 19.

I am a person who has cared for my son for the past 18 years and would now like a life for myself. I would like to work one day a week, but trying to arrange cover until I get home is nigh impossible. If I go out for a meal, or a voluntary meeting, I have to use my direct payments to provide cover for my son. I don't think that is fair, as it reduces the activities that he is entitled to receive in his care plan.

Indeed, parent carers are being expected to provide care to disabled young people that professionals would refuse to provide on health and safety grounds.

Professional risk assessments and manual handling assessments indicate that someone the size and weight of my child needs to be managed by two adults during all manual handling and positional transfers; however I as a parent am not only allowed but am expected to be able to manage his weight safely on my own.

Professionals recognise the burden this is placing on parents.

Many families don't know how they are going to cope once their young person no longer attends school or college, and this rules out any chance of getting a job or life outside the caring role. Health professional

Parent carers surveyed by the National Autistic Society identified social skills training as the form of support most valuable for the person they cared for. Although this result was consistent across all age groups, only 9% of respondents actually received this service.²⁴ This failure to support the development of social and independent living skills in disabled young people increases the likelihood that they will continue to depend on their parents for care into adulthood. As the NAS states, 'in general service providers do not recognise that an absence of social skills often acts as a barrier to independence for people on the autism spectrum.'

Children's and adults services should work together to ensure that families do not experience a drop in levels of support when a young person reaches adulthood. Carers should receive full carers assessments to ensure that they are receiving enough support to facilitate their personal development, as well as meet the support needs of their young person. Furthermore, the caring responsibilities on parents will be reduced if disabled young people have the opportunity to gain self-care and independent living skills to prepare them for adult life.

²⁴ Broach et al (2003).

Recommendation

Government should ensure that the potential for working of parents of young disabled people is not neglected, and that disabled young people have the opportunity to gain self-care and independent living skills to prepare them for adult life.

Future service developments

Health

A large number of submissions on transition particularly focussed on health services, with real concern that adult health services could not meet the needs of disabled young people.

Since turning 18, I have been horrified at the health services which my son recently received when he was hospitalised.

Transition in health services was felt to be particularly abrupt, with young people suddenly losing access to key specialists who may have worked with them throughout their childhood.

All paediatric services cease around 16–19 and adult medical care is not set up adequately to support young adults with severe disabling or life limiting conditions. Voluntary sector professional

It's ridiculous that young people become adults at 16 for health services. Specialist paediatric services, e.g. GOSH, should be available to 18 and beyond if they have the expertise in rare syndromes.

Families often report receiving excellent care from specialists such as the community paediatrician and child health team; they are shocked when this model of care stops at transition to adulthood.

Foundation for People with Learning Disabilities

Our son is now in transition from paediatric services to adult services. This has been nothing short of a nightmare and is on the whole only being achieved because we are assertive parents who plan ahead and have expectations of the professionals who care for our son.

Families who may have had consistent contact with specialist health services while their disabled child was younger have to access primary care services to try to get similar specialist support from adult services.

Having just gone through transition period found health services totally lacking and unhelpful. For example had to have referral from my own GP who has not seen son for years to be referred to go and have specialist foot wear. There was no co-ordination when he left school for this to happen.'

There can be huge problems with transition when there is no designated consultant to hand over to and therapies essentially stop.

Health professional

Where health services are delivered to disabled young people, too often they are simply placed in inappropriate services designed for much older service users.

They did tell us he could have respite but was in a unit with adults up to the age of 70+.

To deal with these difficulties, health agencies should actively contribute to the multi-agency transition planning process. Particular attention should be paid to ensuring that the needs of disabled young people in transition to adulthood are met through the development of care pathways in health services.

Social care

Another consistent theme of our submissions on transition to adulthood was the gap between children's and adult services.

Adult social services have been a complete nightmare, I was told by manager that they do not work in same way as childrens services. When I asked how they differ, did not get a reply.

We did have exceptional services when son was in childrens services, leisure needs met, good respite service but since he's gone into adults – nothing.

