

Support and Aspiration: a new approach to special educational needs and disability

A response from the Council for Disabled Children



Support and Aspiration: a new approach to special educational needs and disability

A response from the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. We are the only national body that brings together the diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. Our work impacts on over 770,000 disabled children and their families.

CDC hosts the Every Disabled Child Matters campaign and four networks that bring together organisations and individuals with a focus on specific aspects of the disabled children's sector:

- Making Ourselves Heard;
- National Parent Partnership Network;
- Special Educational Consortium;
- Transition Information Network.

Through our networks and campaigning we reach over 4000 individuals working with or for disabled children, children with special educational needs (SEN)¹ and their families.

CDC is pleased to have this opportunity to respond to the Government's Green Paper, *Support and Aspiration: a new approach to special educational needs and disability*. This response has been drawn up following a range of consultation events and activities organised by CDC and its members. CDC is submitting this response along with responses from the Every Disabled Child Matters campaign, the National Parent Partnership Network, the Special Educational Consortium and the Transition Information Network. Each network has a different and specific focus and, in its response, explores in more detail the issues that are most relevant to that particular focus.

CDC welcomes the ambition to establish a single assessment and plan, the two ideas at the heart of the Green Paper. Much of our response examines the complexities of the work to be done to implement these proposals. CDC is committed to supporting the DfE and DH in taking these ideas forward and we aim, in this response, to make a significant contribution to the development of the ideas in the Green Paper. This is a unique opportunity to address some of the failings of the current system.

We see this as a significant opportunity to put disabled children and their families firmly in the centre of a multi-agency approach to assessment and to the delivery of services. CDC's longer term aim is to ensure that the development of legislation, policy and practice arising from this Green Paper have a lasting and positive impact on the lives of disabled children.

¹ Throughout our response we refer to disabled children or to children with SEN or to both. Occasionally, for brevity and to maintain meaning, and particularly where we want to refer to young people and families as well, we refer to children and young people with SEND.

1. Aspects of the Green Paper about which CDC has concerns

Although CDC supports the overall direction of the Green Paper, there are some specific aspects about which we have concerns. We address these first:

A bias towards inclusion?

The intention to 'remove the bias towards inclusion' presupposes that there is currently a bias towards inclusion. This does not reflect CDC's understanding of the experience of parents. Many parents encounter difficulties getting their child into a mainstream school. Where parents are successful in securing a place for their child, they may have difficulty securing a welcome there and the right support for their child.

Your child will need full-time 1:1 but we don't have enough money to be able to provide that, therefore your child would only be able to attend part-time.

Your child's statement doesn't give enough money to provide a qualified nurse ..but we can include them if you can come in every day to cover those requirements.

Our school is not as accessible as others in the area.

Our policy is that we do not provide lap-tops for dyslexic children unless they have a statement ... if your child has their own lap-top and it is covered by your home insurance we might consider allowing them to use it in school.

We do not tolerate behaviour like that ...if your child came to our school I can guarantee they would be permanently excluded after a short while.

We are not a special school.²

Children and young people themselves report that, where they are included into mainstream schools, they may be excluded from options and experiences available to other pupils. In a video produced by Whizz Kidz, young ambassadors tell of their experiences of missing out on subjects as diverse as science and French:

I wanted to take French lessons at school but because the class was upstairs and the teacher refused to bring it downstairs, I was told to drop the subject. The school should have met my needs; I had a right to take French lessons.³

Parents tell us that their child's place in a mainstream school is conditional in a way that it is not for children who do not have SEN. Parents may be summoned to take their child home at lunchtime on a regular basis, to administer medication, or their child may be sent home for the afternoon to *cool off and think about what he has done*⁴. It feels to parents as if their child does not have the same entitlement to education that other children have.

2 Quotes from recent school visits, reported by parent partnership services in Bury, Hillingdon, Sandwell, Southwark and Torbay.

3 Janaki Mahadevan (2011) *Disabled young people explain their rights*. Children and Young People Now, Thursday, 02 June 2011 and video: <http://www.youtube.com/watch?v=GuOkGONN7lo>

4 Quotes from recent school visits, reported by parent partnership services in Bury, Hillingdon, Sandwell, Southwark and Torbay.

A reluctance to include and a readiness to exclude disabled children does not just apply to schools. A CDC project exploring inclusion in extended schools and children's centres found:

Parents report how, in a variety of settings, including leisure services, they encounter a range of responses to their child... On investigating one provision, [one mother] was told, 'Your son is too disabled to come here.'

In some instances, where an individual member of staff is allocated to support an individual child or young person, there are further difficulties when that member of staff is absent. Some settings and some parents say that if the particular member of support staff is absent the setting is not able to accommodate that child on that day.⁵

Many parents who eventually choose a special school, do so because the struggle to secure the necessary support in mainstream became overwhelming.

The experience of parents tells us that there is no inherent bias towards inclusion. Nor do we recognise any bias towards inclusion in the legislation: the legislation requires the individual consideration of every child; it supports parents in securing a place for their child in a mainstream school, but falls away if they do not want a mainstream place.

