

Learning from the Aiming High for Disabled Children Programme

Council for Disabled Children

October 2011



Acknowledgements

This report was researched and produced by the Council for Disabled Children. We are grateful to Elizabeth Andrews for conducting the interviews and compiling the report and would like to thank all the advisors, parents, service managers and professional practitioners who participated.

The report reflects contributions from the full range of partners supporting the Aiming High for Disabled Children programme. We would like to acknowledge the advice and support of Together for Disabled Children, Achievement for All and the National Network of Parent Carer Forums and thank:

City of York
Kent
London Borough of Enfield
Plymouth City Council
Sheffield
Stockport

A note on language

For ease of reading, we use the term SEND throughout this report to refer to children and young people with special educational needs (SEN) and/or disabilities and/or complex health needs.

We use the term 'local areas' to mean education, local authority and health agencies with a statutory responsibility for supporting disabled children, young people and their families.

Contents

Executive Summary	3
Introduction.....	10
Section 1: Participation in the shaping of services.....	11
Section 2: Better information for families	23
Section 3: Simplifying access to services and planning with families	31
Section 4: Supporting families through the system: key workers and lead professionals.....	40
Section 5: National programmes as catalysts for change	46
Section 6: Better data.....	49
Section 7: Workforce development and training	54
Section 8: Leadership	61
Section 9: Multi-agency engagement: strategic planning and the management of change.....	64
Reference list.....	66

Executive Summary

This summary consists of the key points made in the *Learning from the Aiming High for Disabled Children Programme* report. The report was written by the Council for Disabled Children and brought together the learning from the Aiming High for Disabled Children (AHDC) programme and local authority projects set up as part of the Lamb Inquiry¹. It aims to place that learning in the context of the Green Paper, *Support and Aspiration: a new approach to special educational needs and disability*.

The material in the report is not a formal evaluation but, rather, is designed to stimulate discussion and support planning in response to *Support and Aspiration* and in a context of economic restraint. It reflects on the rich interplay between different aspects of service development, considered as integral aspects of a single narrative and a single improvement cycle. The report draws heavily on the voices of people² speaking in Spring 2011, as the AHDC programme was coming to an end, and so reflects on what was learned and achieved by involvement with the programme.

The full report contains nine sections:

1. Participation in the shaping of services
2. Better information for families
3. Simplifying access to services and planning with families
4. Supporting families through the system: key workers and lead professionals
5. National programmes as catalysts for change
6. Better data
7. Workforce development and training
8. Leadership
9. Multi-agency engagement: strategic planning and the management of change

1. Participation in the shaping of services

Participation means parents and young people are involved in service planning and decision-making so that services meet their needs, and resources are not wasted on services that families do not want.

The experience of developing participation has highlighted the fact that it takes time to build mutual trust, respect and rapport between children, young people, their families and public services.

Experience from the AHDC programme indicates that where participation is valued and encouraged, it is instrumental to developing more responsive and appropriate services for families and children.

¹ DCSF (2009) Lamb Inquiry: Special Educational Needs and Parental Confidence.

² The Council for Disabled Children would like to thank Elizabeth Andrews for conducting the interviews and compiling the report and would like to thank all the advisors, parents, service managers and professional practitioners who participated.

The AHDC programme required local areas to develop an engagement strategy to support the expansion of Short Breaks. In some areas, this was the starting point from which a parent and carer forum or working group developed.

In Year 3 of the Transition Support Programme, 80% of local areas reported that young people were directly involved with local initiatives to improve transition services.

Key learning points

- Feedback is crucial for sustaining and building more collaborative approaches.
- Experience highlights the importance of flexibility and progress is linked to investment of time and energy.
- It is important to acknowledge and address barriers to participation such as times of meetings, provision of childcare and/or transport costs incurred by families.
- Participation increases when services identify the skills that parents, carers and young people need in order to contribute effectively or run a parent and carer forum and help individuals develop.
- Through joint working, service users develop a better understanding of the complexities within which people employed by local authorities operate, and develop a stronger feeling of ownership for the services they use.

2. Better information for families

Managing the provision of information for families of disabled children is complex and requires planning and coordination. For example, families need different information depending on the nature of their child's SEND, and information needs to alter as children get older, their condition changes or family circumstances change. Also, providing too much information at once can be overwhelming for families.

Tailoring information to fit individual families and young people is as important as providing better information. Developing information materials in partnership with families and young people improves the quality and relevance. The development of targeted information has been significant. In Year 3 of the TSP, over 95% of local areas reported that bespoke information in a range of formats was available for young people.

Transparency about available services and eligibility criteria increases service users' confidence that access to services is equitable. It helps people understand that resources are limited and the needs of a range of families must be met.

Key learning points

- Better information materials and information services enable families and young people to make informed decisions about the support they need.
- Universal services should develop their capacity to meet the needs of a range of families with disabled children.
- A joint information and communication strategy is needed to link information about childcare with other aspects of service provision like Short Breaks.
- The more complex a child's additional support needs, the more important it is to support families to make choices about support as part of a broader, ongoing support relationship that is well co-ordinated and easy for families to access.

3. Simplifying access to services and planning with families

Greater understanding has developed about the contribution that meeting the support needs of parents, carers and siblings makes to the well-being of children with SEND. In general, the more complex a child's need, the more important it is that a holistic package of support for individuals and families is co-ordinated and managed.

It is important that families have a single gateway to information, intervention and practical help, and that there are defined pathways through the system. A multi-agency panel can establish a relationship with a family quickly and is able to co-ordinate assessment and intervention.

Families, children and young people experience many different assessments for different purposes. To reduce duplication these elements need to be brought together into one multi-agency process and should inform a single action plan.

Key learning points

- Simplifying access for families with relatively modest requirements allows local authorities to deploy scarce resources where they are most needed.
- An important initiative in recent years has been to define the services families can access without a formal assessment.
- Relationships between families and schools are important in establishing a collaborative approach and shared responsibility for supporting children's development.
- A personalised approach for young people passing through transition is about young people being asked to describe what's important to them and then to explore the support required to help them achieve their objectives. Young people are encouraged to retain control over the transition process and feel ownership of their transition plan.
- The Transition Support Programme found that person-centred approaches are being used more often, particularly in special schools.

- The challenge is to extend the ethos and practice of person-centred planning to review processes in mainstream schools.
- Joint planning and decision-making must lead to the development of an action plan.

4. Supporting families through the system: key workers and lead professionals

The importance of key workers for families and young people who are using a range of support services has been consistently highlighted within national programmes over the last ten years and in research.³

Families and young people who are using a range of support services need key workers who can:

- provide care co-ordination
- ensure families, children and young people have all the information they need to make decisions and that they are supported to understand and use information over time
- ensure practitioners and agencies in less regular contact with the family are kept up to date with developments
- provide emotional support and build confidence
- act, occasionally, as an advocate for families.

Local areas that have developed key worker or care co-ordination services for children and young people of all ages have found that the issue is about clarifying who needs what and when, and about defining the relationship between key working and core lead professional functions.

For some families, the need for a key worker varies over time. The system must be capable of responding flexibly to the changing pattern of support that is needed.

Key learning points

- Key workers for families children and young people with SEND must have appropriate specialist knowledge of disability and local services and an established network of contacts.
- As children get older, services may need to migrate families from a key worker service towards lighter touch lead professional support.
- Local areas that have already developed key worker or care co-ordination services say it is important to clarify who needs what and when, and to define the relationship between key working for children and young people with SEND and core lead professional functions.

³ For example, *National Service Framework for Children, Young People and Maternity Services*, Standard 8 (Department of Health, 2005) and Sloper et al 'Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?', *Child: Care, Health and Development* 32(2), 2006. <http://eprints.whiterose.ac.uk/973/>

5. National programmes as catalysts for change

National programmes are able to identify priorities and bring a clear sense of direction to service improvement in local areas. The momentum of national programmes can help secure the engagement and support of senior managers.

Key learning points

- National programmes provide an opportunity to build on what has already been achieved and to raise the profile of services for children with SEND.
- Interviewees valued the support received from national programmes and emphasised the important contribution of regional meetings and support networks to the success of national initiatives.
- Interviewees noted the positive influence of increased scrutiny of local working practices associated with national programmes.
- National programmes provide an opportunity to extend joint planning and holistic support for families and to develop a single, coherent strategy for integrated service delivery for children and young people.
- The additional funding that sometimes comes with national programmes significantly increases local capacity to bring about change.

6. Better data

The demand from national programmes for detailed feedback was experienced by many local areas as a significant challenge, and described by one regional lead as 'painful but necessary'. However, it has resulted in improved capacity to estimate and analyse data about local population and has changed working practices associated with data collection and analysis.

Particularly significant learning has taken place through the period of the Aiming High for Disabled Children (AHDC) programme about the value of better data, including satisfaction ratings from service users, numbers of families, children and young people using services and an analysis of patterns of service use.

Key learning points

- Development of Short Break services has been monitored through the period of the AHDC programme. Data has helped local areas to establish a baseline for service provision, decide on priorities for development, and make projections for growth.
- The demand from national programmes for detailed feedback has been experienced by many local areas as a significant challenge, but it has resulted in improved capacity to estimate and analyse data about local

population and has changed working practices associated with data collection and analysis.

- Commissioning that incorporates understanding and assessment of families' needs is an important element in developing better data.

7. Workforce development and training

The report considers training associated with:

- developing better communication and partnership working with families using ES and the 'structured conversation' developed by Achievement for All
- increasing the capacity of universal service providers to meet the needs of families with disabled children, including the need for appropriate information
- developing person-centred approaches to planning and working with young people
- supporting parents and carers to develop the skills they need to participate in the shaping of services and/or run a parent and carer forum, and also involving parents in training with and for professionals.

Key learning points

- ES training is widely used and is relevant for use with families with school-aged children.
- It is important that training focuses on the skills needed by schools to maintain better communication and better relationships with families.
- Continued workforce development is needed to further increase the capacity of universal services to provide for additional support needs of families of children and young people with SEND, including information, advice and guidance.
- Person-centred approaches to planning and working with young people have provided a key focus for workforce development.
- A growing number of parent trainers are working alongside professionals or deliver training to other parents and to professionals on their own.

8. Leadership

Effective leadership of local activity is an important determining factor in the success or failure of work programmes.

The characteristics needed by operational managers leading the development of provision in local areas, as listed by a regional advisors included; good people skills, because service improvement depends on building relationships and partnerships; good project management skills, meaning an ability to make things happen, plan activity well and maintain an overview of activity and good commissioning skills and a realistic understanding of how long it can take to commission new services.

National programmes characteristically require local areas to nominate a named adviser or lead for activity.

Key learning points

- Advisers who work with many different local areas are well placed to reflect on the importance of effective leadership at operational level.
- Local areas have done well where the people leading developments have had the time to do the job and the skills needed to manage the planning and delivery of service change.
- A key theme that came out of interviews was the importance of leading by example, particularly in the context of developing multi-agency cooperation and working practices, and partnership working with families to grow participation.

9. Multi-agency engagement: strategic planning and the management of change

National programmes over the last few years have highlighted the multi-agency nature of additional support that many children and young people with SEND require and the multi-agency nature of engagement at strategic level required to plan and manage service change.

Key learning points

- Many areas established a multi-agency steering group to oversee and manage Short Breaks and other aspects of the AHDC programme.
- A key learning point is the need to sustain high-level multi-agency engagement beyond the life of the AHDC programme in order to maintain focus on continued service improvement for children with SEND, plan and implement better co-ordinated provision for families, and maintain credibility with families and young people as joint planning incorporating a service user perspective is further developed.

Introduction

This report sets out accounts from local areas and individuals involved in the government's Aiming High for Disabled Children (AHDC) programme. The AHDC programme ran from 2008 to 2011 and was sponsored by both the Department for Education (DfE) and the Department of Health (DH). The programme was ambitious in its overarching aims, which were to change culture and significantly improve support for families, children and young people.

Learning from the AHDC programme will now be used to inform proposals set out in the Green Paper *Support and Aspiration: a new approach to special educational needs and disability*⁴.

'We must provide the best quality of life possible to the most vulnerable children and young people in our society. Here, we set out our ambition: to put early support in place for parents to help them navigate the system and influence their child's package of care; to provide ongoing respite care and short breaks for children to help families cope with their day-to-day caring responsibilities; and to help families who are worried about their child's future and independence.'

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

This report summarises learning from AHDC activity associated with:

- increased consultation with families
- the provision of better information for families
- simplifying access to services
- key working and lead professionals
- the general impact of national programmes
- improvements in data collection
- workforce development
- leadership
- multi-agency engagement in planning and managing change.

