

Department for **Education**

Short Breaks for Carers of Disabled Children

Advice for local authorities

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Executive Summary

About this advice

The Government has now published proposals of reform in the education and health support for disabled children and young people and children with special educational needs. Short breaks for children and carers feature throughout the consultation document.¹

The Government has already announced a continued investment in short breaks by providing over £800 million over the 2011 to 2015 period as part of the Early Intervention Grant.

Local authorities, therefore, may find it helpful to consider the following non-statutory advice within the context of the Green Paper proposals.

This first section of the advice is intended to give an overview of the legal position in relation to the Breaks for Carers of Disabled Children Regulations 2011 and then provide examples of good practice which have been developed over the period 2008 to 2011.

This is non-statutory advice from the Department for Education. It has been produced to help local authorities understand how to fulfil their duties under the Children Act 1989 and the Breaks for Carers of Disabled Children Regulations 2011. In this document, these Regulations are referred to as “the Short Breaks Regulations”.

Who is this advice for?

This advice is for local authorities.

Legal context

The Short Breaks Regulations provide further detail on how local authorities must perform their duty in the Children Act 1989 (“the 1989 Act”) to provide, as part of the range of services they provide for families, breaks from caring for carers of disabled children to support them to continue to care for their children at home and to allow them to do so more effectively. In summary, the Short Breaks Regulations require local authorities to do three things:

- to ensure that, when making short break provision, they have regard to the needs of different types of carers, not just those who would be unable to continue to provide care without a break;

¹ Support and Aspiration: A new approach to special educational needs and disability – A Consultation

<http://www.education.gov.uk/childrenandyoungpeople/sen/a0075339/sengreenpaper>

- to provide a range of breaks, as appropriate, during the day, night, at weekends and during the school holidays; and
- to provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.

Summary of advice

Local authorities must:

- provide a range of short breaks services;
- give families the choice to access short breaks services using a direct payment;
- publish a statement of their short breaks services on their website;
- keep their short breaks statement under review;
- state in their short breaks service statement the range of short breaks services available, the criteria by which eligibility for services will be assessed, and how the range of services is designed to meet the needs of families with disabled children in their area;
- consult parents as part of the review of the statement;
- consider the legal implications of the eligibility criteria they apply to short breaks services; and
- not apply any eligibility criteria mechanistically without consideration of a particular family's needs.

Local authorities should ensure that:

- short breaks are reliable and regular to best meet families' needs;
- local authorities should try to reach groups of parents who may be more difficult to engage;
- parents are engaged in the design of local short breaks services;
- short breaks can build on and be offered by universal service providers;
- they are working in partnership with health services to understand the range of short breaks services in their area and to train the workforce;
- short breaks promote greater levels of confidence and competence for young people moving towards adult life;
- local authorities should ensure that those who use short breaks services have the chance to shape the development of those services; and
- they continue to develop their workforce in relation to short breaks services.

The following represents key areas of good practice which have been developed over the Aiming High for Disabled Children short breaks

programme.²

It is good practice for local authorities to ensure that:

- a "local offer" is considered in order to provide families with access to some short breaks services without any assessment;
- formal assessment of families' needs leads to a tailored package of services for them;
- in preparing the short breaks services they have thought about how best to share information about disabled children between agencies within existing data protection requirements;
- they have considered working together with partners to ensure strategic sign-off and shared accountability locally for the statement and the services it refers to; and
- commissioning is leading to more responsive short breaks services.

Related legislation

- Section 10 of the Children Act 2004 provides the legal basis for partnerships working across local authorities, health authorities and other relevant parties. These may be used for the planning and delivery of short breaks services.
- Section 6 of the Carers and Disabled Children Act 2000 ('the 2000 Act') places local authorities under a duty to carry out an assessment of a carer's needs in certain circumstances.³ When assessing a carer's needs under these provisions the local authority must take account of whether the carer works or wishes to work, undertakes or wishes to undertake education, training or any leisure activity. The local authority must take this assessment into account when deciding what services (such as short breaks) to provide under section 17 of the 1989 Act. For further guidance on undertaking integrated assessments of the needs of the child and family, please refer to guidance on short breaks issued as part of the Care Planning, Placement and Review Statutory Guidance.⁴

The other provisions listed here relate to the services which local authorities must provide to disabled children in addition to short breaks:

² Aiming High for Disabled Children was set up as a transformation programme for Disabled Children and their families during 2008-2011 more information can be found at <http://www.education.gov.uk/childrenandyoungpeople/sen/ahdc>

³ Section 6 of the 2000 Act requires local authorities to carry out an assessment (i) where the carers are providing a substantial amount of care on a regular basis; (ii) they request such an assessment; and (iii) where the local authority is satisfied that the child and family are persons for whom it may provide services under section 17 of the 1989 Act.