The position set out in the Green Paper is problematic, not just because it is not borne out in the experiences of parents, but also because it appears to brand inclusion as undesirable and can even be read as endorsing practices that amount to discrimination. CDC sees no bias towards inclusion; it sees a bias against inclusion that often drives parents to seek a special school placement when their child should have been able to attend a mainstream school, learn and make good progress in the company of their peers. This is not choice for parents. The messages in the Green Paper sit alongside wider messages to schools about freedoms and independence. These messages have not been accompanied by messages reminding schools of the responsibilities that go with their new freedoms.

Equality Act duties

Inequalities, clearly articulated in the introduction to the Green Paper, and based in the discrimination that parents and young people encounter, see above, are not adequately addressed in the body of the paper. The duties in the Equality Act sit alongside the SEN framework and improving outcomes for disabled children and young people relies on both frameworks.

The Green Paper focuses almost exclusively on the SEN duties and there is little reference to the disability discrimination duties in the Equality Act. These duties form an important part of the responsibilities of all agencies to disabled children and young people. They are particularly important for disabled young people aged 16-25 after they have left school, as SEN duties do not currently apply to this group, with the Equality Act providing their key rights in terms of securing adjustments and support to access services. All the agencies have a duty to avoid discrimination and to make reasonable adjustments. The duty is anticipatory and the expectation of every school and every agency should be that they will make adjustments for disabled children.

CDC believes there should have been a stronger emphasis on the equality duties in the Green Paper. There is much work to be done:

- to counter the ethos that accepts and condones individual instances of discrimination; and

⁵ Stobbs P (2008) *Extending Inclusion: Access for disabled children and young people to extended schools and children's centres: a development manual* Council for Disabled Children

- to raise expectations and ambition in the objectives set under the Public Sector Equality Duty.

The Equality Act duties should be an important part of the work arising from the Green Paper. Pathfinder projects should have to show how their proposals will help them to meet their duties under the Public Sector Equality Duty.⁶

Where is the voice of children and young people?

Disabled children and young people are experts in the support they need, and are therefore well placed to determine the support and the services which will work best for them. Disabled children and young people contributing to the *Disabled Children's Manifesto for Change* gave advice to policy makers as follows:

Listen to what we say as we are the experts in our own needs and abilities.

We should be involved in all decisions about our education and support.

We are individuals and need different types of support and services to meet our individual needs.

We need to have meaningful choices.⁷

CDC believes there are insufficient references to the importance of the voice of children and young people, and there is no focus on their wishes and aspirations in the proposed assessment and planning processes. We are concerned that this undermines the Government's aspiration to create a more personalised approach to service provision.

There has been significant learning about the participation of disabled children and young people through Aiming High for Disabled Children. The Transition Support Programme has promoted positive developments in the participation of disabled children and young people: participation not only in decision-making about their own future but also in the design of services to better meet their needs:

One of the Transition Support Programme Named Advisors who was interviewed talked about this aspect of service development as a 'significant legacy from Aiming High'.

Transition Support Programme Self Assessment Questionnaire returns indicate that young people and their families are also increasingly participating in the shaping of services as committee members around the tables where strategic decisions about Transition services are taken. Sometimes they participate as members of local 'Shadow Transition Strategy Groups' and feed back ideas to strategic managers following group discussion.⁸

Making Ourselves Heard⁹ also has evidence of a growing number of ways in which disabled children and young people contribute to the development of resources and to service planning and development.

⁶ s149 Equality Act 2010

⁷ *Disabled Children's Manifesto for Change*

⁸ National Transition Support Team (2011) *Information and learning from the Transition Support Programme*

⁹ http://www.ncb.org.uk/cdc/networks/making_ourselves_heard.aspx

CDC believes that the views of children and young people with SEND should be taken into account in relation to their own single assessment process, Education, Health and Care Plan and should have a strategic role in determining what is available through the Local Offer. The proposed pathfinders should be able to demonstrate how disabled children and young people will be able to take ownership of their own Education, Health and Care Plan and, where relevant, their personal budget. This raises issues about the balance between the views of the child and those of their parent or carer. These are complex issues but have to be addressed to ensure that the child or young person is at the heart of the planning process and that the views of the parent are taken into account and valued.

CDC welcomes the proposals to pilot claims and appeals being made to the Tribunal by children and young people themselves. This is an important proposal that has already been consulted upon. There may be helpful learning from the Scottish experience of children and young people making claims under the disability discrimination legislation. CDC is pleased that there is now the potential for these proposals to become a practical reality. However, CDC is concerned that unless the insights of children and young people are central to assessment and planning and making support and services more personalised, proposals to pilot children and young people making claims and lodging appeals in their own right may founder. If children and young people are not significantly included in the assessment and planning process from the start, it will be difficult for them to come in at the end with an appeal or a claim.

Multi-agency?

The Green Paper talks about a multi-agency assessment and plan, but there is little evidence that the proposals adequately take account of the full range of assessments by all the agencies that support disabled children. It is of particular concern that there is no reference to:

- the common assessment framework (CAF);
- the way in which services are provided to 'children in need' because they are disabled under social care legislation; or
- the full range of adult services for 18 – 25 year olds.

It is also unclear what support there is from other government agencies for the proposals in the Green Paper. There is a potentially weak 'commitment' from other agencies at the level of an individual plan but no evidence of a multi-agency strategy to meet the requirements of the individual planning process. CDC argues, below, that the proposals in the Green Paper will not work without the full support of all agencies, both local and national.