The material in this report is not a formal evaluation but, rather, is designed to stimulate discussion and support planning in response to *Support and Aspiration* and in a context of economic restraint. It reflects on the rich interplay between different aspects of service development, considered as integral aspects of a single narrative and a single improvement cycle. The report draws heavily on the voices of people speaking in Spring 2011, as the AHDC programme was coming to an end, and so reflects on what was learned and achieved by involvement with the programme.

⁴ *Support and Aspiration: a new approach to special educational needs and disability*, Department for Education, 2011.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027>

Section 1: Participation in the shaping of services

'Almost all local authorities report having parent representatives sitting on decision-making bodies, which helps to support the effective provision of disabled children's services such as short breaks. The Department for Education will continue to fund parent forums in every local area to build on the good practice that has been developed.'

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

Participation means parents and young people are involved in service planning and decision-making so that services meet their needs, and resources are not wasted on services that families do not want.

The AHDC programme required local areas to develop an engagement strategy to support the expansion of Short Breaks, and to identify dedicated resources to deliver the strategy:

'A Short Breaks service should be based on a needs assessment of the local disabled child population, taking into account the voice of disabled children, young people and their families.'

Aiming High for Disabled Children: Short Breaks Implementation Guidance

In some areas, this was the starting point from which a parent and carer forum or working group developed. AHDC invested in the development of parent and carer forums to:

- give parents of disabled children a voice
- foster better relationships between service providers and parents
- allow parents to contribute their expertise to shaping services.⁵

Developing participation by service users

Early Support, the national programme for families with children under 5, prioritised participation and partnership working. It has been identified by some local areas as an important influence steering policy and practice towards increased collaborative working with service users:

'A key thing about Early Support has been the strength of engagement with parents. It led directly to the formation of our Parent Forum, which gives families a collective

⁵ *Aiming high for disabled children: better support for families*, Department for Children, Schools and Families, 2007.

opportunity to influence and be involved in the development of the services ...'

AHDC Lead and Service Manager Special & Additional Needs

In 2011, Together for Disabled Children (TDC) estimated that 60% of local areas had a steering group of parent and carers, sometimes called a parent and carer forum or council⁶. TDC distinguishes between types of participation⁷ and has produced useful guidance on developing parent participation.⁸

Although local areas developed participation from very different starting points, the general picture is one of significant change. In some places, parent and carer forums and partnership working with families have been established for some time. In others, the critical contribution of service users to service improvement is a relatively new idea, but one that is growing fast. The following comments indicate how quickly attitudes and practice are changing in some areas and how far some individuals have travelled:

'There have been a lot of difficulties in the past and there were times when I dreaded going to those early meetings with parents and carers. Now I meet on a monthly basis with the Chair of the Parent and Carer Forum to discuss issues as they come up – but we're still learning.'

AHDC Lead and Head Children and Young People's Disability Partnership

'... when I first joined my local forum, it was with ... cynicism about how honest the local authority was with families. I wanted ... make sure that other families like ours were represented.'

Parent and Regional Representative, National Network of Parent and Carer Forums

Participation at transition

The participation of young people in shaping services has been a key priority for the AHDC Transition Support Programme (TSP) and has been promoted as a key element in improving the range and appropriateness of Short Break opportunities for older children.

'The young person is the most important person in the transition planning process and therefore should be encouraged to participate in whichever way they feel comfortable. For the transition process to be truly person-centred, young people must have access to information that helps them understand what happens at transition, how to

⁶ *How parent participation and Parent and Carer Forums Lead to Better Outcomes for Disabled Children, Young People and Their Families* Together for Disabled Children, 2011.

⁷ *Parent Participation*, Together for Disabled Children, 2011.
<http://www.togetherfdc.org/Topics/ParentalParticipation.aspx>

⁸ *The How To Guide on Parent Participation*, Together for Disabled Children, 2010.
<http://www.togetherfdc.org/Topics/ParentParticipationHowToGuide.aspx>

participate in the planning process and how to make informed decisions about their future.'

TSP Transition Planning and Development Tool

One manager reflected:

'... we've ... done a lot of work to empower young people. Disabled young people are on the local Youth Parliament, and we have young consultants and young ambassadors. They're involved in interviewing people at all our public events and participate in question-and-answer sessions'

Head of Integrated Services for Disabled Children and C4EO Sector Specialist

In Year 3 of the TSP, 80% of local areas reported that young people were directly involved with local initiatives to improve transition services, and returns to the annual TSP self-assessment questionnaire (SAQ) indicated a range of initiatives being developed to support participation⁹. For example:

'A group of disabled young people aged 16-25 who meet together at a community centre are involved in the development of the protocol and also act as advocates for other disabled young people who are going through transition. They attended the Transition Fair and talked to other disabled young people and their families. The group has now been commissioned to look at supported housing options for young people passing through transition.'

Local Area SAQ 2

Learning from increased participation

Areas reported that parents are involved in:

- auditing and evaluation of service provision
- selection of organisations bidding to become providers
- commissioning of services and award of contracts
- development of information materials and websites
- recruitment of key members of staff
- development and delivery of training for professionals and parents
- representation of service users on local authority and other strategic planning and operational management groups.

'Aiming High was the catalyst to form the Parent and Carer's Forum but things have developed beyond that ... we've got parents sitting on a range of strategic groups to shape service delivery ... They also had a voice as new formulas to support the SEN Budget were developed and

⁹ Transition Support Programme Year 3: Report from the Self Assessment Questionnaire Analysis. <http://www.transitionssupportprogramme.org.uk/pdf/TSP%20SAQ%203%20Report%20-%20March%202011.pdf>

agreed. The Forum ... attended 300 'contacts' with the authority over the last year ... that's a huge improvement.'

Local Authority Service Manager for Strategy and Partnership

Consultation with service users is most effective when it is responsive to:

- the way in which families and young people say they would prefer to be consulted
- what is practical and affordable
- what works best in the particular local area.

The experience of developing participation has highlighted the fact that it takes time to build mutual trust, respect and rapport between parents, carers, young people and public services. Local areas also acknowledged the importance of national programmes prioritising this aspect of service improvement and forcing a change in culture. The following quote is typical of comments made in interviews:

*'It was important that the national programme focused on consultation and feedback. ... there was quite a level of cynicism. People sat with their arms folded, thinking they'd been here before and couldn't see what was going to be different this time around – but it **has** been different.'*

Local Authority Service Manager for Strategy and Partnership

"We put out feelers and direct invitations to the Forum, which then identifies the right people to represent the group on particular issues. This is a big improvement on the past when it felt like a relatively small group of parents wrote to the Authority to complain. I think we now hear the voices of a greater number of parents and the people we meet with are more representative of the experiences families have."

Service Manager Joint Commissioning and Health Strategy

Feedback is crucial for sustaining and building more collaborative approaches. As one parent commented:

*'Where consultation drags on too long, it shouldn't be telling professional agencies anything that they don't already know ... families get sick of being asked for their opinion and nothing's changing or coming out of it. It's about **action**. When you feed back to families quickly what's happened as a result of what was said, you get twice as many people turning up next time.'*

Regional Representative, National Network of Parent and Carer Forums

Experience also highlights the importance of flexibility. Managers in one area said they started with the intention of consulting directly with as many

families as possible. However, parents preferred to form a representative Parent Reference Group through which consultation would be managed. Services now relate in the first instance to this group, which is connected to a network of families and young people, and the group takes responsibility for feeding back ideas.

*'Sometimes the Parent Reference Group has chosen not to send a parent to participate in a working group. Rather, the working group goes to them. Sometimes we do both. For example, when we were developing eligibility criteria, we had two parents on the working group **and** we consulted directly with the Parent Reference Group as well.'*

AHDC Lead and Manager of the Integrated Service for Disabled Children

Barriers to participation include the times of meetings and the provision of childcare facilities or funding to cover childcare and/or transport costs incurred by families. Meetings at weekends, during school hours or in the evenings sometimes suit families but may mean that staff must work outside normal hours.

Experience also suggests that participation increases when parents and public services are able to identify the skills that parents, carers and young people need to develop in order to contribute effectively or run a parent and carer forum. An incidental side effect of this is that parents and carers have an opportunity to acquire transferable skills in a flexible, supportive and child-friendly quasi-working environment. The importance of identifying and responding to the training needs of parents and carers is considered in more detail below.

The relationship between participation, payment and volunteering has been considered in some detail in the context of DCATCH activity,¹⁰ where lack of payment was identified as a significant factor preventing the participation of some parents and carers. In some areas, the use of vouchers in lieu of payment has provided a practical solution. However, parents (both paid and unpaid) interviewed as part of the process evaluation of DCATCH Pilot Areas expressed the view that their time should be valued through payment, particularly if local authorities and other agencies begin to call on them more frequently.

Supporting parents and carers to participate in the shaping of services

A significant area of development over the last few years has been training for parents and carers to develop the skills they may need to participate effectively in the shaping of services and managing a parent and carer forum.

¹⁰ *Disabled Children's Access to Childcare (DCATCH) Process Evaluation of participation and Workforce Development Activity in the DCATCH Pilots*, Department for Education and National Centre for Social Research, 2010. <https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR013>

This has been encouraged by the Early Support¹¹ and AHDC national programmes.

'The course I'm doing presents quite basic information about leadership and it's particularly geared towards forums. That's helpful for some people – eg, if they're not used to talking in a group... I come into contact with quite a few people who are new to participation ... they often haven't done that sort of thing before. It's important.'

Parent and Regional Representative, National Network of Parent Carer Forums

Parent Workshops, written by parents for parents, was developed by the Early Support (ES) programme. Workshops are led by parent trainers with first-hand experience and introduce parents/carers to service provision and how ES can help. Practitioners can attend, but normally only by invitation from a parent.

'In general, the parents who are involved on our Aiming High working groups and steering group are the parents who have participated in Early Support Parent Workshops. They've developed their skills and understanding of how services work.'

Care Co-ordinator and Development Officer

Many parents/carers who have gone on to support the development of participation as part of Short Breaks and other national initiatives have participated in one of these workshops, or were involved in the original development of associated training materials. In some local areas, the workshops are embedded in developing practice and service change:

'The training we provide for families with young children on working in partnership is based on the Early Support Parent's Workshop. I was trained as a trainer for that and then we've worked together to make the course as appropriate as possible for parents in this particular local area. We deliver it through six two-hour workshops because that's what parents asked for. We run it a couple of times a year.'

Parent Trainer and Member, Parent and Carer Forum Steering Group

What difference does it make?

Experience indicates that where participation is valued and encouraged, it is instrumental to developing more responsive and appropriate services for families and children. Rather than local services acting as gatekeepers to services they have designed, services are commissioned in direct response to

¹¹ *About Early Support training*, Department for Education, 2011.
www.education.gov.uk/childrenandyoungpeople/sen/earllysupport/training/a0067198/about-early-support-training

what families say they need. This is a significant shift that enables commissioning to be targeted more appropriately. It encourages professionals to consider involving families in workforce development as trainers and co-trainers so that training for practitioners routinely incorporates a service-user perspective.

Progress is linked to investment of time and energy. Participation does not grow where local authorities and their partners do not recognise the work involved in making it happen and actively support its development.¹²

Parents/carers and service managers in areas with positive experiences of developing participation identify practical examples of how it improves outcomes:

'Parent participation has influenced the choice and quality of the Short Break services we buy, by making sure we ask the right questions in applications and interviews and influencing processes such as the entitlement framework.'

Local Area Commissioning Officer

'Participation and consultation with families makes a huge difference. In relation to Short Breaks, we started out with an expectation that a Short Break was about separation and there was very little consideration of the role of universal services. At the first consultation event, parents were ... saying to us, "Normal things in normal places. I might need a break from the stress of having to care for a disabled child but please don't automatically assume that I want to be separated from my child." That shifted the emphasis completely.'

Local Authority Service Manager for Strategy and Partnership and Lead for AHDC Short Breaks and DCATCH

In a number of local areas, increased participation by children and young people had resulted in the commissioning of a wider range of Short Breaks than had originally been planned.¹³

Unlocking skills and experience

Where participation is valued and develops over time, the opportunity to identify and use the skills and experiences of individual parents and carers grows. A number of interviewees talked about the value of this aspect of their learning:

'We ... discovered we have a parent with a wealth of experience of building projects. He says things like, "You

¹² *Short breaks pathfinder evaluation*, Department for Education, 2010.

<https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR062.pdf>

¹³ *Is the voice of the child having an impact on the development of short breaks for disabled children?* Together for Disabled Children, 2010.

<http://www.togetherfdc.org/SupportDocuments/DCYPParticipationResearch.pdf>

can't put that kind of roof on that sort of structure." That's really helpful. Another ... had worked for a big retail company in her past. She was someone I thought I knew well, but I'd never asked her ... Suddenly she's sitting on the Sponsoring Group with a way of talking about business cases that I don't have. She looked at me in the middle of one meeting as much as to say, "Ha! You didn't know that, now, did you?"