Although concerns with health services dominated, the gaps between children's and adult social care were also highlighted by parent and professionals.

Adult Services have devastated provision of care for learning disabled people by closing day centres and altering the eligibility criteria for those centres that do exist. (Authority) has a good Transitions Protocol on paper – but that is no good if there are no facilities for 18 years olds.

For young adults at the time of their transition from this residential college provision is very patchy and seems to be dependant on which social worker you have, if you are lucky enough to have one. Because our students don't fit into anyone's funding 'box' they really suffer. Social care professional

Local authorities must ensure that the transition to children's services departments does not break the link between children's and adults social services teams around transition.

Co-ordinating transition services

A key solution to the challenges around transition is effective co-ordination of multi-agency services. The Transition Information Network emphasised the need for a specified individual in to have responsibility for the transition process in every local area, and outlined a few possible ways that this is working around the country. 'More and more local authorities are developing posts such as Transition Workers to work with young people and their families throughout the transition to adulthood.'

The responsibility may also lie within a co-located multi-agency transition team, or a virtual team. In some local authorities key workers have responsibility for working with young people and their families through the transition process.

One parent described the impact that a co-ordinated transition team had made to their family.

Our transition team has been excellent. There are three social workers in the disabled children's team and one in the adult team. They have all been in post for some years now. They talk to us, they visited our son to see him for themselves and they listened to what we had to say. They helped us find suitable specialist provision.

Local agencies should have in place multi-agency protocols and agreements that set out how they will work together to support young people and their families throughout the transition process. It should be made clear to families and young people who their first point of contact is throughout the process so that they can quickly and easily gain access to information and services.

Conclusions – making change happen

Our hearings have taken evidence highlighting the implementation gap between government policy on disabled children and the reality of service delivery on the ground. We have found major gaps in service provision and pervasive inequalities in services and outcomes for families.

A major issue in challenging this inequality is the low political priority given to services for disabled children and their families.

The local council have overspent on their budget and yes, disabled children and adults are the first to get their services cut. Diabolical.

We agree with Minister Anne McGuire MP that the role of government is ‘not to take the fight out of the parents but to take the fight away from the parents so they actually get what they are entitled to’. However, at the current moment too many families continue to only receive services at crisis point. As one parent told us, ‘It would be lovely to start with a blank sheet of paper, and actually build services that meet needs.’

Parents and disabled people told us that they wanted services for disabled children and their families to be available as a right.

Help and support for people with disabilities is a right – not ‘charity’. It is a way to level the playing field and enable people with disabilities to make the same choices and lead the same lives as all other citizens. If we believe in equal citizenship, we must recognise this and commit to it.

Disabled adult and voluntary sector professional

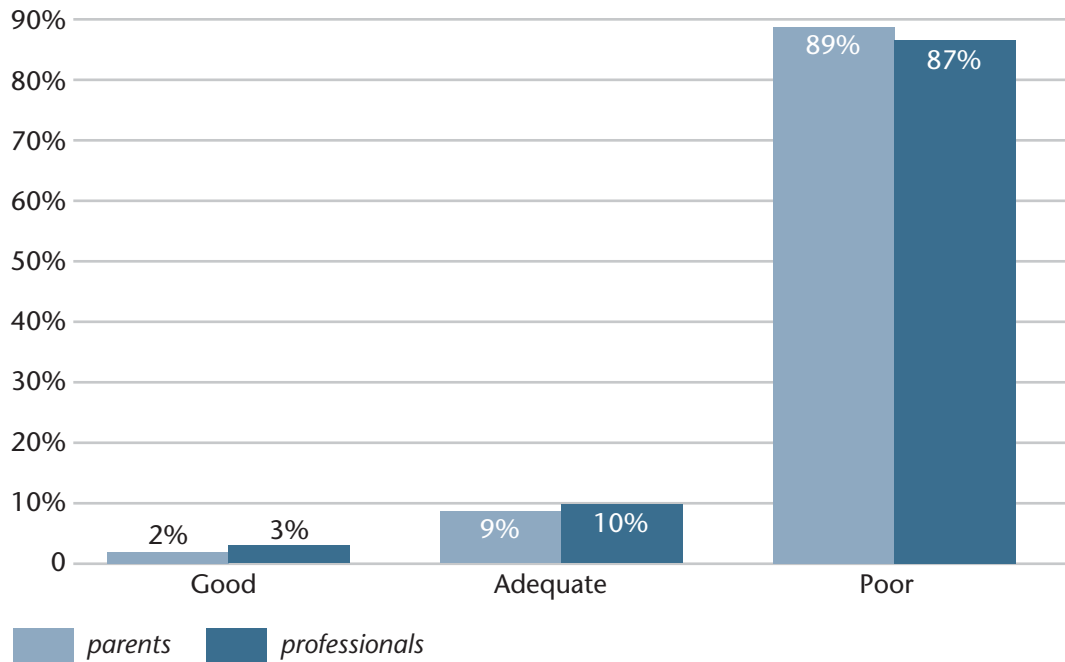
We don’t want to have to depend on charity to have what other families take for granted. CHOICES for Families of Children with Arthritis