Inconsistencies and discontinuities between the Green Paper and other policies

The Green Paper is being discussed at a time when other policy developments could potentially undermine its core intentions:

Independence puts at risk local co-ordination

The promotion of independence and freedom for schools, for both academies and for local authority maintained schools, has omitted reminders of their responsibilities towards vulnerable groups of children including disabled children and children with SEN. It has also failed to highlight the importance of local co-operation and co-ordination which is crucial to meeting

the range of children's needs. Crucially, schools and other education providers will be essential partners in developing the proposals in *Support and Aspiration* and need to be part of local arrangements to secure co-ordination and co-operation.

Proposed health reform

CDC welcomes the Government's commitment to putting patients at the heart of NHS care. However, the Health and Social Care Bill currently going through parliament makes very little reference to children's services and none to children with SEN and disabilities. Yet we know, from *Aiming High for Disabled Children* and from the difficulties in securing health support for children with a statement of SEN, that the involvement of health services is often problematic, not least because inaction can pass responsibility to the local authority.

Sarah Teather summed up parents' experiences well in an interview with The Guardian:

The children and families minister has attacked the health service for failing some of the country's most vulnerable young people.

Sarah Teather said the chance of a child receiving much-needed speech and language therapy was "between low and nil", while the wait for a wheelchair could be "really long".

Teather, who spent most of her own secondary school days in a wheelchair after suffering from a viral infection, said the health service "has not always been good at doing its fair share for children in this position". Families were often left as the "piggy in the middle".¹⁰

Evidence gathered by Every Disabled Child Matters for the *Disabled Children and Health* report also demonstrates that problems with health services can be a barrier to the delivery of services such as short breaks:

Part of my son's condition includes severe epilepsy which causes broken sleep. He can wake up five or six times every night and need moving and suctioning. I slept on the floor next to his bed whilst I was begging the PCT for a night nurse. Constant sleep deprivation with no break meant I couldn't function as a mother let alone a carer for my son. After four years I finally got the PCT to agree to provide a night nurse. Belinda¹¹

Crucially, to secure the proposals within *Support and Aspiration*, disabled children and children with SEN will need to be a priority for Health & Wellbeing Boards and there will need to be an equal responsibility between health and other agencies for outcomes for disabled children and children with SEN.

Welfare reform threatens financial support for families

CDC welcomes the Government's aspiration to reduce complexity in the benefits system. However, we are concerned about the impact on family resilience of:

- reductions in targeted benefits for families with disabled children and who are on low incomes or out of work within the Universal Credit; and

¹⁰ Sarah Teather interview with The Guardian, 23rd May 2011

¹¹ Every Disabled Child Matters (2009) *Disabled Children and Health*

- the significant reduction in the financial support for childcare provided to families with disabled children. These reductions are already in place.

This will have a significant impact on the deliverability of Green Paper reforms, as the acute problem of poverty and worklessness will supercede families' ability to engage in the process of assessment and planning, and the management of personal budgets.

Cuts in the local authority Early Intervention Grant

Last year the Government brought together a number of different grants, including those for Sure Start Children's Centres and short breaks for disabled children, into the Early Intervention Grant. A significant cut of £311m was then made, within 2010-11, to the overall funding in the Early Intervention Grant. A further cut has been made in 2011-12.

Yet, we know that by acting early we can make savings, in both human and financial terms; and we know about the consequences of failing to do so:

The IIPs [Intensive Intervention Projects] represent good value for money. The average cost of a successfully closed case was about £35,000. The IIP intervention generated average savings from prevented expenditure over five years with an average present value of about £280,000 per person for a sample of young people with positive outcomes from the case study sites. With a return of £8 of savings per £1 spent, these figures indicate significant quantifiable cost-benefits from the intervention (as well as the many qualitative benefits for the young people and their families).¹²

The Green Paper itself rehearses some of the financial consequences of exclusions and persistent absence from school. Drawing on the evidence from a report published by New Philanthropy Capital¹³, it quotes the lifetime costs of one exclusion as being £64,000. Speaking at the time of the publication of the report, one of the authors said:

Doing this project made me realise how much school affects all aspects of a child's life. If a child truant or becomes excluded not only will they get worse grades at school and earn less, but they are also up to twice as likely to commit crime and will probably have poorer health as adults.¹⁴

At the time of the publication of the report, the cost to the UK economy of failure to tackle truancy was estimated as £800m a year. The calculation of the benefit of one project was in terms of £11.60 savings for every £1 spent.

Early Intervention has to be re-instated as a top priority to ensure the best longer term outcomes for disabled children and children with SEN.

Wider cuts to local authority budgets

Research by the EDCM campaign reveals that local authority budget restrictions have already resulted in cuts to 'lifeline' services for disabled children and children with SEN:

It was found that a range of services have had their income reduced or cut completely, including short breaks, play and leisure, education, transport, health, training and equipment.

¹² DfE (2011) *Evaluation of Intensive Intervention Projects*

¹³ Brookes M, Goodall E and Heady L (2007) *Misspent youth: The costs of truancy and exclusion*. New Philanthropy Capital

¹⁴ Lucy Heady, speaking at the time of the launch of the report: web ref: http://www.philanthropycapital.org/publications/education/truancy_and_exclusion/truancy_and_exclusion_cost.aspx

There were particular concerns over continued funding for frontline disabled children's services, key professionals losing their jobs, and the withdrawal of social care and health services that are leaving families without vital support.