AHDC Transition Lead

'As developments come, we share that with families and agree where parents need to be directly involved. The Parent Reference Group then nominates people for particular tasks. For example, with the website development group we agreed it would be good if we could identify someone with media skills and experience. The parent who has been involved used to work for ITV – perfect.'

AHDC Commissioning Officer

Matching particular individuals to particular tasks or activities also increases the number and range of parents and carers involved in shaping services:

'We put out feelers and direct invitations to the Forum, which then identifies the right people to represent the group on particular issues. This is a big improvement ... I think we now hear the voices of a greater number of parents and the people we meet with are more representative of the experiences families have.'

Service Manager, Joint Commissioning and Health Strategy

'The number of parents involved has mushroomed ... I don't think parents think ... they have to have a certain level of education or a certain level of involvement with a service to participate – a lot more ... feel it's something they can do.'

Regional Representative, National Network Parent and Carer Forums

The skills and experiences that parents/carers bring fall across a wide range. One parent explained how part of their local forum has formed a group that the local authority commissions to undertake consultation with families. Another operates as a parent-led organisation that develops and provides information for families. Parent organisations that have developed a role as providers of Short Breaks use the skills of many different people.

Parent and carer forums and participation at every level

'There is clear evidence from the evaluation that better outcomes are achieved ... if there is significant investment in mechanisms that involve families at all levels of commissioning and provision. The delivery of clear, timely and relevant information (through a range of routes) is a central part of this. These mechanisms need to reflect the ... diversity of family wishes and experiences and not rely on a single, standardised approach.'

Short Breaks Pathfinder Evaluation

TDC materials to support the development of parent and carer forums explain that job titles and names of departments differ from area to area. Therefore, forums need to find out who makes decisions about services and finances to work out how they can feed into planning. They suggest that forum members map the structure of committees and teams to see how they could link into those.

The managers who were interviewed reflected positively on their experience of involving parents in strategic-level planning:

'Having one or two parent reps sitting on a strategic, decision-making board ... changes the dynamic and the focus. As a professional you have to think differently and pay attention to the person in the room who's living what you're talking about. It alters your perceptionmakes you reflect on your practice ...'

Local Area Service Manager

Two managers said they had taken steps to support parents and carers moving into the role of representing service users on strategic management groups. Both met with parents informally ahead of committee meetings to foster engagement and avoid service users coming into boardrooms unsure about what it was they were being asked to do. One explained:

'The new Inclusive Learning Strategy Steering Group has parents on it ... It's great that we've got them on that group, but we need to invest time in exploring and unpicking what's involved and really get to grips with the questions they raise. They're sent papers ahead of meetings ... but the pace of everything is such that they're not able to raise the questions they have. So I've met with the Parent's Forum about Achievement for All ahead of the last two ... meetings to discuss with them the wider context and how it all fits together.'

Local Authority Achievement for All Lead

In 2010 a task force came together to support the development of a National Network of Parent and Carer Forums to influence and effect change at

national level, to be ambassadors for parent/carer participation and to facilitate communication between government, parent and carer forums, and statutory bodies. One member of the Task Force reflected on the network's value:

'You can respond as a region ... as a local group or as an individual to things ... happening at national level. But you need ... a co-ordinated approach and response from across the country. Sometimes the particular views of regions diverge – the national network is about trying to achieve a representative, balanced view of what people think.'

Regional Representative, National Network Parent and Carer Forums

Partnership, co-production and joint planning for the future

'Parents have a key role to play, in partnership with local authorities, in the development of appropriate Short Breaks services that meet the needs and aspirations of their local community.'

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

Through joint working, service users:

- develop a better understanding of the complexities within which people employed by local authorities operate
- develop a stronger feeling of ownership for the services they use
- can explain to other families the context within which decisions have been taken.

'It's about mutual understanding and finding solutions. Sometimes things are very difficult, but the solutions families suggest are simple, cost effective and mean much more than something that's wrapped up in shiny paper, but doesn't actually mean an awful lot to the family involved. Families are in the best place to identify the small tweaks to their care package that would make a difference. The bus coming at a different time. Something offered in a different way.'

Care Co-ordination Development Officer

The following comment indicates the high value that some service managers place on a collaborative approach:

'Our business development plan for the coming year includes a development plan for the parent and carer group. As we're making that plan ... we have representation from the parent and carers group ... helping us to plan our priorities. Those are the relationships that

we really need to consolidate and sustain in the longer term – the ones that help us build things ... from the grassroots ... to improve services.'

Head, Children and Young People's Disability Partnership and AHDC Lead

Several interviewees talked about the particular value of partnership and collaboration in the context of reduced budgets, for example:

'Because they're engaged, people understand how you want to progress things and that we'll be as frustrated as they are about not having the resources to do the things we want to do.'

Head of Integrated Services for Disabled Children and C4EO Sector Specialist

'Continued participation and engagement by parents is our only possible route to managing cuts well....'

Assistant Director, Children's Services

Summary

- Participation means parents and young people are involved in service planning and decision-making so that services meet their needs, and resources are not wasted on services that families do not want.
- The AHDC programme required local areas to develop an engagement strategy to support the expansion of Short Breaks. In some areas, this was the starting point from which a parent and carer forum or working group developed.
- In Year 3 of the TSP, 80% of local areas reported that young people were directly involved with local initiatives to improve transition services.
- It takes time to build mutual trust, respect and rapport between parents, carers, young people and public services.
- Local areas acknowledged the importance of national programmes prioritising this aspect of service improvement and forcing a change in culture.
- Feedback is crucial for sustaining and building more collaborative approaches.
- Experience highlights the importance of flexibility and progress is linked to investment of time and energy.
- It is important to acknowledge and address barriers to participation such as times of meetings, provision of childcare and/or transport costs incurred by families.
- Participation increases when services identify the skills that parents, carers and young people need in order to contribute effectively or run a parent and carer forum and help individuals develop
- Parents/carers and service managers in areas with positive experiences of developing participation identify practical examples of how it improves outcomes.

- Through joint working, service users develop a better understanding of the complexities within which people employed by local authorities operate, and develop a stronger feeling of ownership for the services they use.

Section 2: Better information for families

'For parents to ... take greater control over their support, they need to be clear about their options and understand how decisions are made that affect their child's support.'

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

This section considers the experience of developing better information materials and information services to enable families and young people to make informed decisions about the support they need.

The AHDC National Core Offer set out expectations that:

'Disabled children, young people and their families should receive information that is:

Accessible: *using everyday language, alternative formats, the internet and community languages as necessary*

Available: *"to hand" without delay in places where families with children routinely go*

Relevant *and accurate: appropriate for every stage of a child's life and up to date*

Joined-up: *co-ordinated across local authorities, schools and colleges, primary care trusts, provider trusts and the voluntary and independent sectors*

User-focused: *so that families know where and how to get help and support.'*

AHDC – Core Offer

Managing the provision of information for families of disabled children is complex and requires planning and coordination. For example, families need different information depending on the nature of their child's SEND, and information need to alter as children get older, their condition changes or family circumstances change. Also, providing too much information at once can be overwhelming.

The Early Support (ES) programme prioritised the production of standard information about:

- a range of different conditions or disabilities (the Information for Families booklets)
- how services are organised and operate (the Background Information booklets)
- how ES and in particular, the Family File, can be used to co-ordinate service provision and achieve joint planning that keeps families at the heart of decision-making.

The Green Paper proposes to maintain and update the ES materials in partnership with the voluntary and community sectors and parents, and to extend their use with families of school-aged children.¹⁴

Improving the information available to young people and their families from Year 9 onwards was an important focus for the Transition Support Programme (TSP). AHDC identified the development of bespoke information packs for young people as a priority. Packs were to include information on further education, training opportunities and work options and about the process of negotiating transition from school and into adulthood. The development of information on this model has been significant. In Year 3 of the TSP, over 95% of local areas reported that bespoke information in a range of formats was available for young people. In Year 2, 122 areas were holding information events or transition fairs for families and young people; 109 were making information available on websites.

Building the capacity of universal information and advice services

Universal services should develop their capacity to meet the information needs of a range of families with disabled children. The DCATCH initiative was a particular focus for such activity. Family Information Services (FISs) are required to provide information, advice and guidance on childcare and early years services in their area, including whether childcare settings are suitable for children with disabilities and special educational needs.¹⁵ However, as one manager noted:

'A lot of families were not using our Family Information Service ... because they felt it was too generic ... Their experience of using the service had not been good. So up-skilling FIS and improving the information they hold about childcare providers has been a priority.'

Local Area DCATCH Lead

In order to provide the information needed by families with disabled children, FISs should develop effective relationships with:

- Parent Participation Services (PPS)
- information teams providing advice on employment and welfare benefits
- specialist services for families with disabled children.

A joint information and communication strategy should be developed, ideally linking information about childcare to other aspects of service provision like Short Breaks. This should be seen as part of the wider transformation of FIS

¹⁴ Section 2.10

¹⁵ *Duty to provide information, advice and assistance: Guidance for local authorities Childcare Act 2006*, Department for Children, Schools and Families, 2008.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00943-2007>

services to become providers of information on all relevant services, facilities and publications for parents of children up to the age of 20.¹⁶

FISs are key partners for specialist services. For example, a DCATCH pilot area created a new post with the initial remit to improve the skills of FIS advisers and provide dedicated information for families looking for appropriate childcare. The post-holder was also to be a point of contact for childcare providers looking for information about how best to include children, and laid the foundations for a new brokerage service for families with disabled children.¹⁷

Many local areas have also used the opportunity of the TSP to develop the capacity of universal information, advice and guidance (IAG) services to meet the needs of young people with SEND. Careers and guidance professionals, sometimes known as Connexions personal advisers (PAs), are at the heart of transition. They provide a free and confidential IAG service to all 13- to 19-year-olds and to young people with learning difficulties or disabilities up to the age of 25. Young people with disabilities rely on these services and so it is important that personnel are knowledgeable and up to date with what is available locally. The focus and investment required to develop the capacity of universal IAG services is indicated by the following SAQ return:

'Connexions allocates named personal advisers to all learning institutions. In addition to generic advisers, the service has specialist Learning Difficulty and Disability (LDD) Champions ... [who] mentor individual Connexions staff and identify and respond to local area training needs. Wider LDD training needs are identified by local LDD Champions and Staff Individual Performance Development Review Plans.'

Local Area TSP SAQ 2

Involving service users in developing better information

Many of those interviewed emphasised that developing information materials in partnership with families and young people improves the quality and relevance of information materials.

'In a couple of areas ... the development of the information families and young people need has all been led by parents and young people themselves. They know what they want and how they want it to be.'

TSP Named Adviser

¹⁶ *Families Information Services (FIS) Development Support Tools: Widening the Information Offer*, Department for Children, Schools and Families, 2009.
<http://collections.europarchive.org/tna/20100423085708/dcsf.gov.uk/everychildmatters/resources-and-practice/iq00633/>

¹⁷ *Disabled Children's Access to Childcare (DCATCH) pilot activity: Information for local Authorities*, Department for Education and National Centre for Social Research, 2009.
<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01203-2009>

Many examples of local information materials developed by or with families and young people as part of AHDC Short Break activity are available online at <http://www.togetherfdc.org>. There are also many examples of local development of information materials about transition in partnership with families and young people. The following comments are indicative:

'We've commissioned our parent's consortium to write a transition handbook for families and young people ...The material's geared towards young people and is very straightforward and pictorial. It's a working document that tells people what they should expect in terms of transition planning. It identifies the people who should be talking to them and outlines opportunities and options.'

Local Area TSP Lead

Parent Champions

A related area of development and learning has been about the role of Parent Champions. The aim is to spread information by word of mouth, sometimes supported by meetings and information events. The contribution of Parent Champions to the wider development of parent and carer forums and participation has been significant in some local areas. Champions spread the word about available services. This links to the ability of parent-led organisations to reach families who may not otherwise engage:

'There are lots of reasons why parents may be worried but may not want to engage, and we're not in people's faces but we can be inventive when parents don't engage, because we have an extensive network of contacts with families and may know another parent who can help.'