To ensure that families get their rights, urgent action is needed on the recommendations in this report, and on those from the many recent policy reviews and reports that have looked at the situation of disabled children and their families and found services wanting. The impact of the failure to improve services is real and present.

I have cried out for help, seemingly into the wilderness, and been left to cope alone. Currently I simply cannot see a future for myself and am frightened for my sons. I don’t so much have a disabled son, as I am a part of a disabled family. Disabled and excluded by a society which seems not to care at all. Years ago a little help would have gone a long way but now I fear that the foundations of my life have been so undermined that there may never be any recovery.

The need for additional resources

Throughout the submissions to our hearings, evidence was presented that delivering improvements to services for disabled children requires additional resources. An overwhelming proportion of written submissions to our hearing from both parents and professionals told us that current funding of services for disabled children is poor.



Source: Written submissions to parliamentary hearings

61% of parent submissions highlighted additional resources as the most important factor in improving services – ahead of legal rights to services, minimum service standards or any other issue. 74% of professional submissions stated that lack of funding was the largest single barrier to service improvement. Parents agreed:

Without the more money being made available, legal rights will be of little value if the level of provision isn't increased.

Having a legal right to then be told that there is insufficient money/resources to provide the services is pointless.

The level of frustration at the inadequacy of current funding for disabled children's services came through in the written submissions.

To create a level playing field for all children, so that disabled children have the same life chances as other children, more resources are necessary.

Disabled adult and voluntary sector professional

I get absolutely fed up with both health and social services telling me that there is not the money to pay for what we are requesting, while at the same time acknowledging with us that our request is entirely reasonable.

There is no escaping the fact that provision of services has been dependent on overstretched services for a long time; a great deal has been achieved and a great deal more could be done with the investment of new money.

Children's services manager

Those staff 'on the front line', I am very aware, care desperately and are working hard to do all they can but rather than the service being child led (as continually promised) it is ALL dependant on financial constraints.

Given the speed with which the needs of disabled children have changed, and current variability in levels of service provision, Government should

establish a transitional funding system to permit service innovation without impacting on existing levels of service. This would replicate arrangements such as the Special Transitional Grant which assisted in the move from institutional to community-based care in the 1990s.

Sustainability of funding and planning

However, while urging Government to recognise the funding shortfall, we are not simply calling for more money to be pumped into services for disabled children. Firstly, funding that is invested needs to be sustainable to allow long-term strategic commissioning of services.

Planning is almost impossible outside the current financial year because nobody can commit to whether funds will be available beyond this time nor to how they will be allocated/shared out amongst clients.

Long-term planning, including the development of specialist local services (to replace use of out of area services), requires additional funding, and local authorities should have funding set aside specifically to do this.

Professional

Minimum service standards

Moreover, funding needs to be 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.