This has had a huge impact on families - many parents and siblings will be affected financially, emotionally, practically and socially. The additional impact on the disabled young people themselves is also considerable. Many will lose their only opportunity to interact with other young people their own age. Many parents and professionals were worried about how this would affect the children at a later age.¹⁵

CDC is hearing about cuts to Child and Adolescent Mental Health Services, Autism Outreach Services and a range of specialist SEN support services. Information obtained by the National Deaf Children's Society under the Freedom of Information legislation shows that:

Almost one in five councils in England have cut services for deaf children, some by scrapping posts for specialist teachers and cutting budgets for radio aids...There have been cuts in 28 local authorities.¹⁶

The National Deaf Children's Society estimate that 75% of deaf children are supported in mainstream schools without a statement. With cuts to services it is more likely that these children will in future need a statement to secure the support they need. We estimate that there will be a significant increase in statements, with an associated rise in the costs of administering the system, before new education, health and care plans are introduced.

Raising the Participation Age

Pupils who are at the end of Year 9 now and at the start of the Transition Planning process, will be required to continue in education or training in 2013. For disabled pupils planning to go on to higher education, there will be little impact. To provide choice for pupils who do not meet some of the current requirements for entry to school sixth forms, there will need to be significant development of school-based and further education provision in order to provide appropriate opportunities for continuing education and training. The issue is recognised in the Isos Partnership evaluation of Phase 1 of the trials for Raising the Participation Age, a research report for the DfE, which argues to:

Better align post 16 funding to promote provision for Learners with Learning Difficulties or Disabilities (LLDD)¹⁷

It will be difficult to meet these challenges at a time of financial stringency. CDC is concerned that these challenges are not mentioned as part of the context for the proposals in the Green Paper to raise to 25 the age at which a single assessment and plan would apply.

¹⁵ Every Disabled Child Matters campaign

¹⁶ Jeevan Vasagar reporting the FoI requests by the NDCS in the Guardian, Tuesday 10th May 2011

¹⁷ Isos Partnership (2010) *Raising the Participation Age (RPA) Trials: Phase 1 Evaluation Final Report* DfE Research Report: DFE-RR020

2. A multi-agency strategy

CDC welcomes the proposals for a single assessment and plan. This is a unique opportunity to improve the way in which the current system works.

However, evidence over a significant period of time has indicated consistently that individual or small scale developments in multi-agency working founder without the support of a joined up strategy and joint ownership^{18, 19, 20}. The Green Paper proposes a plan for individual children and families, for which there is contribution in terms of funding or services from a range of different agencies. All of CDC's work over recent years tells us that these proposals, welcome as they are, will only succeed with a comprehensive local multi-agency strategy supporting their implementation.

A local strategy needs to bring together all the local agencies: health, children's and adults' social care, schools and education, employment and youth services, together with parents, young people themselves and the voluntary and community sector. It will need to assess children's needs, across the community served, and commission services; it will need to be backed by appropriate mechanisms for sharing information, pooling budgets, meeting statutory responsibilities and providing accountability to parents and to children and young people themselves.

Joint investment in such a strategy is fundamental to early intervention; without this it is too easy for one agency's delay or inaction to turn into a cost for another agency.

We repeatedly see local agencies 'passing the buck' when it comes to agreeing care for my son. Social services tell us they can't provide night care for him because it is medical care, while health tells us they can't provide it because it is a family support service. Where are the needs of my son in all of this? We haven't seen any evidence of joined-up working, and we are made to feel like we have to beg to get anything done. Belinda²¹

My son has an acquired brain injury and has a tracheostomy fitted to enable him to breathe. He has been staying at The Children's Trust, Tadworth whilst he receives rehabilitation, and we want him to come home to live with us and his twin sister. We are fighting the local authority to agree the funding and plans for our home to be adapted and until this is agreed he can't come home. In the meantime the PCT has spent many more times that amount on keeping my son in residential care. The local authority and PCT need to work together to plan for my son's future! Suzanne²²

Much work has been done to bring agencies together. It is vital that we do not lose the experiences and learning from this work and that pathfinder activity is informed by both what has worked and what hasn't worked to date.

18 Stobbs P (1997) *Making it work together: advice on joint initiatives between education and social services departments* National Children's Bureau, Society of Education Officers and the Association of Directors of Children's Services

19 Wheatley H (2006) *Pathways to Success* Council for Disabled Children

20 National Transition Support Team (2011) *Case Study: West Berkshire Council for Disabled Children and National Children's Bureau*

21 Every Disabled Child Matters (2009) *Disabled Children and Health*

22 Ibid

Development of joint assessment for young people in transition in West Berkshire.

Working with the Transition Support Programme, West Berkshire set out to develop a joint assessment process and a single plan.

Once the project work started, it became evident that the work would be complex and multi-layered. Assessment processes which, in isolation, may have worked well, had to be challenged and re-examined in a multi-agency context. There were new roles to be created (Lead Professional), and a new group (a Transition Team, with education, children's, and adult social care, FE and health) sharing information, learning to trust other professionals and changing working practices. As the working group came to appreciate the complexities of the project, there was a difficulty in progressing the work.