Parent and Chair, local voluntary organisation providing Short Breaks

Tailored information and brokerage

'The survey carried out for the Inquiry identified the need for face-to-face meetings and for a range of information for parents. Overall, it identified the need for a more consumer-focused and more personalised approach to the provision of information'

**Special Educational Needs and Parental Confidence
– Lamb Inquiry Final Report**

Tailoring information to fit individual families and young people is as important as providing better information. The ES Service Audit Tool specifies

that families should be 'supported to understand information over time and in the context of their own circumstances'.¹⁸

In the context of childcare, tailored information and advice usually takes the form of assessing the needs and circumstances of the family and brokering suitable childcare arrangements available locally. Brokerage services are intended to link duties to provide sufficient childcare with duties to provide information, advice and assistance. Support provided to families by such services might include:

- helping parents navigate and understand information about childcare options
- checking whether cost is a barrier to finding suitable childcare and whether the parent has taken up all possible entitlements. In the case of families with disabled children, this includes information about additional financial support that may be available via the Disability Living Allowance, the Disabled Child Tax premium for those receiving Child Tax Credit, and Carer's Allowance
- contacting local providers on a parent's behalf to explain the needs of individual families and discuss how they might be met, eg because the child is disabled
- brokering partnerships with providers in different sectors to enable parents to access a package of provision that meets their needs
- introducing parents and providers and, where appropriate, arranging and attending initial meetings between them.¹⁹

'If your experience of the Family Information Service is good, you'll come back. On the other hand, if your first experience is that you can't find anyone, it's a significant setback. Brokerage is very important, because parents are often nervous about using childcare services – particularly mainstream providers. Often families need a person with whom they can have an open and honest discussion about their situation and their child's needs.'

Local Area DCATCH Lead

Programme information for DCATCH emphasises that the more complex a child's additional support needs, the more important it is to support families to make choices about childcare as part of a broader, ongoing support relationship that is well co-ordinated and easy for families to access.²⁰

¹⁸ *Early Support Service Audit Tool*, 2nd edition, Department for Education, 2009.

<http://media.education.gov.uk/assets/files/pdf/e/early%20support%20service%20audit%20tool%202009.pdf>

¹⁹ *Duty to provide information, advice and assistance: Guidance for local authorities*, Childcare Act 2006, Department for Children, Schools and Families, 2008.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00943-2007>

²⁰ *Disabled Children's Access to Childcare (DCATCH) pilot activity: Information for local authorities*, Department for Children, Schools and Families, 2009.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01203-2009>

Transparency

'To give parents confidence by giving them more control over the support their family receives, we will introduce more transparency in the provision of services for children and young people who are disabled or who have SEN.'

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

The AHDC specified that disabled children and young people and their families should expect transparency about how:

- overall resources are decided and resources are allocated
- services work together to promote good outcomes
- services are commissioned
- feedback is sought and acted upon and how to complain if necessary
- legal entitlements are being met.²¹

Transparency is essential to build trust and partnership with service users.

'In times of reduced resources, we have to be absolutely transparent. The parents who work with us need to know how much money we have ... We need to come up with proposals that reflect their views and I rely on them to explain to other parents when difficult decisions have been taken ...'

Local Area Service Manager

The development of Short Breaks has provided useful learning about the value of this sort of transparency in relation to a particular aspect of service provision. An evaluation report notes:

*'What most families reported mattered to them was the availability of clear, concise information that described what they could expect in terms of short breaks.'*²²

Local authorities were directed to promote information about provision in their area as part of the Full Service Offer, including details of eligibility criteria and how to access services.²³ The explosion of associated information materials, events and websites has been a striking feature of development. Authorities are required, from October 1st 2011, to publish a statement of their Short Break services on their website and keep the statement under review. The statement must set out:

²¹ *Aiming High for Disabled Children – Core Offer*, Department for Children, Schools and Families, 2008.

²² *Short breaks pathfinder evaluation*, Department for Education, 2010.

<https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR062.pdf>

²³ *Aiming for Disabled Children: Short Breaks Implementation Guidance*, Department for Children, Schools and Families and Department of Health, 2008.

<http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20implementation%20guidance.pdf>

- the range of Short Break services available
- the criteria by which eligibility for services will be assessed
- how the range of services is designed to meet the needs of families with disabled children in their area.

Local authorities are also reminded of their general responsibility to be proactive in disseminating information about children's services, rather than waiting for families to ask.²⁴

Transparency about available services and eligibility criteria increases service users' confidence that access to services is equitable. It helps people understand that resources are limited and the needs of a range of families must be met. As one service manager commented:

'In my experience, most parents don't ask for that much and when information about options and costs is out in the open, they make very sensible and reasonable decisions.'

Parent and Chair, voluntary organisation and Short Break provider

The Lamb Inquiry noted that, in general, confidence in the system is fed by openness about the services that are available:

'Parents' confidence in the SEN system and in schools and local authorities in particular, is significantly coloured by the quality of communication with them. The worst communication generates significant levels of hostility. The best engenders impressive levels of confidence and a sense of partnership.'

Special Educational Needs and Parental Confidence – Lamb Inquiry Final Report

Summary

- Better information materials and information services enable families and young people to make informed decisions about the support they need.
- Managing the provision of information for families of disabled children is complex and requires planning and coordination.
- Families need different information depending on the nature of their child's SEND, and information needs to alter as children get older, their condition changes or family circumstances change.
- The development of targeted information has been significant. In Year 3 of the TSP, over 95% of local areas reported that bespoke information in a range of formats was available for young people. In Year 2, 122 areas were holding information events or transition fairs

²⁴ *Short Breaks for Carers of Disabled Children: Advice for local authorities*, Department for Education, <http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20-%20advice%20for%20local%20authorities.pdf>

for families and young people; 109 were making information available on websites.

- Universal services should develop their capacity to meet the needs of a range of families with disabled children.
- A joint information and communication strategy is needed to link information about childcare with other aspects of service provision like Short Breaks.
- The more complex a child's additional support needs, the more important it is to support families to make choices about childcare as part of a broader, ongoing support relationship that is well co-ordinated and easy for families to access.
- Many local areas have also used the opportunity of the Transition Support Programme to develop the capacity of universal information, advice and guidance services to meet the needs of young people with SEND.
- Developing information materials in partnership with families and young people improves the quality and relevance of information materials.
- Tailoring information to fit individual families and young people is as important as providing better information.
- Transparency about available services and eligibility criteria increases service users' confidence that access to services is equitable. It helps people understand that resources are limited and the needs of a range of families must be met.

Section 3: Simplifying access to services and planning with families

It is important that families have a single gateway to information, intervention and practical help, and that there are defined pathways through the system. A multi-agency panel can establish a relationship with a family quickly and is able to co-ordinate assessment and intervention. At an intake meeting in one local area, professionals reflected on the benefits of this approach for families with young children:

'The ... multi-agency intake meeting ... can prevent weeks of unnecessary delay for families. For example, when I arrived today, I assumed that a referral that had come to me had been copied to a number of other colleagues. It hadn't. All I needed to do as a paediatrician was ... find out who hadn't received it and photocopy the form so everyone who needs the information had it in their hand.'

'The intake meeting focuses on families at the point that they are first referred to our services. People ... only have one form to fill in and one referral to think about. As long as the referral comes here, all they have to think about is sending as much information as possible – then we can sort out initial support arrangements between us.'

In some areas, the Common Assessment Framework (CAF) is the gateway to the system:

'The single door into the system is via CAF referral. Referrals go to a pre-school or school-age panel, which has all the relevant agencies and teams sitting round the table. This enables a multi-agency strategy ... to be developed earlier.'

Head, Children and Young People's Disability Partnership

'The development of a single point of referral into the integrated service for disabled children through CAF happened very speedily because that's what was needed and what parents said they wanted.'

Manager, Integrated Service for Disabled Children

Simplifying access and local offers

'...the absence of big assessment procedures makes communication with services less threatening for families.'

Head, Children and Young People's Disability Partnership

An important initiative in recent years has been to define the services families can access without a formal assessment. In the context of Short Breaks, managers reflected in interviews on the success of approaches that offered easy access to relatively low levels of support:

'Response to the Short Breaks Grant Fund (up to £350 per family) has been phenomenal. It's the lack of bureaucracy and flexibility ... We give the family the grant and they determine what their Short Break provision will be. They have to provide receipts and answer a few questions. That's it. It works well for many families who say they don't want to come within a million miles of social care services – they just want to get on with it. That's interesting, because the fear from the service side was that it would open the floodgates and in the past, we were more used to dealing with a few parents with very high level, specialist support needs. Now we're accessing and supporting a much wider range of families, many of whom are looking for something quite modest to enable them to carry on.'

Local Authority Manager for Strategy and Partnership and AHDC SB Lead

In addition, the importance of avoiding some of the perceived connotations of assessment came up a number of times in interviews:

'It's important that social workers don't have contact with every child who has a disability. Bringing up children is hard and life is tough if you have a child who still isn't sleeping through the night at 8, 9 or 19 years of age. You shouldn't feel that you need to be assessed by a social worker if you fear they might be looking at your parenting capacity when, actually, all you need is a break and a good night's sleep.'

Local Area Service Manager

'Formal assessments can be long and intrusive and they're a long way away from ongoing contact with someone you know and who you feel you can ask when you don't know something. In some of our high-priority areas we know parents have been reluctant to access Short Breaks because of the negative connotations of a social worker being involved.'

Head, Children and Young People's Disability Partnership and AHDC Lead

The point was also made that simplifying access for families with relatively modest requirements allows local authorities to deploy scarce resources for assessment where they are most needed.

Maintaining relationships and sharing information

'Parents have told us that good, honest and open communication is one of the important components of building confidence and good relationships. Face-to-face communication with parents, treating them as equal partners with expertise in their children's needs is crucial to establishing and sustaining confidence. Where things go wrong, the root causes can often be traced to poor communication between school, local authority and parent.'

Special Educational Needs and Parental Confidence – Lamb Inquiry Final Report

The ES programme promoted effective working relationships between services and families on a partnership model through the early years of a child's life. The ES programme introduced the Family Service Plan to parents as:

'...a simple set of pages to record discussions and decisions about services and support that will be provided over the next few months so that everyone knows what's happening. As with other Early Support publications, the talk that goes on as you fill out the sheets together is more important than exactly what you write or exactly how the plan is completed.'

The ES model of engagement resonates with the development of 'structured conversations' in Achievement for All pilot areas. Improving the engagement of parents of children with SEND with their schools is a key aim of Achievement for All. The purpose of a structured conversation is to:

- establish an effective relationship between parent and the key teacher
- allow the parent an opportunity to share their concerns and, together, agree their aspirations for their child
- set clear goals and targets for learning and improvement in wider outcomes
- determine activities which will contribute to the achievement of those targets
- identify the responsibilities of the parent, the pupil and the school;
- agree the date and time of the next meeting
- clarify the most effective means of communication between meetings.²⁵

Achievement for All recommends that parents have structured conversations about three times a year with a 'key teacher' who has good knowledge and

²⁵ *Achievement for all the structured conversation: handbook to support training (National Strategies)*, Department for Children, Schools and Families, 2009. <http://dera.ioe.ac.uk/2418/>

understanding of their child, someone who has regular contact with the child, is aware of their needs and achievements, and can influence provision. This is usually a class teacher, form tutor or sometimes a head of year.

'There needs to be dialogue, not an annual review process. For example, a parent may know there's a Breakfast Club at the school, but isn't confident to send their child into a less structured, more free-flowing environment. The teacher may be thinking, "Why don't they send him?", while the parents may be thinking, "Don't think we can". When teachers get to know the parents through structured conversations, they're able to build mutual understanding and find solutions. Joint decisions can be taken and the right support put in place.'

Local Area Achievement for All Lead

This underlines the importance of continuity of contact and the relationships between families and schools in establishing a more collaborative approach and shared responsibility for supporting children's development. A shift in culture within schools towards 'receiving' as well as 'transmitting' information is required, because, as one parent reflected in an interview:

'...Parents want to share information with schools. It's not so much about how many hours their child has got with a Learning Support Assistant, it's about confidence and communication. Regular communication with your child's classroom teacher is fundamental – it can make or break a child's education and your confidence as a parent.'

Parent

A holistic approach

In the context of providing services for young children, the term 'holistic' is sometimes used to denote support for the whole family, rather than support targeted exclusively on the child or young person. For example:

'Families have different requirements and multiple identities. Where a young child has a disability, Early Support enables an integrated, tailored approach that takes account of language, literacy and cultural factors and considers the needs of children and families holistically.'

DfE website

'Holistic' may also be used to describe the range of support provided. For example, a holistic evaluation of a young person's need for additional support may consider the appropriateness of buddying to facilitate access to sport and leisure services in the community, alongside medical care, therapy, and support for learning and equipment. The Green Paper proposal for a single statutory assessment process and an 'Education, Health and Care Plan' from birth to 25 promotes a more holistic approach.

Recent advice for local authorities on Short Breaks emphasises the importance of a holistic approach to supporting families:

*'We know that short breaks benefit both disabled children and their parents. Children benefit from new interests, relationships and activities, while parents can catch up with 'everyday activities' (sleep, cleaning, shopping), attend to their physical and psychological wellbeing, and maintain and develop social networks. Short breaks should be used to enhance the ability of parents to care for their disabled child and any other children they may have.'*²⁶

A personalised approach

A personalised approach to planning for families with children with SEND implies flexible provision of additional support tailored to the particular circumstances, preferences and aspirations of families.