If there were minimum standards below which NO service should fall & at least these were funded appropriately then it would be less of a post code lottery. Families would have clear explicit guidance as to what they could expect and not have to fight for resources, this would lead to more control for service users. Head of pre-school specialist support service

Minimum standards should be challenging, continuously developed and promote development of services. Education professional

Minimum standards would put pressure on organisations to provide them, however, without extra funding we would be in a catch-22 situation.

Health professional

Improvements in wheelchair services requires minimum service standards with benchmarking and targets. The under-funding of wheelchair services must be addressed by the Government as part of this spending review.

Barnardo's Policy and Research team

Government will need to issue guidance on how to commission services to meet these minimum standards across multi-agency teams.

Alongside the 'core offer', we endorse calls from parents for greater legal rights to support for families with disabled children.

You can make this work by enshrining a legal right to appropriate provision, with penalties for any authorities that do not fulfil this obligation.

In particular, we reiterate the need for a legal minimum entitlement to short breaks for families with disabled children, as the evidence of the positive impact of short breaks is overwhelming.

Inspection frameworks

Inspection frameworks for children’s services need to prioritise service delivery for disabled children and their families. This will help make a reality of any minimum standards framework. The lack of effective inspection frameworks was identified by respondents as a barrier to implementing the existing Children’s National Service Framework standards – alongside insufficient finances.

Have Government inspected targets attached to the children’s NSF.

Health professional

The Children’s NSF is struggling to make a real impact because there are no financial resources to support it. Health professional

Inspection of services for disabled children has not been as challenging as it should be in schools, PCTs, acute trusts or local authorities – it should address the quality of family life and the long term impact of pragmatic decision-making. Children’s services manager

The Council for Disabled Children told us that current inspections of children’s services are weak on disabled children, identifying areas of weakness failing to drive improvement cycles. ‘Despite the introduction of joint area reviews, inspection processes still appear to deliver a fragmented picture of the lives of disabled children. The superficial nature of inspection also gives us no understanding of whether the Every Child Matters outcomes for disabled children are being achieved.’

Local area agreements/Public service agreement targets

Delivering improvements to services for disabled children will involve spreading existing good practice, improving service co-ordination and targeting additional investment. Ensuring that additional resources lead directly to improvements in services and outcomes for families was a key theme in our hearings. Local Area Agreements (LAAs) were highlighted by Cllr Les Lawrence on behalf of the Local Government Association in his oral submission. Cllr Lawrence described LAAs as ‘a way of aligning resources such that you can target those resources to much greater effect at the front line.’

In an additional meeting with the hearings panel, Local Government Minister Phil Woolas MP reiterated the importance of LAAs in delivering local flexibility within a common framework of minimum standards. The Minister highlighted the Government’s desire to incentivise local authorities by devolving targets, reinforced by nationally-agreed minimum standards. Coupled with stability of funding, created by the three year funding settlement, LAAs are intended to deliver more effective multi-agency service delivery while providing better value for money.

We understand from our meeting with Phil Woolas MP that the forthcoming Local Government white paper will revise and extend LAAs. We urge Ministers to ensure that services for disabled children are part of every LAA, and that the national minimum standards for the children’s elements of LAAs make specific reference to services for disabled children and their families.

In addition, we support the many submissions to our hearings that called for national Public Service Agreement targets on services for disabled children. These targets need to be closely linked to the Comprehensive Performance Assessment for local authorities, so that services for disabled children become a key element of any local authority performance assessment.

Is ring-fenced funding needed?

To ensure that resources allocated to services for disabled children reach the intended recipients, many submissions to our hearings called for additional funding to be ‘ring-fenced’.

I do not believe that children and parents will get the support they need and value from health professionals without funding within health being ring fenced for children’s services to meet the Children’s NSF markers of good practice. Health professional

Teams who work with disabled children have always seemed to be the ‘cinderella’ service historically, and sufficient funding which is targeted and ring fenced would stop possible finance being drained away to other areas. Professional

Ring fence money for services and then be flexible on how these are delivered locally and have parents (plural) on the decision panels and at every level of management. Professional

If resources are not ring fenced when budgets are over spent those sections where clients do not present an overt social and political problem and are not vociferous the money is withdrawn. Social work professional

However, support for ring-fencing additional resources was far from universal.