⁴ <http://www.education.gov.uk/childrenandyoungpeople/families/childrenincare/a0065502/care-planning-for-looked-after-children-and-care-leavers>

- Local authorities are required to ensure their services are accessible to disabled people, to promote equality for disabled people, and to encourage their participation in public life. The scope of the Equality Act 2010 to extend to schools and other public authorities.
- Local authorities are required to secure sufficient childcare to meet the requirements of parents in their area to enable them to work, or to take up training and educational opportunities which could lead them to work.⁵ When determining whether the provision of childcare is sufficient, local authorities must have regard to the needs of parents in their area for the provision of childcare which is suitable for disabled children.⁶
- Local authorities must also make sure they provide information about local services for children, including specifically families with children with special educational needs and/or disabilities. Local authorities must be proactive in the way they disseminate information about children's services, rather than waiting for families to ask.
- Local authorities are required to ensure disabled young people aged between 13 and 25 have access to sufficient educational and recreational leisure-time activities which are for the improvement of their wellbeing.⁷

⁵ Section 6 of the Childcare Act 2006.

⁶ The Disabled Children Access to Childcare programme funds to local authorities to support the development of childcare for disabled children.

⁷ Section 507B of the Education Act 1996.

1. Who should be considered for access to breaks from caring

- 1.1 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 not just be there for those at crisis point

- 1.2 Short breaks should be used to enhance the ability of parents to care for their disabled child and any other children they may have. In performing its duty under the Short Breaks Regulations, the local authority will need to consider a broad spectrum of families and family circumstances – families should not have to reach crisis point before they receive a short break.
- 1.3 Local authorities should carefully consider the needs of the parent and should look out for signs that a short break is needed. It is likely that short breaks will have a positive impact where a carer is:
- unable to attend regular training, education or leisure activity because of the level of care required by the child;
 - unable, or limited in their ability, to provide care for other members of the family or attend to maintenance of the household because of the care needed by the child;
 - struggling to find the capacity to care for the disabled child without a short break; and
 - where the provision of short breaks would clearly enable a carer to provide more effective parenting and care.

'For some parents the provision of short breaks simply means the difference between being able to cope with their disabled child and not being able to cope.'

(A report on Themes Emerging from the Qualitative Research into the Impact of Short Break Provision on Families with Disabled Children
Centre for Disability Research, December 2009)

Access to short breaks must not be judged on impairment alone

- 1.4 Impairments vary in severity and their impact on family life. Caring for children with profound and multiple disabilities, complex health needs and challenging behaviour may be particularly demanding for families. The impact, particularly on the health and wellbeing of carers and

brothers and sisters, is hugely variable and will strongly influence the determination of need.

- 1.5 The Framework for the Assessment of Children in Need and their Families provides the statutory guidance for local authorities to assess the impact of any disability on family life by considering:
 - the child's developmental needs;
 - the parents' parenting capacity; and
 - family and environmental factors.⁸
- 1.6 Local authorities have a duty to assess the needs of carers taking account of their wish to undertake work, education, training or leisure activities. Parents often report how highly they value opportunities to participate in ordinary everyday activities. It enables them to overcome the social isolation and stresses often associated with having a disabled child. Having a break from caring responsibilities reinforces the long-term resilience of families to continue to care for disabled children.
- 1.7 The impact of a child's disability on their siblings must be an integral part of the family's assessment. One of the most frequently mentioned benefits to families of a short break for their disabled child is time to attend to the needs of their non-disabled children.

Local Offer

- 1.8 A local offer presents a choice of short break opportunities to families. It can enable local authorities to direct resources to services, rather than funding unnecessary assessments. Families accessing a local offer are not subject to any additional assessment by the local authority, and instead provide existing evidence of a disability. In some local authorities, disabled children are all registered, and all those registered can access the local offer. In others, families already registered with health or other local authority services relating to their disability are able to access a local offer.
- 1.9 An advantage of the local offer approach is that families can refer themselves to these services. The child's eligibility has already been determined and is generally well known to one or more services, for example through attendance at a child development centre or specific educational provision. Families often find the local offer accessible and in keeping with their wish to lead lives which are as ordinary as possible. They will often not need or wish to have an additional assessment. This allows local authorities to deploy scarce resources for assessment where they are most needed.