'You have to be very creative about the packages you offer. It's about understanding ... the different levels that young people operate at and the comfort zones of parents and carers. Different families want and need different things ... we'll try to keep friends together ... and provide a more inclusive package if that's what the family want.'

Parent and Chair, local voluntary organisation and Short Break Provider

'As part of its Short Break strategy one London borough has piloted a project to develop confidence and promote independent living. Individuals pool part of their self-directed support budgets to promote friendships and develop wider social networks and activities. An independent charity has produced a guide and ... offers support to disabled young people and their families to employ personal assistants to support them in their chosen activities with their chosen friends. Young people ... feel more grown up and able to enjoy the activities without their parents and with the support of a worker ... they have recruited and chosen. This option enables young people to be more in control, to have consistency in support and continuing friendships into adulthood.'

Short Breaks for Carers of Disabled Children: Advice for local authorities

A personalised approach in the context of support provided for young people passing through transition is about planning what kind of life a young person wants. Young people are asked to describe what's important to them and explore the support required to help them achieve their objectives. Young

²⁶ *Short Breaks for Carers of Disabled Children Advice for local authorities*, Department for Education, 2011. <http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20-%20advice%20for%20local%20authorities.pdf>

people are encouraged to retain control over the transition process and feel ownership of their transition plan:

'... transition planning ... can only be effective if a person-centred approach is taken. This means ... the disabled young person is at the centre of the planning process, and that plans are made based on [their] needs and aspirations.'

TransMap: from theory into practice

TSP SAQ returns indicate that person-centred approaches are being used more often, particularly in special schools. Year 2 responses showed that person-centred planning was part of developing transition plans in 88% of local areas; this figure rose to 95% in Year 3. The challenge is to extend the practice of person-centred planning to review processes in mainstream schools, given that:

'... person-centred planning fits nicely into special school environments. They're used to working in an interdisciplinary way ... When you walk into a big mainstream secondary school, I'm not sure that you feel the same vibes ... It's ... a very different learning environment than that provided by special schools.'

TSP Named Adviser

The principle of a single plan

'Services will work together with the family to agree a straightforward, single plan that reflects the family's ambitions for their child from early years to adulthood, which is reviewed regularly to reflect their changing needs, and is clear about who is responsible for provision.'

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

Families, children and young people experience many different assessments for different purposes during the course of their lives. Assessments inform, and should come out of, ongoing discussion and joint planning with families. For example, young people passing through transition may experience an assessment to establish eligibility for support from adult social care, another to ascertain their learning support needs in continued education or training, and another to assess their need for medical care, therapy and/or equipment. To be helpful, these elements need to be brought together into one multi-agency process and should inform a single transition plan that develops from Year 9 onwards.

'The way that professionals work together during the assessment process is crucial. A coordinated approach to gathering information about a child is key if parents are to avoid the frustrating and often distressing experience of having to "tell their story" again and again to different people.'

Together from the Start 2003

ES encouraged better co-ordination of assessment processes for young children, tied into a single process of discussing issues, sharing information and agreeing what to do next. One senior manager reflected on the relevance of experience from the early years to other age groups:

'We all recognise the need for a single plan for transition, but we can't agree yet on how far other processes can be compromised to achieve a single plan ... We're trying to use learning from ES Family Service Plans to say, "This is how you achieve it." The way we deliver Team Around the Child support and Family Service Plans for younger children is 'multiple assessments, but one plan' and it works ... the focus is on planning with and for the whole family. At transition, young people will have a more independent voice supported by their family but a single plan at transition should look similar.'

AHDC Lead and Manager of the Integrated Service for Disabled Children

The power of action points

Joint planning and decision-making is of limited use if it does not lead to the development of an action plan. For this reason, ES Family Service Plans use a standard template focusing on action planning.

'Family Service Plans mean that parents go away with a piece of paper that says, "We will do this, this and this" with dates for delivery. That's been really powerful from the perspective of parents and it's really helped professionals to come together and work more collaboratively.'

Senior Commissioning Manager for Disabled Children and Children with Long Term Conditions

'Care co-ordination for me is about having the Care Plan ... You've got it and you've got timescales. You know who's doing what and when they're doing it by.'

Parent and Chair, Parent Forums

The following comments in the context of transition illustrate the need to keep in mind the basic function of planning as a trigger to action and review:

'When we consulted with people about transition, it became clear that person-centred planning had been in use for some time, but ... had not lead to purposeful action. People viewed it as a piece of paper that somehow exists in addition to the transition plan. We've concentrated on understanding person-centred planning as a process – the manner in which a plan is developed. Whatever you do has to use that approach. It informs the plan, which should have action points.'

AHDC Lead and Manager of the Integrated Service for Disabled Children

'The question should not be how many people have experienced a person-centred process and have a person-centred plan at 14. The questions we should be asking is, "Who's got an action plan?", "Who's got a key worker?", and "What's the tangible outcome of this process?" Someone has to translate aspiration into actions and make things happen in a way that allows everyone to tick things off the list as they are done.'

TSP Named Adviser

Summary

- Greater understanding has developed about the contribution that meeting the support needs of parents, carers and siblings makes to the well-being of children with SEND. In general, the more complex a child's need, the more important it is that a holistic package of support for individuals and families is co-ordinated and managed.
- It is important that families have a single gateway to information, intervention and practical help, and that there are defined pathways through the system. A multi-agency panel can establish a relationship with a family quickly and is able to co-ordinate assessment and intervention.
- An important initiative in recent years has been to define the services families can access without a formal assessment.
- Simplifying access for families with relatively modest requirements allows local authorities to deploy scarce resources where they are most needed.
- Relationships between families and schools are important in establishing a collaborative approach and shared responsibility for supporting children's development.
- A personalised approach for young people passing through transition is about young people being asked to describe what's important to them and then to explore the support required to help them achieve their objectives. Young people are encouraged to retain control over the transition process and feel ownership of their transition plan.
- The Transition Support Programme found that person-centred approaches are being used more often, particularly in special schools. In Year 2 of the programme, person-centred planning was part of developing transition plans in 88% of local areas; this figure rose to 95% in Year 3.

- The challenge is to extend the ethos and practice of person-centred planning to review processes in mainstream schools.
- Families, children and young people experience many different assessments for different purposes. These elements need to be brought together into one multi-agency process and should inform a single action plan.
- Joint planning and decision-making is of limited use if it does not lead to the development of an action plan.

Section 4: Supporting families through the system: key workers and lead professionals

This section considers experience of, and learning from, the use of key workers and lead professionals. The Green Paper proposes to extend training in this area and test the role of key workers in pathfinder areas developing use of 'Education, Health and Care Plans'.

Key worker functions

'Too many parents feel that they are left to negotiate ... a massively complicated system. They don't feel they're given enough information or support. Or ... they're given too much information without the support of someone who could help them understand it ... they're left on their own. Families are overwhelmed, particularly if their child has complex needs and they're seeing lots of people. Having a reliable and consistent point of contact is really important.'

Regional Representative, National Network Parent and Carer Network

The importance of key workers for families and young people who are using a range of support services has been consistently highlighted within national programmes over the last ten years and in research.²⁷

Guidance published in 2009 described the functions that lead professionals or key workers need to carry out to deliver effective integrated support:

- act as a single point of contact for a child, young person or family
- co-ordinate the delivery of actions agreed by a multi-agency team around the child and family
- reduce overlap and inconsistency in services received by children, young people and families.²⁸

Key worker services, sometimes known as care co-ordination services, already operate for children and young people in some local areas on a number of different models. In some places, designated key workers are

²⁷ For example, *National Service Framework for Children, Young People and Maternity Services*, Standard 8 (Department of Health, 2005) and Sloper et al 'Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?', *Child: Care, Health and Development* 32(2), 2006. <http://eprints.whiterose.ac.uk/973/>

²⁸ *The Team Around the Child (TAC) and the lead professional: a guide for practitioners*, Children's Workforce Development Council, 2009. <http://www.cwdcouncil.org.uk/lead-professional>

employed specifically to provide care co-ordination for many families. But whatever model is used, experience indicates that in addition to the functions set out above, it is important for key workers to:

- ensure families, children and young people have all the information they need to make decisions and that they are supported to understand and use information over time
- ensure practitioners and agencies in less regular contact with the family are kept up to date with developments
- provide emotional support and build confidence
- act, occasionally, as an advocate for families.

Key worker and lead professional activity is presented in national guidance in the context of a Team Around the Child (TAC) approach. TAC is an operational mechanism to deliver integrated support in partnership with families and young people. It helps practitioners from different services come together to co-ordinate and deliver solution-focused support. A key assumption of this way of working is that one practitioner will sometimes take on the role of key worker on behalf of the group of practitioners in most regular contact with a family. This 'non-designated' model of provision expects practitioners from different professional disciplines to take responsibility for co-ordinating things in addition to any support or therapy they are already providing. This provides families with greater continuity of support than they might otherwise experience and practical help with co-ordinating and negotiating the system. Their key worker becomes their single point of contact in the sense of being the person they build a relationship with and who they contact, in the first instance, when questions or issues arise.

Key workers for families children and young people with SEND must have appropriate specialist knowledge of disability and local services and an established network of contacts.²⁹

The experience of key working in the early years

The ES programme actively encouraged the development of key worker services for families with children under 5. It provided standard materials to help key workers co-ordinate services and facilitate joint planning with families using a Family Service Plan. One senior manager interviewed in 2010 about the impact of ES reflected:

²⁹ For more background, see the Care Co-ordination Network UK (CCNUK) Key Worker Standards and CCNUK Guide to Key Working in Practice at <http://www.ccnuk.org.uk>

'As an Early Support key worker, you feel empowered to pull the meeting together, because that's your role and certainly there's been ... more people coming together around families since we've used Family Service Plans. We've always had a culture of working together in this area, but now it's more formalised.'

Senior Portage Worker

Parents interviewed for the same project³⁰ emphasised the importance of lead professionals or key workers as single points of contact.

'What it means for me is ... having that one person who's your point of contact.'

Parent

'Families are looking for someone who can co-ordinate everything. As a parent, you have ... to pull everything together and find out what's out there yourself. People are knocking on your door left, right and centre ... It's hard to take each thing on board before you're told about the next thing. You need what's being offered, but it's overwhelming and you don't even know what half the different people involved are for.'

Parent and Face2Face co-ordinator

The critical role of key workers in co-ordinating service delivery was also highlighted:

'To me it's critical that services are family focused ... If a parent's got ... a hospital appointment and they've got three other children and they don't have their own transport that will all have an impact on their ability to attend. It also makes a difference if the time is inconvenient and if there have been three other appointments set up in the same week. This is basic stuff.'

Regional Representative, National Network Parent and Carer Network

'I spent three out of every five days in hospital with various appointments and things, and travelling. I've a younger daughter and so I had to take her along as well. When I had a key worker, we managed to cut that down by a half. It made a huge difference when they were able to make some of the appointments on the same day. Now I can have physio in the morning, see the doctor in the afternoon and get his feet checked in between.'

Parent

³⁰ Support and aspiration: experience and learning from the Early Support programme, Council for Disabled Children, 2011. www.ncb.org.uk/cdc

Sometimes the parents interviewed talked about key working as advocacy and about the importance of the emotional support key workers sometimes provide:

'The weird thing is that you've got all these people involved, yet you feel so alone. When you get a key worker, it feels like there's someone's on your side, fighting your corner if you need them to.'

Parent

'The emotional support's important. Sometimes when your child's poorly, you have to speak to the consultant. I find my voice wobbling. I can't remember what I need to remember. Key workers are more detached.'

Parent

Key working for children of school age

All disabled children should benefit from co-ordinated service planning and delivery from local authorities and their partners, and support to help navigate the system, according to the Green Paper.

In some local areas, the challenge to develop key working hinges on the opportunity to migrate families from a key worker service towards lighter touch lead professional support as children get older. For example:

'In this area we have dedicated key workers for children aged 0-7. The question is how a dedicated key worker can pass the baton on to a lead professional as a child gets older. We've spent quite a lot of time thinking about that ... Each school seems to need its own light bulb moment. Once a head teacher looks at the value of TAC models of intervention, they tend to embrace the approach ... at the moment, the approach is working well in some schools where a more person-centred approach is emerging, but our experience is that the light bulb moment has to happen school by individual school for things to change.'

Senior Commissioning Manager for Disabled Children and Children with Long-Term Conditions

Local areas that have developed key worker or care co-ordination services for children and young people of all ages have found that the issue is about clarifying who needs what and when, and about defining the relationship between key working and core lead professional functions. Focusing on how the support needs of children and families fall across a continuum is a useful starting point (see the figure below).