Ring fenced funding doesn’t help anyone and leads to services developing in a disjointed manner, without proper thought for population needs and other wider issues. Health professional

If you have targeted resources what happens to those who fall just outside the target – it depends how high the thresholds are set which enable access to the ring-fenced resources. Professional

Professionals emphasised the need for flexibility and creativity in the way services are developed and commissioned with additional resources.

Resources are key to developing services, not necessarily more but freedom to utilise in new ways and jointly. Health professional

Ring-fencing should be global, not too prescriptive as between types of services. TreeHouse

Additional resources also need to be linked to accurate recording of data on the number of disabled children in any area.

It would help if there was a funding mechanism which took into account the number of high need disabled children in each area and weighted funding accordingly. Social care professional

Other responses emphasised sustainability of funding ahead of ring-fencing.

Long-term sustainable funding is needed (for voluntary sector providers) to make a real difference. Barnardo's Policy and Research team

This review should look to create different funding streams so that there are commissioning funding streams for long term planning, separate from year on year revenue streams. Virginia Bovell

Government has been able to offer us some assurance on this point, with Lord Adonis, DfES Minister, highlighting the introduction of longer-term budgets for schools and LEAs. However, we recommend that additional investment in services for disabled children needs to be sustained over a period of many years. We recognise the arguments raised against ring-fencing additional resources, despite the strong support for ring-fenced funding expressed to us by many parents and professionals.

If government is not persuaded to ring-fence additional resources for disabled children released through the Comprehensive Spending Review, Ministers must be able to convince parents and professionals that alternative mechanisms exist to ensure that the resources reach the children who need them. Local area agreements, minimum service standards and enhanced inspection frameworks may all be part of the package of measures that can deliver enhanced services from additional resources without requiring ringfencing.

Final conclusions

Ending the final session, Ed Balls MP, Economic Secretary, stated his hope that this report, and the Treasury/DfES review that is running in parallel to our hearings, will help the government make a difference, both in the terms of the way in which money is spend and the way in which services deliver better life chances to disabled children and their families. We echo the Minister's statement. Our hearings have found that services for disabled children are failing to deliver the government's stated objectives for children and families – the Every Child Matters outcomes. In addition, we have found convincing evidence for significant under-funding of services for disabled children across the board.

I think the current level of funding reflects society's attitude towards disabled children – sympathetic, but not prepared to contribute towards high-quality services. Professional

We hope that our report will be part of the process of changing attitudes to services for disabled children and families. Our evidence sessions and written submissions identified wonderful examples of good practice in delivering services to these families. What is needed now is additional resources and political prioritisation to drive up the level of service that every family receives. We commend Ministers for inviting us to set up these hearings, and we welcome the all-party response to this initiative. We urge Ministers to ensure that disabled children remain a political priority, both locally and nationally, long after this report has been delivered to HM Treasury and DfES.

Recommendations

- Significant additional resources targeted at disabled children and their families need to be made available to planners and commissioners of universal and specialist services, to enhance areas of good practice and develop effective support systems in all communities.
- Given the pace of policy change and the variability of service provision, Government should establish a transitional funding system to permit service innovation without impacting on existing levels of service. This would replicate arrangements such as the Special Transitional Grant which assisted in the move from institutional to community-based care in the 1990s.
- Additional funding should be 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, based on existing standards such as those contained in the Children's National Service Framework.
- Ministers should ensure that services for disabled children are part of every Local Area Agreement (LAA), and that the national minimum standards for the children's elements of LAAs make specific reference to services for disabled children and their families.
- National Public Service Agreement targets should be developed on services for disabled children.
- Inspection bodies need to work together to develop themed multi-agency inspections using agreed indicators. Once national minimum standards are agreed, inspection bodies should report regularly on compliance by all agencies with these standards.

