

Parliamentary hearings on services for disabled children

Summary report

Introduction

This report results from an invitation from government Ministers to Rt Hon Tom Clarke MP and Joan Humble MP to lead fellow parliamentarians in holding hearings on services for disabled children. This report from the hearings will feed into the current HM Treasury/Department for Education and Skills review of services for disabled children.

During the hearings, a cross-party panel of MPs, chaired by Tom Clarke and supported by Joan Humble as vice-chair, took written and oral evidence from disabled children and young people, parents, professionals and eight government Ministers on the current state of services for disabled children and their families. The hearings were supported by a consortium of charities working with disabled children, and by Children Now magazine. This report and its recommendations represents the consensus view of all the MPs who were members of the hearings panel.

Giving evidence to our hearings, Prof. 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'. This comment by the Children's Commissioner reflected the written and oral submissions we received from parents, professionals and organisations working with disabled children and their families. We hope this report acts as a catalyst for improvements in services for all disabled children and their families.

Context

The changing population of disabled children

Our hearings heard evidence that the population of disabled children is changing, with increasing numbers of children diagnosed with autistic spectrum disorders and greater numbers of children with complex health needs. There are also more children requiring rehabilitation following acquired brain injury. Funding levels have not kept pace with the rising levels of need.

What services do disabled children and their families need?

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. 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.

The consequences of getting services right – or wrong

The hearings panel took evidence of a number of excellent services for disabled children that had dramatically improved the lives of children and families. 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.
Parent

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.

The current policy context

Disabled children and their families have been the subject of significant policy developments in recent years. The Children's National Service Framework has set standards for the services disabled children should receive. The Every Child Matters agenda has the potential to benefit disabled children, who use a large number of different services. The Strategy Unit report *Improving Life Chances of Disabled People* sets a cross-governmental programme of action covering early years and transition to adult services.

However, we took evidence of significant barriers that remain to delivery of these policies on the ground. Many submissions also spoke of the need to adequately fund policy initiatives, to prevent local agencies being set targets without additional resources to deliver improved services. Stakeholders also felt that government could do more to co-ordinate policy and ensure that agencies treat disabled children as a delivery priority.

Prof. 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?

Pervasive themes

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

Families with disabled children face additional costs and reduced income through barriers to work for parents. 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.

The major barrier to work for parents is access to affordable and appropriate childcare. Despite welcome new duties in the Childcare Act 2006, we received evidence that the national childcare strategy is failing to deliver more appropriate and affordable childcare for disabled children.

With families struggling to access work, many rely on benefits for financial support. Yet half of all written submissions described benefit levels for disabled children and their families as poor.

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. Parent

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. Some groups of families with disabled children experience even higher rates of social exclusion, including families from BME (Black and Minority Ethnic) communities and families with children who have profound and multiple learning disabilities.

Inequality

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

An overriding theme of the evidence received by our hearings was inequality in service delivery. Many submissions told us that only those parents who are able to fight sustained battles with agencies can access services. Even those families able to fight for services have highly unequal service outcomes dependent on their location. The lack of strategic planning by local agencies was blamed in submissions for inequalities in service delivery.

The lack of data

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. Parent

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.

The voice of children and parents

Involvement of disabled children, young people and parents should be actively sought, welcomed and implemented – no more ‘consultations’ that lead nowhere. Kids, disability charity

The final theme from the evidence concerned the need for disabled children and parents to influence the way that services are planned, commissioned and delivered. There was significant demand for additional advocacy for both disabled children and parents.

Early years

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, with many mentioning the Early Support programme (see below). However, challenges in 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. Just as critical for families is the delivery of appropriate information at the point of diagnosis.

Parenting support

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

Early intervention

Government has now recognised the crucial importance of early intervention in improving outcomes for a range of children – including disabled children. 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.’*

The hearings panel received written evidence highlighting the potential for a National Centre of Excellence in Early Intervention to identify and fill evidence gaps and promote good practice in early intervention for young disabled children.

Early Support

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.

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. 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. Professionals pointed out that services up the age range could benefit from the principles of coordination that worked so well in Early Support.

Family support and children's services

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.

Submissions to our hearings expressed a high level of dissatisfaction with the services that disabled children and their families 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. However, there was substantial evidence that children's centres, extended schools and other universal services are struggling to meet the needs of disabled children. A major issue hindering the accessibility of universal services is staff training. 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.

Education is a key universal service, however the Special Education Consortium told us that *'the consensus amongst our members is that while there are some excellent examples of practice in education services, too many disabled children are currently let down by the education system'*. While training is a key issue in all universal services, it is particularly critical in education. 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.

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

Summing up his contribution to our hearings, Prof. Sir 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.
Parent

In addition to services available to all children, disabled children require specialist services to allow them the best chance of reaching their potential. Yet significant weaknesses were identified in the provision of specialist 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 level of specialist support appears to be falling away rather than increasing. Autism education charity 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".'* A direct link was made in submissions between cuts in local authority support services and delegation of funding to schools.

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

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.

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.

Families experienced a similar level of difficulty in accessing specialist therapeutic services. Specialist health services for disabled children are frequently overstretched and struggle to meet the demands of children with increasingly complex health needs.