The continuum underlines the fact that families' need for support varies widely. Families with children and young people with SEND (those represented on the left of the Figure 1) benefit from the model being successfully developed by Achievement for All using structured

conversations. Where a child or young person has multi-agency support requirements in addition to special educational needs (in the middle of the Figure 1), it is likely that light touch help will be required from a lead professional to co-ordinate support and planning. Children and families with the most complex pattern of interaction with additional services (a relatively small number on the right) require more regular contact and support. The need for a key worker grows in proportion to the number of people or agencies involved with a family and in response to changing circumstances.

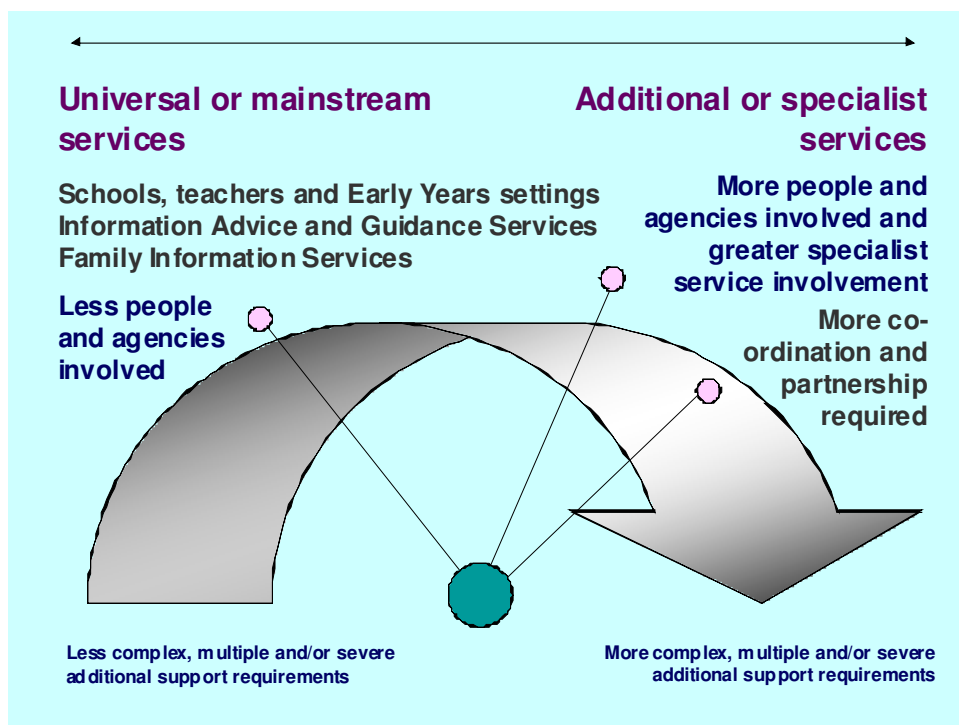


Figure 1.

Many families continue to need help co-ordinating activity:

'Co-ordination is my bugbear – a lot of what I spend my time doing is co-ordinating things that I feel somebody else could quite easily do. My son's just starting at secondary school and I'm sure that some of the other parents wonder what I do with my time. When they suggest I might go back to work, I don't even bother answering. It just isn't possible.'

Parent and Regional Representative, National Network of Parent and Carer Forums

For some families, the need for a key worker varies over time. Therefore, service providers must be able to respond flexibly to the changing types of support that are needed.

'It's critical that we develop a 'step up, step down' approach, where, if there's a crisis, there's a clear pathway to access more intense support, but we can move children and families back down to a lower level of support when needs change. Our job is to enable that journey in and out of higher levels of support.'

Head, Children and Young People's Disability Partnership

The Green Paper creates an opportunity to apply learning in this area more widely and to link service development to the use of Education, Health and Care Plans. It presents an opportunity to identify situations in which key working and joint planning is required and for public services to consider more clearly the relationship between key working, brokerage and information, advice and guidance.

Summary

- Families and young people who are using a range of support services need key workers who can:
 - provide care co-ordination
 - ensure families, children and young people have all the information they need to make decisions and that they are supported to understand and use information over time
 - ensure practitioners and agencies in less regular contact with the family are kept up to date with developments
 - provide emotional support and build confidence
 - act, occasionally, as an advocate for families.
- Key workers for families children and young people with SEND must have appropriate specialist knowledge of disability and local services and an established network of contacts.
- As children get older, services may need to migrate families from a key worker service towards lighter touch lead professional support.
- Local areas that have already developed key worker or care co-ordination services say it is important to clarify who needs what and when, and to define the relationship between key working for children and young people with SEND and core lead professional functions.
- For some families, the need for a key worker varies over time. The system must be capable of responding flexibly to the changing pattern of support that is needed.

Section 5: National programmes as catalysts for change

'The learning from AHDC has been massive. The programme has taught us about better evaluation, better monitoring of projects and better contracts, outlining exactly what is required.'

Head, Children and Young People's Disability Partnership and AHDC Lead

National programmes are able to identify priorities and bring a clear sense of direction to service improvement in local areas. Many of those interviewed spoke positively about the 'national programme effect':

The momentum of national programmes can help secure the engagement and support of senior managers. Many highlighted the opportunity national programmes provide to build on what had already been achieved and to raise the profile of services for children with SEND in their area:

'The national programme has raised the profile of disability ... it's always felt like the poor relation. The national programme has fixed it in people's mind that this should always be a priority. It's also given us an opportunity to identify general themes emerging across the city.'

Local Authority Service Manager for Strategy and Partnership

'I'm always very careful not to use an acronym but to spell out that it's a National Transition Support Programme because, rightly or wrongly, it gives the work more gravitas and underlines that this is a national priority.'

Local Area TSP Lead

Interviewees valued the support received from national programmes like TDC and the TSP. They also emphasised the important contribution of regional meetings and support networks to the success of national initiatives:

'Regional exchange through the national programme has been a huge opportunity to accelerate the speed of change. For example, we've been grappling with ... eligibility criteria and transparency ... and what the full service offer is really asking us to deliver ... We've got immediate access to ten colleagues through the regional network – a couple had already found solutions that we've been able to use and ... we've been able to provide examples that other people have found useful.'

AHDC Lead and Manager of the Integrated Service for Disabled Children

For more information on working across local boundaries see the Year 3 Transition Support Programme Regional Activity Report here: <http://www.transitionsupportprogramme.org.uk/resources/regional.aspx>.

Interviewees also noted the positive influence of increased scrutiny of local working practices associated with national programmes:

'I wanted to be absolutely sure that if we were contributing information about local activity on transition, it should be properly done. If there's a national programme scrutinising what's said, we want to do it right.'

Local Area Assistant Director

'It's important that the national programme has TDC playing a monitoring, support and challenge role and that we've had to report back to central government. Local areas understand that and they've wanted to do a good job.'

TDC Local Programme Adviser

The most candid comment on the influence of national programmes was made in relation to partnership working with families:

'Aiming High has transformed parent participation in this area. The money and breathing space to develop this work was helpful but having the clear directive that things must be done in this way gave us the kick we needed. You know you should do things this way, but we needed a bit of a stick to make us do it.'

Service Manager, Joint Commissioning and Health Strategy

One interviewee described how national programmes had provided the opportunity to extend joint planning and holistic support for families on an ES model up the age range and to develop a single, coherent strategy for integrated service delivery for children and young people:

'We ... knew from the outset we had to develop a framework that would last beyond April 2011 and the national programme gave us the thrust to get it done. It enabled us to develop a strategic overview group with full

multi-agency engagement ... to deliver and oversee different strands of activity. That helped us develop an integrated Disabled Children's Strategy. So we're ending this phase of activity with a strategy in place for 2011-15 that picks up on our local priority themes and that has been signed off by the Children's Trust.'

AHDC Lead and Manager of the Integrated Service for Disabled Children

'Early Support has been used by many local authorities for families with disabled babies or children under 5, but ... clear information and resources, with parents holding the plan for their child's support, is relevant to older children too.'

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

The additional funding that sometimes comes with national programmes significantly increases local capacity to bring about change:

'Aiming High gave us the opportunity to create a development post away from the normal pressures of everyday operational management responsibility and to focus on the issues. Without that additional capacity, we wouldn't have been able to move things forward in the same way. The positive impact of enhanced capacity can't be over-stated.'

Local Area AHDC and TSP Lead

Summary

- National programmes are able to identify priorities and bring a clear sense of direction to service improvement.
- The momentum of national programmes can help secure the engagement and support of senior managers.
- National programmes provide an opportunity to build on what has already been achieved and to raise the profile of services for children with SEND.
- Interviewees valued the support received from national programmes and emphasised the important contribution of regional meetings and support networks to the success of national initiatives.
- Interviewees noted the positive influence of increased scrutiny of local working practices associated with national programmes.
- National programmes provide an opportunity to extend joint planning and holistic support for families and to develop a single, coherent strategy for integrated service delivery for children and young people.
- The additional funding that sometimes comes with national programmes significantly increases local capacity to bring about change.

Section 6: Better data

'Better data and good intelligence are essential elements in thinking through how we can continue to provide services well when we have more restricted resources.'

Local Authority Service Manager for Strategy and Partnership

Particularly significant learning has taken place through the period of the AHDC programme about the value and use of better data, including satisfaction ratings from service users. In 2007, *Aiming high for disabled children* highlighted the patchy nature of information about children with SEND at both local and national level. The following examples from work associated with transition, Short Breaks and childcare services demonstrate the scale of the challenge for some areas:

- In the first year of the TSP, many areas struggled to provide information on the percentage of children and young people attending and participating in their Year 9 Reviews, particularly if they attended mainstream schools.
- In January 2009, information systems were generally not sufficiently developed in DCATCH pilot areas to support a basic benchmarking exercise. It was a challenge for most of the local authorities involved to provide quantitative data on the number of disabled children and demand for childcare in their area.³¹
- Implementation guidance for Short Breaks specified that services should be based on a needs assessment of the local disabled child population, taking into account the voice of disabled children, young people and their families.³² However, many Pathfinder areas reported difficulty working with local systems beset with problems such as incomplete data, voluntary completion and under-resourced collection methods, all of which undermined the accuracy of any data produced.³³

National programmes have led to improved performance in this area, with local areas responding to demands from central government for hard facts in return for investment – in particular, numbers of families, children and young people using services and an analysis of patterns of service use.

³¹ *Disabled Children's Access to Childcare (DCATCH) pilot activity: Information for local Authorities*, Department for Education and National Centre for Social Research, 2009.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01203-2009>

³² *Aiming High for Disabled Children: Short Breaks Implementation Guidance*, Department for Children, Schools and Families and Department for Health, 2008.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00755-2008>

³³ *Short breaks Pathfinder Evaluation*, Department for Education, 2010.

<https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR062>

Development of Short Break services has been monitored through the period of the AHDC programme by annual completion and return of a Local Area Implementation Plan (LAIMP), a planning tool that also enables data collection about provision of Short Breaks and the numbers of children using them. Data has helped local areas to establish a baseline for service provision, decide on priorities for development, and make projections for growth. The LAIMP has also been used for reporting to TDC to demonstrate growth in the number and range of Short Breaks and to explain how national programme resources have been deployed. TDC provided guidance to local areas on collecting a wide range of data to support service development, including:

- population or demographic data
- data on the local disabled children population
- the views of service users (children and families)
- information about existing and potential service provision
- workforce data
- evidence on outcomes.³⁴

Progress on transition in local areas has been monitored in a similar way by annual return of the TSP self-assessment questionnaires (SAQs).

Some local areas have also used a DCATCH Implementation Planning Tool and Benchmarking and Planning Tool to support their work on improving the quality and supply of affordable childcare for families with disabled children. In the case of DCATCH, the collection of better information has been underpinned by a new statutory requirement on local authorities to have particular regard to the provision of services suitable for disabled children when assessing the sufficiency and supply of childcare in their area.³⁵

The demand from national programmes for detailed feedback has been experienced by many local areas as a significant challenge, and described by one TDC regional lead as 'painful but necessary'. However, it has resulted in improved capacity to estimate and analyse data about local population and has changed working practices associated with data collection and analysis.

The following comments indicate how far some local areas have shifted their practice and expectations over the last three years:

'The first time we looked at the data feedback forms we thought, "How can we possibly provide this information? ... We have no idea what this information even looks like." But we soon found out and we got on with it. When I write a statement or number now, I can be confident it's accurate. We're building on that and thinking through what data we need to continue to collect.'