Recommendations – collated

Funding

- Significant additional resources targeted at disabled children and their families need to be made available to planners and commissioners of universal and specialist services, to enhance areas of good practice and develop effective support systems in all communities.
- Given the pace of policy change and the variability of service provision, Government should consider establishing a transitional funding system to permit service innovation without impacting on existing levels of service. This would replicate arrangements such as the Special Transitional Grant which assisted in the move from institutional to community-based care in the 1990s.
- Additional funding should be 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, based on existing standards such as those contained in the Children's National Service Framework.

National planning

- Ministers should ensure that services for disabled children are part of every Local Area Agreement (LAA), and that the national minimum standards for the children's elements of LAAs make specific reference to services for disabled children and their families.
- National Public Service Agreement targets should be developed on services for disabled children.
- Inspection bodies need to work together to develop themed multi-agency inspections using agreed indicators. Once national minimum standards are agreed, inspection bodies should report regularly on compliance by all agencies with these standards.

Data collection and local planning

- All local areas should establish a single multi-agency database. This should:
 - hold data on all disabled children in the area, based on an agreed definition of disability shared across all agencies
 - inform the local needs analysis and children and young people's plan
 - inform commissioning agendas
 - be used to plan services to anticipate future need.
- To address service inequalities, as part of their children and young people's plans, local authorities should develop a needs analysis and

commission a range of services to meet the level of need in their population of disabled children and give families meaningful choice. Clear information then should be made available to families, outlining the minimum service standards they can expect and how to complain if these standards are not being met.

- All agencies should ensure that disabled children and their families have meaningful input into the way that services are planned, commissioned and delivered

Training

- Training and continuing professional development frameworks within the children's workforce should ensure that all professionals have the skills and competencies necessary to deliver services to disabled children.

Advocacy for children and families

- Government should issue clear guidance on the use and commissioning of children's advocacy and parent advocacy services. Government should target resources at independent providers of advocacy support to parents and disabled children, to ensure that disabled children stay safe and to help every family have an equal chance of accessing services.

Early intervention

- Government should commit to funding the National Centre of Excellence in Early Intervention, to pilot and deliver new approaches in early intervention and commit to the roll-out and mainstreaming of the Early Support programme, which will require further focussed resources.

Family support

- Families with disabled children should have a statutory minimum entitlement to short break services, set to reflect the level of their child's needs and that of the family.
- Local authorities should target funding at providing a flexible menu of short-term breaks, as a proven preventative measure to further costs later. A multi-agency approach should be taken to funding and commissioning short breaks, recognising the potential cost savings to a range of agencies.
- Governments in the other UK nations should investigate establishing a Sitter Service along the model evaluated as successful in Scotland, with a clear priority to increase the availability of childcare for parents with disabled children.

- Direct Payments and Individual Budgets should be a choice for those parents and young disabled people who want to manage them. However, parents, families and young people should also be able to choose to receive services directly provided or commissioned by local agencies. Sufficient funding should be made available so that all those eligible can receive Direct Payments should they choose. Direct Payment support services should also be established in every area, to assist parents in managing payments and care workers.

Benefits

- The childcare element of the Working Tax Credit (WTC) should recognise the additional costs of securing childcare for a disabled child.
- DLA forms should be further simplified and Government should consider awarding DLA for longer periods, without the need for further forms, for children with long-term conditions where variation in the level of need is likely to be marginal. Government should also consider waiving the 90 day eligibility period where children have additional time-limited care or mobility needs as a result of medical intervention.
- Government should give serious consideration to extending winter fuel grants to parents of disabled children on benefits, particularly those with disabled children under five who are at home all day.

School exclusion

- Government should reinforce guidance to schools and LEAs preventing exclusions of children with recognised disabilities and/or special educational needs.

Key working

- Families caring for a disabled child needing support from multiple agencies should be entitled to a key worker to oversee and manage the delivery of support from all agencies. The vital importance of this method is emphasised by the success of the key worker element to Early Support. Key working should be extended up the age range into transition to adulthood.