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http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4003256

The local offer in Wiltshire has been designed to let families choose the type of short break that works best for them. Wiltshire has published a leaflet setting out who can access the local offer, what short break services are available and how to register.

www.wiltshire.gov.uk

In Enfield the local offer was devised in the light of extensive consultation with disabled children and their parents whose views are at the heart of local developments.

http://www.enfield.gov.uk/info/200012/children_with_disabilities_and_special_educational_needs/1050/enfield_joint_service_for_disabled_children

2. The range of short breaks the local authority must provide

2.1 Local authorities must provide a range of short break services.

The range of short breaks

2.2 Local authorities should enable carers of disabled children to have breaks from caring by providing, as appropriate, a reliable range of services. The local authority should secure, as appropriate:

- a) Provision of day-time care for disabled children in both their own homes and elsewhere, including befriending, sitting (for example where someone is commissioned to look after a child who for example cannot leave home) and sessional services;
- b) Provision of overnight care for disabled children in both their own homes and elsewhere;
- c) Provision which will enable disabled children to participate in educational and recreational activities; and
- d) Emergency care, for example, due to illness in the family. If the emergency relates to safeguarding concerns the guidance in Working Together must be followed.⁹

Together for Disabled Children found that:

“An analysis from seventeen self-selected areas provides overwhelming evidence that lead us to conclude that the development and delivery of a wide range of short breaks has led to a reduction in the number of disabled children and young people becoming ‘looked after’. All the participating areas stated that the short breaks programme had enabled them to focus on early identification and support and as a result disabled children and young people are no longer requiring emergency and long-term looked-after placements at the level they were before Aiming High for Disabled Children. This, of course, has led to some significant cost savings across a range of services, and these are analysed in depth within the report.”

While this study is not representative across the country it provides a number of case examples where savings have been identified as a result of investment in short breaks as a preventative service.

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

Short breaks should be culturally appropriate

2.3 Short break provision should be culturally appropriate so that it meets the racial, cultural, linguistic and religious needs of disabled children

⁹ <http://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00305-2010>

and their families. The information about short break provision should be provided in community languages and accessible formats. Evidence suggests that families with disabled children from particular ethnic minorities are less likely to access short breaks and other support, so it is important that local authorities find ways to reach those families.

'Bollywood' comes to town

Bollywood movies are very much part of the South Asian family culture in Bolton. Families get together and make a night of it, but families with disabled children have often found it difficult to go to the local cinemas together.

Usually one parent or family member has stayed behind with the disabled child, meaning they've both missed out on a fun opportunity. Families said they wanted somewhere they could all enjoy the movies together 'without being judged by the public', not worrying about their children running around or not having to sit in the front row.

In December 2009 the resource worker organised a Bollywood night. An events room at a local restaurant was set up as a cinema space and nine families attended its premier event, with some additional support on hand. A good night was judged to be had by all. This has become a popular monthly event and a new venue is being sought to meet the demand for more space.

Council website is: www.bolton.gov.uk

Paul McGinney, Commissioning Manager from Durham, said:

Our short break programme has delivered not what we thought people needed, but what people actually wanted. As a result we have delivered a hugely successful programme at a low cost per unit price. We have supported more families and made progress on our strategy of reducing high cost residential places. If we reduce just one place per year a saving of around £220,000 will be made. As disabled children currently in residential placements move to adulthood we will see a real reduction in placement costs of potentially £500,000. In consultation with parents we have invested substantially in a broad range of short breaks based in the voluntary sector. This has already reduced the number of placements made in crisis and the costs of formal assessments. If we can develop this trend we are confident, and research supports this, that we can reduce our high costs cases substantially.

<http://www.durham.gov.uk/Pages/Service.aspx?ServiceId=1173>

2.4 While each area will make its own decisions about the appropriate range and balance of different types of short breaks to meet local need,

it is apparent from the experience of the Aiming High for Disabled Children programme that certain guidelines are important to follow:

- families should be involved in decisions about the types and volume of services which should be commissioned;
- families should have choice;
- services should be age appropriate;
- choices should reflect the changing needs of families;
- families value services which are flexible, reliable, and where they are confident their children will be looked after safely and sensitively by staff with the necessary expertise; and
- ease of access to services is a key consideration.

Short breaks should be reliable and regular to best meet families' needs

2.5 Local authorities will want to ensure that they develop a dynamic short break provision with a mixture of both innovative short break options and reliable and regular services. Reliability and regularity are hallmarks of a quality short break service in the eyes of parents. There are considerable consequences of the sudden loss of a short break service for family routines and commitments. Some children, for example those with autistic spectrum disorders, are particularly distressed by an unexpected change in routine. That said, we know some parents appreciate, and their children often appreciate more, a range of exciting and innovative options. The exposure of disabled children to a range of new activities, for example playing golf and skiing, has developed children's confidence and provided them with the kind of enjoyment many other children take for granted.