Local Area AHDC Commissioning Officer

³⁴ *Transforming Short Breaks: What information do we need and how should we use it?*, Together for Disabled Children, 2009. <http://www.togetherfdc.org/SupportDocuments/Data%20Collection%20Final.pdf>

³⁵ Introduction - Disabled Children's Access to Childcare (DCATCH) <http://www.togetherfdc.org/DCATCHNew/default.aspx>

'The TSP questionnaire was onerous. I hated every moment of doing it, but it does help you think about where you've got to and where you need to go. We're going to carry on recording everything next year, even though we don't have to anymore.'

AHDC Lead and Head, Children and Young People's Disability Partnership

Linking data collection to commissioning

Looking ahead, one manager commented:

'Having data is essential for planning and commissioning – just knowing your numbers and where they are. We didn't have any of that when we started. As an interim measure we'll continue to collect exactly the same data in the same way, but as we set our own priorities we'll begin to refine our thinking. We need to review it and ask what other areas we can begin to pull in.'

Local Authority Service Manager for Strategy and Partnership

The same theme is picked up in a report from the National Transition Support Team (NTST) in March 2011:

'Many local areas have reflected positively on the experience of completing SAQs as an opportunity to focus minds and review joint working practice. The TSP has responded by developing a version of the SAQ for local areas to continue using in coming years, as part of the TIN TRO [Transition Information Network Transition Resources Online³⁶] resource ... being developed for use by local areas from April 2011. This will be a focus point for information and resources to support the continuing improvement of activity in local areas.'

**National Transition Support Team SAQ 3 Report
March 2011**

Linked to better data and joint working is commissioning that incorporates the following elements:

- understanding and assessing the needs of the target audience
- planning and designing the services
- taking steps to secure services
- monitoring and reviewing services.³⁷

'Taking steps to secure services' covers a wide range of working practices, particularly associated with supporting providers of universal services that

³⁶ Transition Information Network Transition Resources Online (TIN TRO)

<http://resources.transitioninfonet.org.uk/>

³⁷ *Aiming High for Disabled Children: Short Breaks Implementation Guidance*, Department for Children, Schools and Families, 2008.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00755-2008>

are including disabled children and young people for the first time. The following comment sums up the growing confidence and flexibility with which many local areas are now developing their practice:

'We've changed a lot of our contracts with providers along the way in response to information we've had ... from parents and from children and we've tried to share risks so that providers don't feel that they've been just left to get on with it. Voluntary organisations can't be something they're not – they have to grow into things over time. To develop a mixed market, we've had to recognise they have strengths in some areas, but not others and try to work with the strengths. We don't want to set new providers up for failure, particularly if they're a small organisation and so we've opened up conversations, expecting them to develop over time.'

AHDC Commissioning Officer

Another substantial learning point has been that providers can make a key contribution to collecting feedback from families on outcomes and the quality of provision experienced. This point relates to effective monitoring of services and to collection of more accurate information about local service provision. A TDC regional adviser recommended a model for collecting feedback to inform an analysis of the impact, quality and cost effectiveness of services involving both direct feedback from families using the parent and carer forum (where appropriate) and information supplied by Short Break service providers.

Critically, one commissioning manager talked about building a requirement to collect feedback from children, young people and families who use services into contracts:

'Historically, contracts on both NHS and local authority sides have focused on activity and the question, "What have you done?" rather than "How do you know it's made a difference?" When you introduce more qualitative performance measures into service specifications, those services cannot deliver performance data without engaging parents and children. That's important, because you can say, "We want children and parents to be actively involved in the transformation of services", but it's just words unless you feed that perspective into contracts.'

Senior Commissioning Manager for Disabled Children and Children with Long-Term Conditions

Summary

- Particularly significant learning has taken place through the period of the AHDC programme about the value of better data, including satisfaction ratings from service users, numbers of families, children and young people using services and an analysis of patterns of service use.
- Development of Short Break services has been monitored through the period of the AHDC programme. Data has helped local areas to establish a baseline for service provision, decide on priorities for development, and make projections for growth.
- Progress on transition in local areas has also been monitored.
- The demand from national programmes for detailed feedback has been experienced by many local areas as a significant challenge, but it has resulted in improved capacity to estimate and analyse data about local population and has changed working practices associated with data collection and analysis.
- Commissioning that incorporates understanding and assessment of families' needs is an important element in developing better data.

Section 7: Workforce development and training

This report considers training associated with:

- developing better communication and partnership working with families using ES and the 'structured conversation' developed by Achievement for All
- increasing the capacity of universal service providers to meet the needs of families with disabled children, including the need for appropriate information
- developing person-centred approaches to planning and working with young people
- supporting parents and carers to develop the skills they need to participate in the shaping of services and/or run a parent and carer forum, and also involving parents in training with and for professionals.

Developing better communication and partnership working with families

'Training in working with parents needs to be available to those already in service who have regular contact with parents of disabled children and children with SEN, in particular:

- *local authority officers working in SEN sections;*
- *teachers in their induction;*
- *SENCOs, through the training developed for them;*
and
- *a wide range of professionals.*

Special Educational Needs and Parental Confidence: Lamb Inquiry Final Report

Accredited and non-accredited training was developed by ES to support professional agencies in developing this way of working and has been regularly updated since 2005. The following quote from the introduction to training materials gives a flavour:

'Practitioners in this field have to appreciate that helping is part of a process where the helper comes to understand what the situation looks and feels like to the parent. This may involve a change in the helper's construction of the situation... The training focuses on an approach that:

- *takes a holistic view of the child's and family's needs*
- *focuses on working in partnership with the family, to identify and address needs*
- *uses resources on an appropriate, timely and family-focused manner*
- *shares information where relevant and appropriate.*

Working in Partnership through Early Support: Trainer's Guide

ES training is widely used and is of renewed relevance in the light of the Green Paper proposal to extend use of ES to families with school-aged children.³⁸ Some areas have already extended use of this training up the age range, others are thinking of doing so:

'Another thing we've been thinking about recently is the need for that Working in Partnership course to be delivered up the age range. Our aim is to get the philosophy of multi-agency working in partnership with parents embedded across the system.'

Senior EP Head of Early Years Pre-School Teaching, Portage Early & Support

One Achievement for All lead reflected on the importance of training that focuses on the skills needed by schools to build and maintain better communication and better relationships with families:

'Newly qualified teachers have responded particularly positively to structured conversation training. They need to know what the purpose of a meeting is. Is it to provide an update or to get down to agreeing the next steps for a child's learning? Teaching staff feel better equipped going into meetings with parents because they've got a structure to work to. That's important for the training schools provide for their staff and it also has implications for initial teacher training.'

Local Area Achievement for All Lead

³⁸ Support and aspiration: A new approach to special educational needs and disability Section 2.10. Department for Education 2011.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027>

Increasing the capacity of universal services to provide for additional needs: Short Breaks and childcare

The evaluation of Short Break pathfinders reported that:

'A number of factors can be identified that are important components of inclusion ... Firstly, investing in the workforce – both the mainstream workforce who are not accustomed to working with disabled children and elements of the disabled children's workforce who have worked for many years from a presumption of separation.'

Short breaks pathfinder evaluation

Many interviewees talked about this aspect of development activity. Activity has been intense, as the following comment indicates:

'As part of Short Breaks activity, we developed an extensive capacity building and training programme working in partnership with a range of training organisations. We started by asking universal service providers what would make a difference and then brought together the trainers, parents and carers and universal services and developed a training programme. Young people with disabilities have been directly involved in the delivery of training. To date more than 600 training courses have been delivered and the reach across the county has been extraordinary – people from very diverse backgrounds have participated.'

Local area AHDC Lead and Disabled Children's Services Manager

TDC recently published materials to support strategic planning for workforce development. The materials promote the idea of 'core training' to inform attitudes and expectations and build the following skills and attributes needed by all Short Break workers:

- knowledge of the social model of disability and how society creates barriers to inclusion for disabled children and their families
- a positive attitude towards disability, reflecting that disabled children have the same rights to opportunity, inclusion, fun and achievement as all children
- open-mindedness and a solution-focused approach to removing barriers, with an ability to challenge traditional expectations
- the skills to develop open, supportive and respectful relationships with parents and carers as well as children.
- readiness to learn about a disabled child's skills and talents and what a child has to offer, as well as learning about their individual support needs, including specific medical needs
- willingness to undergo and use relevant training in any child or young person's preferred method(s) of communication

- responsiveness, flexibility and an ability to adapt to families' changing circumstances.³⁹

National guidance on workforce development requirements associated with the DCATCH initiative covers similar ground, directing local authorities to secure training for universal providers in the following areas:

- disability equality, attitudinal barriers and the importance of developing positive attitudes to meeting the needs of disabled children and children with disabled parents
- the SEN Code of Practice and the role of the Early Years SENCO
- ES approaches to working with disabled children and their parents, and with other agencies, including the use of key workers, to ensure effective, flexible, joined-up services that put children and their families at the centre
- specific conditions – eg, autistic spectrum disorders, cerebral palsy, sensory impairments, or speech and language difficulties.⁴⁰

Training mainstream service providers is a major theme of the process evaluation for DCATCH pilot areas. The evaluation identifies the following success factors for effective workforce development:

- reducing barriers to accessing training (providing training free of charge and at a time preferred by childcare staff)
- providing incentives, for example, in the form of kite marks linked to Inclusion Quality Standards
- continuity of ongoing support from the same person rather than one-off training (so there is someone you know at the end of a phone if you need them)
- designing training to fit the audience, which means bespoke training written with the particular needs of providers of Short Breaks and childcare in mind.⁴¹

As with other aspects of service development, success has been associated with a flexible and open approach. One interviewee explained:

'We've provided a menu of training, according to ... the needs of provider organisations ... Some has been condition specific – basic awareness and then training on associated strategies. We've also linked them into inclusive play and leisure training ... for example, about how to keep young children safe but also challenge them to get outdoors and try new things.'

AHDC Commissioning Officer

³⁹ *Planning and Developing the Short Breaks Workforce*, Together for Disabled Children, 2011. <http://www.togetherfdc.org/SupportDocuments/Planning%20and%20Developing%20the%20Short%20Breaks%20Workforce.pdf>

⁴⁰ *Securing Sufficient Childcare: Guidance for Local Authorities Childcare Act 2006*, Department for Children, Schools and Families, 2007. <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00600-2007>

⁴¹ *Disabled Children's Access to childcare (DCATCH): Process evaluation of participation and workforce development activity in the DCATCH pilots*, Department for Education, 2010. <https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR013>

Increasing the capacity of universal services to provide for additional needs: information, advice and guidance services

Training is a core component of supporting Family Information Services (FIS) to extend their remit and meet statutory responsibilities to provide information about childcare for families with disabled children. One DCATCH pilot area created a new FIS post to skill up other FIS advisers and provide dedicated information and support for families who were finding it hard to find appropriate childcare. Creating the post was also the means to identify a point of contact for childcare providers looking for information about how best to include children, at the same time as establishing a new brokerage service for families with disabled children.⁴²

Workforce development to improve the capacity of information, advice and guidance (IAG) personnel to work with young people with SEND has been a similar focus of attention for the TSP programme. Most local areas report that IAG advisers who work regularly with special schools and with young people included in mainstream schools at School Action and School Action Plus receive training on statutory and mandatory aspects of service delivery (the SEN Code of Practice and the Equality Act) and on person-centred planning. They often undertake additional training on Direct Payments and welfare benefits and have the opportunity to participate in additional training provided for other professionals working with children or young people with disabilities.

Some local areas provide a specific training course for IAG advisers specialising in providing a service for young people with SEND:

'Our specialist personal advisers have attended a three-day accredited course in working with disabled young people. The course covers: policies and initiatives relating to disabled young people; the role of professionals working with young people; assessment and planning with disabled young people; transition and transition planning; supporting disabled young people's aspirations.'

TSP SAQ 2 Local Area

Person-centred approaches

Person-centred approaches to planning and working with young people have provided a key focus for workforce development. The scale of activity in some local areas is indicated by the following comment:

'Multi-agency training has taken place across the authority, focusing initially on the special school population. This has

⁴² *Disabled Children's Access to Childcare (DCATCH) pilot activity: Information for local authorities*, Department for Children, Schools and Families, 2009.
<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01203-2009>

involved some 240 professionals whose responsibility it will be to cascade the principles of person-centred planning and promote the use of the transition protocol. Some special schools are receiving more extensive training using the materials promoted through the Getting a Life project. In schools that have received this additional training, activity will be maintained through teaching and learning meetings and departmental meetings. Training is currently being planned for mainstream school SENCOs. It is anticipated that Connexions will take a lead role in this training, which will need to be carefully planned, as there are more than 200 mainstream secondary schools in the authority. PCP training has also been cascaded to social care services by the Learning Disability Teams and trained trainers.'