The barriers they encountered included:

- 'Silo' attitudes in individual services
- Lack of willingness to discuss budget implications of decisions on out of authority placements
- Current cut off points between children's and adults services
- Professional protectiveness
- The difficulties they encountered were exacerbated by cuts in adult services

Main transferable learning points

- Having a "shared" database is essential for positive joint working in transition;
- The use of "lead professional" could be considered so that young people and their families know who they can ask for advice and support. This is particularly important if young people are not going to meet the criteria for adult services;
- The development of a joint assessment process is tricky with a complexity of agencies involved. It is worth considering one plan with a range of assessments relevant to the needs of the young person;
- Person-centred planning needs to be at the heart of any assessment process for a holistic and positive transition;
- When developing any new system ensure you have sign up from Director level

Schools, with their front line responsibilities, are a vital part of a multi-agency approach. Their delegated budget for additional educational needs should be seen as part of any strategy for underpinning early intervention.

In order to establish a shared understanding of aspirations for children with special educational needs and disabilities, there should be a set of nationally agreed outcomes to underpin local strategies. These outcomes should be driven by an expectation that children should be able to lead ordinary lives with their families and as active members of their community and should include an expectation that young people should be involved in decisions about their support.

There is broad support for the principles of closer integration of services in the report from the NHS Future Forum:

Commissioners should also seek more opportunities to pool budgets to simplify buying of services across health and social care; as proposed in the Forum's report on Patient Involvement and Public Accountability. For example, there is a real opportunity to improve care by bringing together all the funding to support someone in their last year of life, for disabled children or those with child protection needs. This principle of ensuring care is joined up across health and social care and education reflects the vision of the Government's Green Paper on children with special educational needs and disability currently out for consultation.²³

...and a recognition that the Green Paper provides a unique opportunity to join up services in new ways:

We have been told there is now a historic opportunity to drive much greater integration of care around patients, particularly those with long-term conditions and complex care needs.

When people discussed integration they referred to several different things. We believe integration should cover:

- integration across primary and secondary care – GPs, community services and hospitals working together;*
- integration across health, public health, education, and social care;*
- integration across public, independent and third sectors; and*
- integrated commissioning.²⁴*

We do not underestimate the massive cultural change involved in bringing agencies together in this way, or the significant leadership that will be needed from national agencies, including government departments. We are equally clear that the proposals in the Green Paper will not work without this multi-agency approach.

²³ NHS Future Forum (2011) *Choice and Competition: Delivering Real Choice* A report from the NHS Future Forum

²⁴ *ibid*

3. Single assessment

CDC welcomes the proposals for a single assessment process for children from the age of 0-25. The process will need to encompass a wide range of existing assessment processes, from the Common Assessment Framework through to statutory assessment and from early years, through the school years and into further and higher education and supported employment.

It is essential that the development of the single assessment draws on learning from recent good practice programmes such as Early Support, the Transition Support Programme and Achievement for All.

During the consultation period CDC has discussed what the process might look like. The following are some of the recommendations that CDC considers should be taken into account in turning the proposals into reality:

Triggers for an assessment

If the single assessment process is to include children who are currently assessed through a number of different routes, any agency should be able to trigger the process: health, social care or education, as well as a parent or the child or young person themselves. There will need to be a relatively low threshold in order to include a range of children who currently have a plan and in order to ensure an early response and easy access to support.

Person- centred assessment

Assessment should be person-centred and identify clearly the aspirations of children and young people and their families. This represents a significant cultural shift from current models which are more focused on service needs than on the child's right to have a say. Such a shift would require training for professionals and information and support and potentially advocacy to ensure that the young person's voice is taken into account.

Developments in assessment should build on the success of Early Support and the building of a Team Around the Child, the positive developments in Transition Planning, Achievement for All and approaches such as Making Action Plans (MAPS)²⁵.

Early Support was evaluated by the University of Manchester and was found to be extremely popular with both parents and practitioners, as well as *cost effective compared to no Early Support*.²⁶ The evaluation also stated that Early Support achieved an *improvement in multi-agency working and significantly improved practice in the domains of: agencies co-operating to plan, manage and develop services effectively; the co-ordination of ongoing support for families; making straightforward and smooth the processes of referral, identification and initial assessment*.²⁷

Early Support has introduced the *Team Around the Child/Team Around the Family* approach to early years services. However, it has been recognised that families with disabled children require ongoing support, *a passport through the system*, as their child grows up. Every time a family reaches a key stage in their child's life, including diagnosis/early years (age 0-5), starting school

25 *Making Action Plans*, developed by Marsha Forest and Jack Pearpoint, see DfES (2006) *Implementing the DDA in schools an early years settings*

26 *Early Support: An Evaluation of Phase Three of Early Support* (2006) University of Manchester in collaboration with University of Central Lancashire

27 *Early Support: An Evaluation of Phase Three of Early Support* (2006) University of Manchester in collaboration with University of Central Lancashire

(age 4/5), changing schools (age 11) and planning transition to adult services (14-19), they are once again thrown into confusion and are required to undergo a further round of multiple assessments.

In a 2010 research paper for the DfE on the contribution of Early Support to improving services for disabled children, Liz Andrews concluded that:

Positive experiences of Team Around the Child approaches were widely reported. There was a marked consensus that it was desirable for frontline service delivery on this model to be extended up the age range for older children and younger people.²⁸

CDC supports this proposal.