Parents should be engaged in the design of local short breaks services

2.6 Many local authorities have found that the key to getting the balance right when developing a broad range of short break activities is the engagement of local parents in service design. Parents can support local authorities to identify the best ways to provide personalised packages of care to meet individual family need.

In April 2009 Enfield Council collaborated with The Family Fund, Wilf Ward Trust and Haven Holidays to support seven families to enjoy a holiday with assistance provided by carers – a minimum of 10 hours and maximum of 20 hours per week. This opportunity meant that families were able to enjoy additional relaxation and leisure opportunities.

One parent described it as like 'winning the lottery' and another stated that being able to have a coffee by the poolside and read the paper for half an hour while her husband played with their son and the carer supported their daughter in the pool made all the difference. Families remarked that having 'bite-size' periods of support made a huge difference to all family members in enabling them to have a fulfilling and memorable holiday. For some families

this was the first time they had ever taken a family holiday because the prospect of managing alone was too much.

www.enfield.gov.uk

Rochdale has commissioned Barnardos to provide a short breaks service promoting increased access for disabled children to universal provision. Depending on the child's own interests, personalised short breaks are provided in a wide range of community settings, from cheerleading to cycling.

www.rochdale.gov.uk

Short breaks can build on and be offered by universal service providers

- 2.7 Universal services and other community facilities can provide exciting, positive opportunities for disabled children and young people to socialise with other children, and to access fun and/or educational activities in a safe environment. There is an increasing role for universal services in the delivery of short breaks, and they can provide local authorities with opportunities to easily extend the range of breaks they offer.
- 2.8 Local authorities should be clear that the short break must be in addition to the universal positive activities to which families should normally have access. For example, local authorities should consider how they can improve general access to their local swimming pool to enable more disabled children to use it. That might include some training for pool attendants and other staff to better understand how to support children with challenging behaviour, for example. An individual disabled child on a short break might also need some additional one-to-one support when in the pool to enable them to swim safely and enjoyably.
- 2.9 Childcare providers have often been trained to support disabled children, and are in a good position to support those children in short breaks. Where local authorities find ways to use childcare providers and facilities to offer short breaks, they must ensure that the short break is in addition to the childcare all families should normally have access to. In general, it might be helpful for local authorities to think of childcare as enabling more parents to work, or to undertake training and educational opportunities which can lead to work. A short break should be supporting parents to care for their disabled child more effectively by giving them a break.

Under the Disabled Children's Access to Childcare programme, Solihull Council has undertaken a number of initiatives to ensure disabled children have access to childcare provision. To ensure families' needs were at the centre of service developments Solihull established:

- a team of parent champions who provide information, advice and assistance to parents to enable them to access childcare, activities and other services;
- a support service to enhance the skills of childcare settings to meet the needs of disabled children;
- additional resources to settings to reduce ratios of children to adults where necessary.

<http://www.solihull.gov.uk/health/aiminghigh.htm>

Hampshire County Council is working with other key service providers and service user representatives to ensure disabled children enjoy a choice of leisure and recreation activities within their local community, providing parents and carers with a short break from caring knowing that their children are in a fun, safe and supportive environment. A multi-agency commitment underpins this work.

<http://www3.hants.gov.uk/childrens-services/specialneeds/aiminghigh.htm>

Local authorities should work in partnership with health services to understand the range of short breaks services in their area and to train the workforce

2.10 Health services have multiple roles to play in the provision of short breaks for disabled children in their areas. They will directly provide and commission some services, for example, short breaks for children with complex health needs. (For some children, this may involve spending some time in a hospice.) They will also support local authority and voluntary and Community sector provision, for example, by training the workforce and providing nursing support and timely access to necessary equipment.

Local authorities must give families the choice to access short breaks services using a direct payment

2.11 Local authorities are under a duty to provide families the choice of receiving a direct payment in lieu of the support they would have been provided with under section 17 of the 1989 Act.¹⁰

¹⁰ The duty can be found in section 17A of the 1989 Act and the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009.