TSP SAQ 2 Local Area

Introducing a service-user perspective into training for professionals

A growing number of parent trainers now work alongside professionals or deliver training to other parents and to professionals on their own. For some local areas this is an expression of encouraging and modelling increased participation by families in the shaping of services.

The ES programme developed training for professional practitioners and for parents/carers through a process of consultation. From the start, the programme encouraged families who used services to participate in training alongside professionals and to contribute to the development of training materials. This approach, described by one Director of Services as 'ahead of its time' added obvious value, particularly in the context of promoting a model of partnership working with families.

'Leadership and influence coming from the families and young people who use services are key. Time and time again, the evaluations that come back about workforce development say, "Yes, that was good, but the penny dropped when that mother got up to speak." That's when the light bulb goes on and the penny drops.'

Local Area AHDC and TSP Lead

'It's not just about having parents co-presenting training, it's about parents participating in training alongside professionals. You need parents there to grow partnership and participation. The benefit cuts both ways. Parents get a better understanding of how much professionals want change to happen and the things that get in the way and slow things down. Everybody gains.'

Senior EP and Head of Early Years Pre-School Teaching, Portage & Early Support

Parents/carers have also been successfully involved in many local areas in the development and delivery of training for providers of Short Breaks and childcare services. The following comments are indicative:

'The Parent and Carer Forum has written disability awareness training with the local authority. It's delivered by a member of staff ... with a parent or a young person and the way in which it's done is important. It's not emotive. It's not accusatory. It's matter-of-fact. It's gone really well and we continue to get a lot of requests for the training. It makes a huge difference to have people who use services there. It's always the parent's contribution or the young person's contribution that changes hearts and minds and the examples that are used are real. We can't say, "Oh well, we're not like that here, we're better than that." These things happened recently and here.'

**Head of Integrated Services for Disabled Children and C4EO
Sector Specialist**

Summary

- ES training is widely used and is relevant for use with families with school-aged children.
- It is important that training focuses on the skills needed by schools maintain better communication and better relationships with families.
- Continued workforce development is needed to further increase the capacity of universal services to provide for additional support needs of families of children and young people with SEND, including information, advice and guidance.
- Person-centred approaches to planning and working with young people have provided a key focus for workforce development.
- A growing number of parent trainers are working alongside professionals or deliver training to other parents and to professionals on their own.

Section 8: Leadership

Many interviewees highlighted the importance of effective leadership of local activity as a determining factor in the success or failure of work programmes for particular groups:

'Leadership is key. Transition leads must have the power and authority to work across services and agencies and the vision and energy to take other people with them.'

TSP Named Adviser

'Achievement for All has been most successful in schools where it's been wholeheartedly embraced by leadership and management. All schools have a project lead but where you see amazing practice developing is where you have direction from the top...'

Local Area Achievement for All Lead

'If I think about the places where things have moved on, it's usually someone who really understand the issues who has a defined strategic development role that has been able to progress things. Areas that don't have a post or a person like that often struggle.'

TSP Named Adviser

Capacity to lead

National programmes characteristically require each local area to nominate a named adviser or lead for activity. Advisers who work with many different local areas are particularly well placed to reflect on the importance of effective leadership at operational level. They talk about the positive impact of:

- clearly defined responsibilities, linked to a clear vision
- support from strategic managers
- appropriate knowledge and experience.

A TDC regional adviser made the same point when reflecting that local areas have done well where the people leading developments have had the time to do the job and the skills needed to manage the planning and delivery of service change. She elaborated by listing the characteristics of effective operational managers leading the development of Short Breaks in local areas:

- good people skills, because service improvement depends on building relationships and partnerships
- good project management skills, meaning an ability to make things happen, plan activity well and maintain an overview of activity

- good commissioning skills and a realistic understanding of how long it can take to commission new services
- a good understanding of data to arrive at a clear assessment of need and vision for service improvement
- an ability to evaluate the quality, cost-effectiveness and impact of service changes and develop markers of quality for families and the local authority and partners.

Leading by example

Another key theme emerging from interviews is the importance of leading by example, relating to the leadership qualities of managers, particularly in the context of developing multi-agency cooperation and working practices, and partnership working with families and participation. For example, the following comment reflects on the impact of ES on the development of multi-agency working practices:

'What works is having champions for particular agendas. There've been a number of times when we've wanted to move on something and we've tried to do it through a steering group of some kind ... But if the person involved is skilled enough to model the behaviour that's required, and to empower other people to do it – that's what the work needs.'

Director of Children's Services

'The attitude of professionals in leadership roles and whether the Forum has access to them is a critical factor in success.'

Regional Representative, National Network of Parent and Carer Forums

'It's critical that the person leading the development of parent participation from the service side is open minded and leads by example. They need to involve a range of other managers and make sure that everyone who needs to be engaged is involved. They open the door to parents and carers and enable them to be much more proactive and positive. That's where the positive attitude from parents of, "How can we help? How can we contribute?" comes from.'

Local Area Parent and Chair of local organisation providing Short Breaks

Summary

- Effective leadership of local activity is an important determining factor in the success or failure of work programmes.
- National programmes characteristically require local areas to nominate a named adviser or lead for activity.
- Advisers who work with many different local areas are well placed to reflect on the importance of effective leadership at operational level.

- Local areas have done well where the people leading developments have had the time to do the job and the skills needed to manage the planning and delivery of service change.
- A key theme emerging from interviews is the importance of leading by example, particularly in the context of developing multi-agency cooperation and working practices, and partnership working with families to grow participation.

Section 9: Multi-agency engagement: strategic planning and the management of change

'It's important that people in leadership roles are able to "think multi-agency" and translate vision into a robust strategy.'

TSP Named Adviser

National programmes over the last few years have highlighted the multi-agency nature of additional support that many children and young people with SEND require and the multi-agency nature of engagement at strategic level required to plan and manage service change.

In the development phase of the ES programme, local areas were advised to bring together a multi-agency steering group to oversee developments for children under 5 and their families. Many areas established a similar high-level group to oversee and manage Short Breaks and other aspects of the AHDC programme. The need for such a group to develop and agree multi-agency protocols and pathways was also a particular focus for the TSP. An adviser with experience of working with many different local areas commented:

'It's important that when senior managers engage, they form some sort of multi-agency board or steering group. It's about taking transition seriously and driving a development plan that identifies exactly what's going to be developed. Boards or steering groups feature in all the places I can think of that are doing really well and if I think about the local areas that perhaps could have done better I think not having such a group has been an important factor holding them back.'

TSP Named Adviser

In some areas, learning from this aspect of TSP has been particularly significant:

'We've learnt from the Transition Support Programme to focus on getting everyone around the Transition Strategic Planning table. To begin with, people weren't even there to have a debate with but now they're hearing what young people need them to become.'

AHDC Lead and Manager of the Integrated Service for Disabled Children

High-level multi-agency engagement is an obvious prerequisite for decision-making that will impact across more than one agency or affect a number of different teams. A key learning point from the last few years is the need to sustain such high-level multi-agency engagement beyond the life of the AHDC programme, in order to:

- maintain focus on continued service improvement for children with SEND
- plan and implement better co-ordinated provision for families who use a range of additional support services
- maintain credibility and integrity with families and young people as joint planning incorporating a service user perspective is further developed.

Summary

- National programmes over the last few years have highlighted the multi-agency nature of additional support that many children and young people with SEND require.
- Many areas have established a multi-agency steering group to oversee and manage Short Breaks and other aspects of the AHDC programme.
- A key learning point is the need to sustain high-level multi-agency engagement beyond the life of the AHDC programme in order to maintain focus on continued service improvement for children with SEND, plan and implement better co-ordinated provision for families, and maintain credibility with families and young people as joint planning incorporating a service user perspective is further developed.

Reference list

Children's Workforce Development Council, *The Team Around the Child (TAC) and the lead professional: a guide for practitioners*, 2009.

<http://www.cwdcouncil.org.uk/lead-professional>

Department for Children, Schools and Families, *Achievement for all the structured conversation: handbook to support training (National Strategies)*, 2009. <http://dera.ioe.ac.uk/2418/>

Department for Children, Schools and Families, *Aiming high for disabled children: better support for families*, 2007.

<https://www.education.gov.uk/publications/RSG/publicationDetail/Page1/PU213>

Department for Children, Schools and Families, *Aiming High for Disabled Children – Core Offer*, 2008.

Department for Children, Schools and Families, *Disabled Children's Access to Childcare (DCATCH) pilot activity: Information for local authorities*, 2009.

<https://www.education.gov.uk/publications/eOrderingDownload/DCATCH-Report.pdf>

Department for Children, Schools and Families, *Duty to provide information, advice and assistance: Guidance for local authorities - Childcare Act 2006*, 2008.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00943-2007>

Department for Children, Schools and Families, *FIS Development Support Tools: Widening the Information Offer*, 2009.

Department for Children, Schools and Families, *Securing Sufficient Childcare: Guidance for Local Authorities Childcare Act 2006*, 2007.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00600-2007>

Department for Children, Schools and Families, *Special Educational Needs and Parental Confidence – Lamb Inquiry - Final Report*, 2009.

<http://www.education.gov.uk/childrenandyoungpeople/sen/sen/types/a0063735/lamb-inquiry-special-educational-needs-and-parental-confidence>

Department for Children, Schools and Families/Department of Health, *Aiming for Disabled Children: Short Breaks Implementation Guidance*, 2008.

<http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20implementation%20guidance.pdf>

Department for Education, *Disabled Children's Access to childcare (DCATCH): Process evaluation of participation and workforce development activity in the DCATCH pilots*, 2010.

<https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR013>

Department for Education, *Early Support Service Audit Tool*, 2nd edition, 2009

<http://media.education.gov.uk/assets/files/pdf/e/early%20support%20service%20audit%20tool%202009.pdf>

Department for Education, *Short Breaks for Carers of Disabled Children: Advice for local authorities*, 2011

<http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20-%20advice%20for%20local%20authorities.pdf>

Department for Education, *Short breaks pathfinder evaluation*, 2010.

<https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR062.pdf>

Department for Education, *Support and aspiration: A new approach to special educational needs and disability – A consultation*, 2011.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027>

Department for Education and National Centre for Social Research, *Disabled Children's Access to Childcare (DCATCH): Process evaluation of participation and workforce development activity in the DCATCH pilots*, 2010.

<https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR013>

Department of Health, *National Service Framework for Children, Young People and Maternity Services*, 2004.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089101

National Transition Support Team, *TransMap: from theory into practice*, 2009.

http://www.transitionsupportprogramme.org.uk/pdf/TransMap_Final.pdf

Sloper P, Greco V, Beecham J and Webb R, 'Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?', *Child: Care, Health and Development* 32(2), 2006.

Together for Disabled Children, *Is the voice of the child having an impact on the development of short breaks for disabled children?*, 2010.

<http://www.togetherfdc.org/SupportDocuments/DCYPParticipationResearch.pdf>

Together for Disabled Children, *Planning and Developing the Short Breaks Workforce*, 2011.

<http://www.togetherfdc.org/SupportDocuments/Planning%20and%20Developing%20the%20Short%20Breaks%20Workforce.pdf>

Together for Disabled Children, *The How To Guide on Parent Participation*, 2010.

<http://www.togetherfdc.org/SupportDocuments/How%20to%20Guide%20PP%20FP%20Intro%20Ackn.pdf>

Together for Disabled Children, *Transforming Short Breaks: What information do we need and how should we use it?*, 2009.

<http://www.togetherfdc.org/SupportDocuments/Data%20Collection%20Final.pdf>

Transition Support Programme, Year 3: Report from the Self Assessment Questionnaire Analysis, 2011.

<http://www.transitionsupportprogramme.org.uk/pdf/TSP%20SAQ%203%20Report%20-%20March%202011.pdf>

Young People and Their Families Together for Disabled Children, *How parent participation and Parent and Carer Forums Lead to Better Outcomes for Disabled Children*, 2011.

<http://www.togetherfdc.org/Topics/ParentalParticipation.aspx>

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. CDC is a semi-independent council of NCB, and has a staff team reporting to its director. The CDC Council is made up of a wide range of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations. CDC hosts the following networks;

- The National Parent Partnership Network
- The Special Educational Consortium
- The Transition Information Network
- The Every Disabled Child Matters Campaign
- Making Ourselves Heard

© NCB 2011



National Children's Bureau
8 Wakley Street
London EC1V 7QE

tel +44 (0)20 7843 6000
fax +44 (0)20 7278 9512

Registered Charity Number 258825

Useful numbers

Book Sales: 0845 458 9910
Conferences and Training: 020 7843 6041
Fundraising: 020 7843 6329
Library and Information Services: 020 7843 6008
Membership: 020 7843 6080
Young NCB: 020 7843 6099

www.ncb.org.uk