Co-ordination of the process

A single assessment process will not prevent the need for multiple assessments; children with complex needs will still need to see a variety of different specialists. Improved co-ordination of assessments within any one agency requires better management of appointments systems and an increased customer focus.

The co-ordination of the assessment process across agencies is more complex. There needs to be an identified individual or agency with responsibility for co-ordination and who provides a single point of contact for parents. The key worker, as part of the Team Around the Child, provides a good model for this role; it has been tried and tested and is valued by parents.²⁹

The Parliamentary Hearings on Services and Support for Disabled Children highlighted the importance of key workers:

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.' Parent³⁰

Care Co-ordination UK has published a range of case studies exemplifying the importance of key workers:

We did indeed have a key worker. It worked brilliantly – made life a lot easier and there was only one phone number to remember! Small problems were never allowed to fester and become big ones! Parent³¹

28 Andrews E (2010) *The contribution of Early Support to Aiming High for Disabled Children and the transformation of services for Children with SEN and disabilities*. Report for DfE

29 *Early Support: An Evaluation of Phase Three of Early Support* (2006) University of Manchester in collaboration with University of Central Lancashire

30 Parliamentary Hearings on Services for Disabled Children

31 <http://www.ccuk.org.uk/>

...and parents speak for themselves on the Early support website:

As a working mum raising a child with special needs, my time is precious. I have to fit in four working days, endless appointments, daily physiotherapy as well as find time to enjoy my child and family. Before our key worker came into our lives I was struggling to achieve this.³²

The recent evaluation of the Intensive Intervention Projects also highlights the importance of key workers as part of a holistic approach to family support:

The strengths of the IIP (Intensive Intervention Project) model included: the perceived independence of IIPs; the use of key workers; a holistic whole family approach; relatively small case loads and flexible working hours; ability to effectively engage and assess young people and families and support them over a significant period of time; the use of personalised budgets; the diversity of IIP workers' roles; and co-ordination of multi-agency support.

*Partnership working was essential to the effectiveness of IIPs. This required access to specialist services and flexibility in statutory provision, combined with support for families to engage effectively with a range of agencies.*³³

Good use of key working is a powerful way to get everyone to think outside their particular service provider box and consider how they might contribute more effectively to a co-ordinated experience of service provision for children, young people and families.

Information, advice and support

Local authorities are currently required to provide parents with information, advice and support on special educational needs. They do this through parent partnership services. To provide equivalent support in the new environment, the role would need to be extended to include information, advice and support across agencies.

32 What families think about key workers: <http://www.education.gov.uk/childrenandyoungpeople/sen/earllysupport/a0067107/what-families-say-about-early-support>

33 DfE (2011) *Evaluation of Intensive Intervention Projects*

4. The Education, Health and Care plan

Currently there is a wide range of children who have a plan; they have a plan for a wide variety of reasons. Children with plans include: children who have a CAF; children with health needs in school who have a care plan; children who are identified as 'in need' under the Children Act 1989 because they are disabled; children who are looked after and have a care plan; children who are at School Action or School Action Plus who have an IEP and those who have a statement; and young people who have had a learning disability assessment. CDC anticipates that the same children would continue to have a plan under the new arrangements, but an Education, Health and Care Plan for a disabled child or child with SEN would need to encompass any or all of these plans where they were relevant.

CDC is advocating a low threshold for an assessment as this is more likely to lead to early intervention. Any child or young person with an additional need who would benefit from a plan should have one. It is proposed that the process covers children and young people from 0-25, so it also needs to take account of a young person who may, even in their early 20s, become eligible for a plan.

Person- centred plan

The plan should be person-centred and outcomes focused. It should build on the aspirations of children and young people and their families identified during the assessment process. The ownership of a plan would need to shift from the family to the young person as they approached adulthood and as they chose to, with appropriate support for the young person and their family.

There is significant learning to draw on from the Transition Support Programme. The consistent messages from this work are about the importance of young people feeling ownership of their action plan and of young people and families feeling they are at the centre of reviews. There is important wider learning that, importantly should inform the development of work by pathfinder projects:

- Person-centred planning brings a shift in culture and significant changes to working practices;
- A local workforce development strategy is required to support the systematic introduction and use of person-centred approaches across schools, children's services and adult services;
- Quality assurance measures should concentrate on evidence how person-centred approaches improve things for young people and their families;
- The introduction of person-centred approaches in mainstream secondary schools should be carefully monitored and linked to broader consideration of Team Around the Child and Family approaches and 'structured conversations' with families.³⁴

Co-ordination with the wide range of agencies involved post-16

With a single plan from 0-25, the process needs to build in the wide range of services that become relevant to the lives of young people at 16 and at 18. This will be a challenging process as it needs to involve children and adult services across education, health, social care and

³⁴ National Transition Support Team (2011) *Information and learning from the Transition Support Programme*

housing support as well as specific targeted services such as careers and employment services. CDC is concerned that the Green Paper does not reflect the complexity of the processes involved.