- 2.12 Direct payments are a useful way of giving families with disabled children greater choice and flexibility to access the services they want and need to support them.¹¹
- 2.13 The evaluation of short breaks pathfinders found that more and more families are choosing to access short breaks services through direct payments, and that they are enjoying the ability to buy exactly what they want.
- 2.14 There are a number of things local authorities should do to help ensure the provision of direct payments is beneficial to families:
- All families should be supported to understand how a direct payment might benefit them;
 - Families should not be forced to take a direct payment where they are not confident to do so;
 - Families who choose direct payments should be supported to make confident appropriate choices for their family; and
 - Local authorities should not use direct payments as a way of limiting access to support. The funding provided through a direct payment must enable a family to access all the support they have been assessed as needing.
- 2.15 Direct payment initiatives have led to a number of positive outcomes, for example:
- a) increasing the choice of short breaks for families and increased access to community-based provision;
 - b) enabling some children with rare and complex conditions to access breaks; and
 - c) expanding the workforce of short break carers by families approaching people they know to offer short breaks to their child; for example members of the extended family and the family's social network.
- 2.16 A number of pathfinders have promoted the increased uptake of direct payments as a key component in helping more families to access short breaks. One outcome of this approach for many families has been to raise their expectations and ambitions for themselves and their disabled child.

¹¹ A parent's guide to direct payments can be found at <http://education.gov.uk/publications/standard/publicationDetail/Page1/DFES-0202-2006>. More formal guidance is available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840

- 2.17 As part of the Department for Education Aiming High pilots, some local authorities are using individual budgets to draw together social care and non-mainstream education funding. Some are linked to the Department of Health's personal health budget pilots, enabling NHS resources to be drawn into a single combined budget.
- 2.18 The individual budget is controlled by the parents or the young person with appropriate support from either the local authority or voluntary organisation and used to support a set of agreed outcomes for that child. The budgets are not necessarily provided to parents as cash payments, but decisions about how the money and/or resource is spent is made by them. The purpose is to encourage a parent-led and personalised approach to funding for disabled children. Local authorities using personalised funding are finding that as parents gain confidence in managing the fund they become more creative in the services they chose to meet their child's needs.

Derbyshire is a site for an individual budgets pilot and also for piloting personal health budgets. This allows service users to access different funding streams to devise a personal package of care which best meets their needs. For example, one young man was funded jointly by health and children's services to attend an independent special school which also provided much of his short break care. With support from the pilot projects this young man and his family opted for an alternative range of short breaks. They employed a personal assistant to support their son at home and ultimately to support him to go on a family break with them. The individual budget enabled the family to consider a broader range of possibilities for the young man's adult life.

www.derbyshire.gov.uk

Short breaks can be a key service to promote greater levels of confidence and competence for young people moving towards adult life

- 2.19 It will be important for short breaks to be planned and provided to enhance independence with a view to continuity of provision once the young people become young adults. This will require close liaison with adult services and local health care agencies.

As part of its short break strategy the London Borough of Richmond upon Thames has piloted a project to develop confidence and promote independent living here individual's 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, promotes 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 have stated that they feel more grown up and able to enjoy the activities

without their parents and with the support of a worker that 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.

www.richmond.gov.uk

3. The short breaks services statement

3.1 Parents frequently comment on the difficulty of finding information about the short break services. Families need to receive timely information about the full range of service in plain language and in accessible formats so they can make informed choices.

3.2 Families with disabled children need clear information to access services. This is why each local authority must publish a statement about short breaks services in their area.

The short breaks services statement must state:

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

3.3 The statement must be kept under review and it should be revised when new services become available, or when there are changes to existing services. Carers' views must be taken into consideration when preparing and revising their statement. The views of disabled children and young people and of voluntary sector organisations working with disabled people should also be taken into account.

Wiltshire County Council and the London Borough of Enfield have prepared draft short breaks services statements which will form the basis for local consultation with families with disabled children and other partners. These two examples show how the regulatory requirements can be met and how differences in approach reflect local circumstances.

www.wiltshire.gov.uk
www.enfield.gov.uk

3.4 The experience of Wiltshire and Enfield would suggest that the statement is best prepared and reviewed in a partnership with local organisations (parent forums, local health services, the voluntary sector and schools).

Local authorities should consider how best to ensure strategic sign-off and shared accountability locally for the statement and the services to which it refers.

3.5 It would be good practice to consider how partners from local health services should be involved, as well as delivery partners from the voluntary and charity sectors, and local parent groups. The Children's

Trust or local health and wellbeing board could both provide an appropriate forum.

Cambridgeshire has funded a small voluntary organisation, a parent information service called Pinpoint, to develop a website which not only gives a range of local activities but also allows families to comment.

<http://www.pinpoint-cambs.org.uk/>

In preparing the short breaks services statement, local authorities should consider how best to share information about disabled children between agencies (bearing in mind the need to operate within existing data protection legislation).

3.6 This will ensure a coordinated provision according to need. It will be helpful for local authorities and Primary Care Trusts (PCTs) and other relevant partners to use a common database of disabled children.