Short break provision

A key service priority for parents with disabled children is a regular, reliable and appropriate short break. However, the lack of short breaks was the biggest single cause of unhappiness with service provision in submissions to our hearings, mentioned unprompted by 3 in 10 submissions from parents. 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. 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.'*

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 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. Parent

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

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

Multi-agency commissioning and working

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

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 at the level of the family. However, the continuing failure to fully co-ordinate budgets and services has huge negative consequences on families. Concerns were raised that recent reforms to children's services may have a negative impact on multi-agency working with health.

For individual families, key working schemes received universal support from parents. Parents stressed the importance of key workers in co-ordinating services and appointments and avoiding endless repetition of information. However, although key workers are necessary to ensure coherent packages of services for families, a multi-agency approach to commissioning services is equally important.

Transition – the black hole

The transition to adulthood is an exciting time for all young people. However, it is also a time when disabled young people have few options, become more isolated and families experience a drop in levels of support. 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 during childhood simply disappeared at transition to adulthood.

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. However, transition planning is not currently giving families confidence

that they will continue to receive support as the young person moves into adulthood.

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. Yet disabled young people are twice as likely to be NEET (Not in Employment, Education or Training) as other young people.

Future service developments

A large number of submissions on transition particularly focussed on health services, with real concern that adult health services are not meeting the needs of disabled young people. Another consistent theme of our submissions on transition to adulthood was the gap between children's and adult social care services.

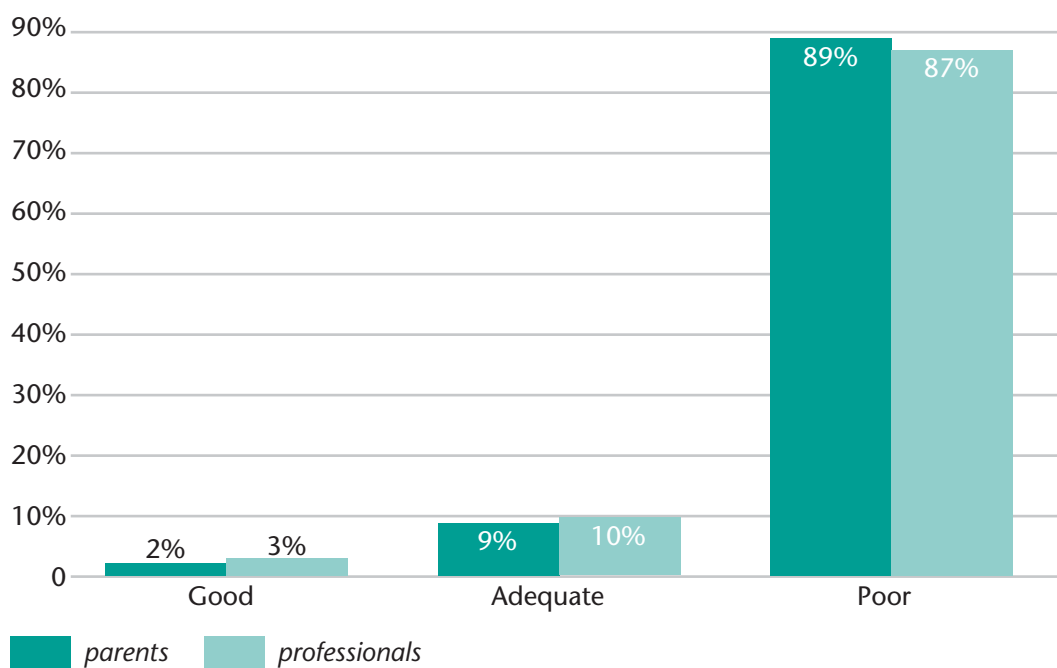
A key solution to the challenges around transition is effective co-ordination of multi-agency services. A number of models of service co-ordination were presented to the hearings panel, including a co-located multi-agency transition team, or a virtual team of staff working across agencies. There was a consensus that however services were configured, co-ordination was essential to the delivery of effective support during transition to adulthood for young disabled people.

Making change happen

Our hearings 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. Parents and disabled people told us that they wanted services for disabled children and their families to be available as a right. To ensure that families get these rights, urgent action is needed on the recommendations in this report.

Evidence was presented throughout the hearings that delivering improvements to services for disabled children requires additional resources. Almost 9 in 10 submissions from parents and professionals described current funding levels as poor. 61% of parent submissions highlighted additional resources as the most important factor in improving services. 74% of professional submissions stated that lack of funding was the largest single barrier to service improvement.

Funding for services for disabled children is ...



Source: Written submissions to parliamentary hearings

New funding invested needs to be sustainable to allow long-term strategic commissioning of services. Transitional funding mechanisms may be necessary to permit service innovation without impacting on existing levels of service. 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.

Local and national targets should prioritise disabled children and incentivise delivery agencies to improve access to universal and specialist services. Inspection regimes need to pick up those agencies that are not making disabled children a priority and create improvement cycles linked to performance ratings and resources. 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.

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 urge them ensure that disabled children remain a political priority, both locally and nationally, long after this report has been delivered to Government.

Recommendations

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 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.

Diagnosis and assessment

- 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.

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.
- 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.

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 5 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.

Endnote

The parliamentary hearings on services for disabled children were supported by a consortium of charities working with disabled children – Contact a Family, Council for Disabled Children, Mencap and the Special Education Consortium – and by *Children Now* magazine.

Copies of the full report are available to download from the following websites:

Contact a Family – www.cafamily.org.uk

Every Disabled Child Matters – www.edcm.org.uk

Mencap – www.mencap.org.uk

A limited number of hard copies of the full report are available from the Council for Disabled Children, telephone 020 7843 1900.