During the transition process, various plans will be made in relation to different aspects of the young person's life – further/higher education, vocation and training, leisure and independence, where they wish to live and ongoing healthcare. Health professionals working with a young person with complex health needs or a disability can prepare them for adulthood by developing a health transition plan, which takes an approach that is much broader than the medical diagnosis and helps the young person to address other lifestyle issues that may be concerning them. This needs to form an integral part of the broader Transition Plan, linking closely with education and social care.³⁵

The Transition Support Programme provided the opportunity to some local areas to focus on the development of an integrated assessment framework. The efficient sharing of information across agencies and teams proved critical to sustaining the principle of a single plan (into which different assessments feed), to forward planning, quality assurance and the efficient commissioning of services. It is important that the pathfinders build on the learning from the Programme.

Statutory or non-statutory

Many of the plans referred to above are not statutory. There is then a question about whether all Education, Health and Care Plans would be statutory, or whether there would be both a statutory and a non-statutory plans. CDC is proposing that one of the triggers for a statutory plan could be the failure to make the provision in a non-statutory plan. If statutory plans were a joint responsibility there would be strong incentives for all agencies to intervene early.

There should be a single point of appeal against the decisions set out in a plan. Parents and children and young people themselves should be able to lodge an appeal. CDC welcomes the proposals to pilot appeals by children and young people.

Ensuring the plan happens

The delivery of the provision in the plan needs to be co-ordinated, with joint responsibility across all agencies and over time. There must a clearer and more binding commitment on all agencies than currently exists. Accountability must be focused on outcomes, with a rigorous review process and a single point of redress for parents and young people themselves.

³⁵ Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or disability

5. The Local Offer

The Local Offer builds on requirements in Education Regulations (SI 2001 no: 2218) and the Core Offer developed through Aiming High for Disabled Children. Combining the two brings together the specific information requirements and a set of principles that governs working relationships with parents

Crucially, the development of the Local Offer can draw on models developed through the AHDC short breaks pathfinder programme. These were designed to make a minimum level of provision without formal assessment. Examples of this include the Wiltshire Council 'Local Offer for Disabled Children and Young People'³⁶, and Enfield Joint Service for Disabled Children's 'Local Offer.'³⁷

There is a crucial link between the development of a Local Offer and the way in which a local area gathers information on local needs and commissions services. The development of the short breaks service statements based on local need due in October 2011 under the local authority duty to provide breaks from caring³⁸ could be used as an early exemplification of this approach.

CDC believes that this approach has significant potential to improve clarity about what provision is available and to whom; this will have further benefits in terms of positive partnership with parents. A local offer, clearly articulated, should also be amenable to review as the evidence of the impact of different approaches develops, as children's needs and parents' wishes change.

Developing the local offer

The local offer must be jointly developed and owned by all local agencies and service providers. This needs to include: education, including schools, further and higher education, social care and health agencies, parents and disabled young people and young people with SEN themselves, the voluntary and community sector, leisure, transport and employment support services.

Information

Clear and accessible information must be provided about the local offer. It must be up to date, accurate, user focused and readily available in a range of alternative and accessible formats, ensuring families and young people know where and how to get support.

Transparency and feedback

The local offer should provide transparent information about the way that local agencies make decisions about services provision, particularly in terms of eligibility for services, and on the way in which parents, children and young people can provide feedback and seek redress

Duty to deliver the local offer

There needs to be a clear duty to deliver the local offer. This needs to bite on all agencies through clear accountability in terms of statutory and financial responsibility to deliver.

36 <http://wiltshireparentcarercouncil.co.uk/Documents/FINAL%20VERSION%20of%20Local%20Offer%20Leaflet%202011-2012.pdf>

37 http://www.enfield.gov.uk/info/200012/children_with_disabilities_and_special_educational_needs/1049/short_breaks_and_support_services_for_families_with_disabled_children/6

38 s25 Children and Young Persons Act 2008

4. Personalisation

Welcome

CDC welcomes the clear intention to make services more personally tailored to the needs of each child and young person.

Personalisation means tailoring support to an individual's needs and giving individuals a greater level of choice about and control over the services they use. This term encapsulates the idea that the person using the service is an active participant who controls the way in which their services are delivered. Personalisation is also used to mean a whole system change in the way in which resources are allocated. It is a wide-reaching term employed within health, social care, education and other public services.³⁹

Personal budgets

Personal budgets should only be offered as part of a much wider personalised approach to service delivery.

There are numerous ways through which personalisation is developing within the children's sector. One of the most widely known ways is through funding mechanisms. These include direct payments, budget holding lead professionals, individual budgets and 'menu of choice' services where individuals choose from a menu of services provided by accredited providers. Also underlying the philosophy of personalisation is the move towards person-centred approaches where disabled children and their families are put at the centre of processes for developing support rather than being passive recipients of services. Finally, brokerage support systems are enabling the personalisation agenda to be taken forward. There is a growth in advice and support for families who are taking on the role of employer in commissioning support for their children.⁴⁰

Practicalities to be addressed

There are significant issues to be addressed for personal budgets to work and to work well: there needs to be a range of services to choose from, or there is no choice at all; there needs to be information and support available to parents and young people who wish to use personal budgets; allocations must be reviewed and changed to meet the changing needs of children, young people and their families; young people should be supported to take control of their own personal budget at an appropriate stage should they wish to. The availability and cost of effective brokerage arrangements for personal budgets also needs to be taken into account.