3.7 Relevant information which might support a good description of local services could include:

a) data on the current and projected prevalence of disability in the child population, available in the Joint Strategic Needs Assessment;¹²

b) aggregated data from the assessment of individual children and families – this will indicate which needs can be met currently and which cannot readily be met; and

c) views of all concerned (disabled children and young people, parents; voluntary organisations and service providers).

During the operating year April 2008 to March 2009 Durham County Council worked with parents to undertake an analysis of needs and services, including costs and gaps in services. They identified target groups, particularly children with autism, where local provision was insufficient and subsequent costs of residential placements were high. This needs analysis formed the basis of the short break strategy which has been underpinned by substantial investment.

www.durham.gov.uk

12

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_081097

Halton – Bright Sparks

Halton has commissioned an independent local advocacy service to support young disabled people to participate fully in all consultations for young people in the borough. A group of disabled young people, Bright Sparks, has been provided with a training programme covering topics such as time management, planning a schedule, listening skills, confidence building, and the ability to speak up and ask questions in a group. They have produced a DVD.

<http://www3.halton.gov.uk/healthandsocialcare/childrenandfamilycare/disabledchildrenandyoungpeopleshortbreaks/>

Wiltshire County Council focuses on outcomes in its service contracts.

Working in partnership with parent carers, in particular through the Wiltshire Parent Carers Council, is at the heart of the Aiming High for Disabled Children programme. Parent carers have been involved in the commissioning of services (including the planning of service specifications and tender evaluation), have provided feedback on the delivery of the services, and have been involved in the review of services. Wiltshire Council's partnership approach to working with parent carers is supported by the contract for each commissioned service, which requires the service provider to seek feedback regularly from the parent carers and children and young people using the service, and to present this in their service review reports. A focus of each service review meeting is how the feedback from service users is influencing the development of the service. Parent carers have attended service review meetings so commissioners and providers can hear first hand their feedback on the quality of the service and suggestions for service development.

http://www.wiltshire.gov.uk/healthandsocialcare/carers/supportforcarers.htm#Support_for_carers_of_disabled_people

3.8 The examples provided by Wiltshire and Enfield may help local authorities think about short breaks service statements. Local authorities should prepare and agree their own statements based on their individual local circumstances.

3.9 Local authorities may wish to consider, in drafting their short breaks services statement, the extent to which:

- services meet the needs of all disabled children and promote improved outcomes;
- universal services are including disabled children;
- services are available and accessible fairly across the authority;
- information is available to all disabled children and their families;

- there is choice for families and a range of providers including the voluntary and community sector;
- services are culturally appropriate;
- services are age appropriate;
- the availability of suitable transport is supporting access; and
- services are supporting the transition to adult services.

And also:

- the balance of provision between direct services and direct payments; and
- the advice and guidance available to support families who opt for direct payments.

Local authorities must publish their statement of short breaks services on their website

3.10 Families with disabled children must have access to a statement which is concise and clear. It would be good practice for local authorities to also consider additional ways of making the information available, for example in paper format for people without computer access. Public notice boards in doctors' surgeries and children's centres can also ensure information is accessible.

Local authorities should ensure that those who use short breaks services have the chance to shape the development of those services

3.11 The standards for participation and feedback set out in the Aiming High for Disabled Children Core Offer provide a good framework for effective consultation.¹³

3.12 Carers and children and young people should be involved in the decision making about the nature of services and their relative priority. Feedback by authorities to families about the outcomes of the consultation is essential.

3.13 Participation is more effective when:

- families are involved in decision making about provision (and setting budget priorities); and
- there are structures (such as parent forums) to support systematic and sustained participation of both parents and children.

3.14 Local support groups and grassroots organisations can be key partners in ensuring broad-based and effective consultation. Local decision making with full consultation is more likely to lead to local service users achieving their desired outcomes.

¹³ <http://www.chimat.org.uk/resource/item.aspx?RID=66227>

Local authorities should try to reach groups of parents who may be more difficult to engage

3.15 This may be:

- because English is not their first language;
- because they live in rural areas; and
- due to the nature of their child's impairment.

3.16 Failure to engage could lead to widening inequalities.

3.17 Local authorities may also consider the views of families whose disabled children have been placed out of their home area in order to have their needs met. Such children may be placed in health, education or social care establishments. This will enable authorities to consider whether some families would have been able to continue to care for their children at home given higher levels of short breaks support.