Transition to adulthood

- Government should make available specific programme funding to encourage the development and dissemination of models of good practice in transition service provision. Local agencies should put in place multi-agency protocols and agreements that set out how they will work together to support young people and their families throughout the transition process.

- Government should re-examine the funding available for adult and community learning, to ensure that all disabled young people can access appropriate courses.
- Disabled young people should have full access to individualised learning and vocational pathways into chosen employment and other meaningful occupation opportunities.
- Government should ensure that the potential for working of parents of young disabled people is not neglected, and that disabled young people have the opportunity to gain self-care and independent living skills to prepare them for adult life.

Membership of hearings panel

Anne Begg MP

John Bercow MP

Annette Brook MP

Paul Burstow MP

Martin Caton MP

Rt Hon Tom Clarke MP *Chair*

Michael Connarty MP

Janet Dean MP

Jim Dobbin MP

Clive Efford MP

Ian Gibson MP

Helen Goodman MP

Sylvia Heal MP

Jeremy Hunt MP

Joan Humble MP *Vice-Chair*

Sally Keeble MP

Tim Loughton MP

Anne Milton MP

Brooks Newmark MP

Dan Norris MP

Helen Southworth MP

Betty Williams MP

Anne Milton MP, Gordon Marsden MP and Clive Betts MP also made written submissions to the hearings.

List of participants – hearings

Ministers

Lord Adonis

Department for Education and Skills (DfES)

Ed Balls MP

HM Treasury

Beverley Hughes MP

DfES

Ivan Lewis MP

Department of Health

Anne McGuire MP

Department for Work and Pensions (DWP)

Jim Murphy MP

DWP

Dawn Primarolo MP

HM Treasury

Phil Woolas MP

Department for Communities and Local Government (separate meeting with review team)

Oral presentations

Prof. Sir Al Aynsley-Green

Children's Commissioner for England

Virginia Bovell

Parent and co-founder of TreeHouse

Ajay Choksi

Disabled young person

Gail Hanrahan

Parent

Sharon Kelly

Parent

Cllr Les Lawrence

Local Government Association/Birmingham City Council

Diane Packham

Local Government Association/Lord Mayor of Newcastle

List of written submissions – organisations

Afasic
 Association of British Dispensing Opticians, Association of
 Optometrists and Federation of Ophthalmic & Dispensing Opticians
 Association of Children’s Hospices (ACH) and the Association for
 Children with Life-Threatening and Terminal Conditions and their
 Families (ACT)
 Barnardo’s
 Care Co-ordination Network UK
 Challenging Behaviour Foundation
 The Children’s Trust
 The Children’s Society
 College of Occupational Therapists
 Council for Disabled Children (CDC)
 Contact a Family
 DARE Foundation
 Daycare Trust
 Disability Challengers
 Family Fund
 Foundation for People with Learning Disabilities
 I CAN
 Kids
 Mencap
 Myotonic Dystrophy Support Group
 National Autistic Society
 One Parent Families
 Prader Willi Syndrome Association
 Rescare
 Rett Syndrome Association
 RNID
 Royal College of Speech and Language Therapists
 Scope
 SENSE
 Speakeasy Advocacy
 Special Educational Consortium (SEC)
 Transition Information Network
 TreeHouse – the national charity for autism education
 Unique – Rare Chromosome Disorder Support Group
 Whizz-Kidz

Written submissions were also received from professionals in a wide range of statutory bodies, including children’s services departments, Primary Care Trusts, parent partnership services, inclusion outreach teams and pre-school specialist support services.

At the time the data was analysed, 145 submissions had been received from parents, 105 from professionals and eight from disabled children and young people.

Sample written submission forms are available on request from the Council for Disabled Children on 020 7843 1900 or from cdc@ncb.org.uk

ChildrenNow

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for families with disabled children

Council for
Disabled
Children

MENCAP
Understanding learning disability

**special
educational
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