Richmond upon Thames

A group of young college leavers with learning disabilities in Richmond upon Thames have piloted an innovative way of getting more from their direct payment care package. Pooling budgets to pay for PAs, activities and transport can mean disabled people get more from their benefits.

³⁹ Council for Disabled Children (2010) *Personalisation: An Introduction*

⁴⁰ Council for Disabled Children (2010) *Personalisation: An Introduction*

Responsibilities in education services

Under both the Equality Act and the SEN framework, the responsibility for providing an appropriate, accessible education lies firmly with providers, mostly schools. A personal budget held by a parent or young person could undermine this responsibility. Other ways of improving transparency and increasing personalisation need to be found.

Recent developments through Early Support, Assessment for Learning, Making Good Progress, the Transition Support Programme and Achievement for All provide a wide variety of approaches to personalisation, including person-centred planning. All have led to improved outcomes for children and young people.

Beacon Hill School has developed a whole school approach to personalisation:

... that includes person centred planning, work experience, personalised curriculums and support into mainstream college settings.⁴¹

It demonstrates how a person centred approach is adopted from the year 9 review and leads to personalised work experience, personalised curriculum and clear and supported transition to college, a process that can take up to 2 years for some students. It focuses on work with young people with severe learning disabilities and profound and multiple learning disabilities and explores how traditional person centred tools have been adapted to meet the needs of these young people. It highlights the importance of sharing information across agencies, of securing a high level commitment to joint assessment and of the need for change in order to secure improved outcomes for disabled young people.

Assessment for Learning has improved personalisation and children's progress. The Ofsted report on Assessment for Learning provides examples of good practice:

The school had developed a very effective system to track pupils' progress from term to term. For each class it showed graphically the rate of progress each pupil made and which were above, at, or below national expectations for their age. For those who were not making sufficient progress, a very detailed plan was drawn up which specified the support the pupils would receive, based on analysing their individual needs. As a result of good provision, these pupils made very good progress. The tracking system was also used to set challenging but relevant targets for each class. Teachers used these effectively to plan work at the right level for the range of pupils. The local authority was disseminating the system to other schools as an example of good practice.⁴²

Building on the learning from *Making Good Progress*⁴³, *Achievement for All* places children and their parents at the heart of a process that has a clear focus on improving outcomes for disabled pupils and pupils with SEN. A key element in this is a *structured conversation with parents*.

A key element in...Achievement for All has been 'designated time to get to know what parents feel and take onboard their hopes and aspirations for their children'. It is felt that the structured conversations have offered school staff something new and unique that has enabled them to get to know about their pupils' needs, aspirations and lives beyond school in much more depth than they had previously, contributing to a much more holistic view...the process of having three conversations per year was seen by some schools as a chance to

41 Beacon Hill School case study: http://www.transitionsupportprogramme.org.uk/pdf/CSThurrock_Personalisation.pdf

42 Ofsted (2008) *Assessment for Learning: the impact of National Strategy support*

43 PriceWaterhouseCoopers (2010) *Evaluation of the Making Good Progress Pilot* DCSF Research Report DCSF-RR184

*formulate a joint working agreement with parents in which they can map progress throughout the year.*⁴⁴

Core duties in the provision of a universal education service sit with providers:

- to provide an *education appropriate to pupils' ages, abilities and aptitudes*⁴⁵;
- to make reasonable adjustments for disabled pupils⁴⁶;
- to plan to increase access for disabled pupils⁴⁷;
- to make special education provision for children with special educational needs⁴⁸.

We support proposals to increase personalisation and improve transparency in education, in particular where these are shown to have improved outcomes for children and young people. Personal budgets in education risk undermining the SEN and equalities responsibilities and the broader principle of a free and appropriate education for all children.

44 Humphrey N and Squires G (2010) *Achievement for All: National evaluation* DfE Research Report DFE-RR123

45 s14 Education Act 1996

46 s20 Equality Act 2010

47 s88 and Schedule 10 Equality Act 2010

48 Part 4 Education Act 1996

7. Pathfinders, time and timing

There are significant cultural and organisational issues to be addressed through the development of the new ideas in the Green Paper. We have argued in our response that the necessary changes will not be achieved without a robust multi-agency approach. Changes as significant as these cannot be achieved quickly and will need significant resourcing. The Parliamentary Hearings on Services for Disabled Children highlighted the importance of a multi-agency strategy which is adequately resourced:

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

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 team⁴⁹

CDC would encourage the government to plan a long-term programme of change that proceeds with support from all the parties involved. This may make development slower to get under way but the resulting changes will be more likely to be real and enduring.

The ideas in the Green Paper require significant development. This is likely to require at least two main phases of development: an initial and innovative phase with a number of areas testing out creative ideas, and a second phase which would need to be more prescriptive. The prescription of the second phase would need to be based on evidence from the evaluation of what worked and what didn't work in the first phase. Following the evaluation of the second phase the Government will be well-placed to consult on changes to the legislation.

It is vital that the proposed developments secure the support of all parties. They will not work without it. Pathfinders should be required to submit joint proposals supported by all agencies, parents and the voluntary sector before submitting proposals for the innovative phase of development. This approach will set the tone for and the expectation of a more collaborative approach in the future.

Council for Disabled Children

June 2011

⁴⁹ Parliamentary Hearings on Services for Disabled Children