Nottinghamshire – messages from families

Nottinghamshire County Council and NHS Nottinghamshire County asked ibk initiatives (a parent led development agency specialising in raising the voice of disabled children, young people and their families) to find out the views and experiences of disabled children, young people and their families using support services for children and young people with complex medical conditions and/or life-limiting illnesses.

www.nottinghamshire.gov.uk

Good practice in commissioning is leading to more responsive short breaks services

3.18 In some authorities the nature of commissioning has fundamentally changed in order to provide innovative and responsive services. Small community led and family-led processes appear to be better able to provide services tailored to specific local needs.

Kent – parental involvement

Kent is developing innovative approaches to ensure families with disabled children remain at the heart of service development. There are five resource centres across the county. Based on an established parent consortium in North West Kent, the other centres are developing parent-led bodies which in time will be the managing agents of the resource centres and have the ability to subcontract service delivery. It is hoped in time they will be able to attract

additional sources of revenue and be a powerful local voice speaking up for disabled children. A number of organisational options have been considered and each area is developing a model of a parent-driven charity which best fits its needs. Training for parents as well as expert advice and support have been essential in preparing the local groups for greater autonomy.

http://www.kent.gov.uk/childrens_social_services/disabled_children/resource_directories.aspx

Local authorities must keep their short breaks statement under review

3.19 The local authority must review its short breaks services statement and where necessary revise its statement. The frequency for review is a matter for each local authority to decide. This flexibility allows the local authority to revise and keep the document current according to local circumstances. Carers' views must be considered. The views of disabled children and young people are equally important and should also be considered.

Manchester summer activity evaluation report

A programme of play schemes and activities were commissioned over the summer period in and around Manchester. An evaluation report has been produced which puts together whether the activity/scheme had a positive outcome and met the needs of parents and children.

<http://www.manchester.gov.uk/aiminghigh>

3.20 Local authorities should be able to monitor how far children and families using services match the overall profile of disabled children in their area. Local authorities will want to ensure there is equity of access according to ethnic origin of family, the nature of the child's disabilities, as well as other socio-economic factors.

3.21 Following an assessment of local needs, some authorities have targeted specific groups within the population of disabled children, for example children with autism or children living in remote areas.

Local authorities should continue to develop their workforce in relation to short breaks services

3.22 Increasing the provision of short breaks for disabled children has made new demands on the workforce employed by short break providers and by families through direct payments. Local areas are meeting this challenge in a number of innovative ways.

Buckinghamshire – training guide

This new training guide is aimed at people who work with disabled children and young people. The training is also available to those who want to enhance their skills for working with disabled children, young people and their families. The guide includes details about the Short Break Carer Training Pathway and the Inclusion Training for mainstream providers.

http://www.buckinghamshirepartnership.gov.uk/partnership/CYPT/aiming_high/training_guide

Solihull Borough Council has developed a programme of work to help achieve its vision of 'a diverse, integrated workforce which is flexible, competent, confident, respected and safe, and fully equipped to enable all children, young people and their families to grow and develop'. The plan focuses on universal and specialist services and its implementation is supported by a dedicated part-time post.

<http://www.togetherfdc.org/DCATCHNew/default.aspx>

4. Eligibility (and the Islington judgment)

Local authorities must publish, as part of their short breaks service statement, details of the eligibility criteria they apply to short breaks services

- 4.1 The application of eligibility criteria to short breaks and other services for disabled children and their families should be considered within the context of the requirements of the Chronically Sick and Disabled Persons Act 1970 (“the 1970 Act”) and the 1989 Act.
- 4.2 The 1970 Act imposes various duties on local authorities towards disabled people of all ages. Section 2 of this Act requires authorities to consider whether it is necessary, in order to meet the needs of a disabled person (including a child), for the authority to provide services of the type categorised at section 2(1)(a) to (h). These services include practical assistance in the home, adaptations, assistance in accessing leisure and recreational activities, help with meals, travel and holidays. If the local authority identifies that a person will need a service from the list at Section 2 of the 1970 Act, they must provide that service.
- 4.3 Section 17 of, and Schedule 2 to, the 1989 Act set out the general duties and powers conferred on local authorities to provide family support services to children in need, which includes disabled children.
- 4.4 There is considerable overlap between the services which can be provided under the 1989 and the 1970 Acts. The essential difference is that under the 1970 Act, once the local authority has decided that there is a need for services under section 2, it has a duty to provide those services, while services provided under section 17 of the 1989 Act are discretionary.

Local authorities can provide families with access to short breaks services without any assessment

- 4.5 Many local authorities are achieving the expansion of short break services through a ‘local offer’ of disabled children’s services, to which families with disabled children refer themselves.
- 4.6 Local authorities who provide access to services through a local offer must think through their criteria for access to it. For example, it’s no good only allowing access to children who attend special school; some families will have opted to send their child to mainstream school. Equally, the single criterion of the higher level of Disability Living Allowance (DLA) is discriminatory, due to the nationally uneven uptake of this benefit and the specific residency requirement of 26 weeks in the last year. Eligibility criteria should be applied with some flexibility in order to ensure fairness to all potential beneficiaries.

For many families, a formal assessment of their needs will enable the local authority to provide a tailored package of services to them

- 4.7 Where the local minimum offer does not meet the needs of the child and family, local authorities should undertake further assessment of the child and family.
- 4.8 Local authorities should refer to the statutory guidance *Framework for the Assessment of Children in Need* when they wish to establish a family's need for additional services. Where it is apparent that a child is 'in need' within the meaning of section 17 of the 1989 Act, the local authority should consider carrying out an initial assessment. This initial assessment should determine whether the child is a child in need of services or not, the nature of the services that are required and whether more detailed assessment is necessary. This can be a brief assessment and may be dependent on whether the child's disability has already been established. Much of the information required may already have been supplied through the Common Assessment Framework.
- 4.9 Having completed the initial assessment, and the core assessment if necessary (paragraph 3.11 of the *Framework*), the local authority should next consider what provision it will make to meet the assessed needs.
- 4.10 In order to meet its duties under section 2 of the 1970 Act, the local authority should carry out a two-stage analysis. First, it must consider whether it is necessary, in order to meet the needs of a disabled child, for the authority to provide support of the types outlined in section 2, such as appropriate housing. Eligibility criteria may apply at this stage of assessment to provide local authorities and service users with clarity about which services they could expect to receive.
- 4.11 Where the local authority is satisfied that it is necessary to provide section 2 support to a disabled child, the local authority must, in the second stage of analysis, ensure that it meets the needs in question. At this stage no further eligibility criteria can be applied.
- 4.12 Where there is an obligation to provide services to disabled children under section 2 of the 1970 Act, those services can be provided under section 17 of the 1989 Act. However, local authorities must not avoid their duties (and apply additional eligibility criteria) towards a disabled child under section 2 of the 1970 Act by purporting to act under their powers under section 17 of the 1989 Act.

Eligibility criteria must not be applied mechanistically without consideration of a particular family's needs

- 4.13 Local authorities may apply eligibility criteria if they are using their powers to make provision, for example to provide overnight short

breaks through section 17(6) or section 20(4) of the 1989 Act. Such criteria should not be applied mechanistically without consideration of the particular needs of the individual child and their family, and must take account of the duties specified in section 149 of the Equality Act 2010.

- 4.14 Eligibility criteria have a much more limited role where local authorities are complying with their duties in making provision. For instance, eligibility criteria must not be applied where a duty to provide accommodation under section 20(1) of the 1989 Act arises or where the local authority has decided that support of the types categorised in section 2(1)(a) to (h) of the 1970 Act are necessary in order to meet the needs of a disabled child.

There is a legal precedent for a parent to challenge the eligibility criteria applied to their access of short breaks services

- 4.15 The case of R (on the application of JL and another) v Islington London Borough Council [2009] (the Islington judgment) clarified a number of issues in respect of how and whether criteria for eligibility for services should be used and, in particular, whether or not a local authority should use such eligibility criteria in relation to services for disabled children.¹⁴

- 4.16 The following principles can be drawn from the judgment:

- Local authorities should be aware of the specific legal powers and duties they are using when making decisions about services;
- Eligibility criteria are appropriate in those situations where local authorities are using their discretionary powers to meet needs (for example, under section 17 or section 20(4) of the 1989 Act) but not in situations where they have established there is a duty to meet need (for example under section 20(1) of the 1989 Act and section 2 of the 1970 Act);
- Eligibility criteria must not be applied before there has been adequate assessment of the child and family's needs;
- Local authorities should ensure that there are two distinct processes: the assessment of need and decisions on the provision of services. They must not allow their eligibility criteria to confuse or distort the assessment process;
- Eligibility criteria should never be applied mechanistically. Decisions should always take into account the particular circumstances and needs of the child and family; and

¹⁴ EWHC 458 (Admin)

- Eligibility criteria should be informed by the local authority's duties under section 149 of the Equality Act 2010, which includes duties to have due regard to the need to eliminate discrimination, to advance equality of opportunity and to encourage participation by disabled persons in public life.

Examples of local authority eligibility criteria

Local authorities may find it helpful to refer to the attached eligibility criteria developed in Enfield and Wiltshire. However, each local authority should seek its own legal advice in developing its own criteria.