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# Best Practice Guidance

Breaks for Carers of Disabled Children (Wales) Regulations 2012

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This best practice guidance is intended to give an overview of the legal position in relation to the Breaks for Carers of Disabled Children (Wales) Regulations 2012.

This is non-statutory advice from the Welsh Government. 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 (Wales) Regulations 2012. In this document, these Regulations are referred to as "the Short Breaks Regulations"

#### 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;
- 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, and any 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, children and young people as part of the review of the statement;
- consider the legal implications of the eligibility criteria they may apply to short breaks services; and

#### 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.

#### **Related legislation**

- Section 10 of the Of the Children Act 2004<sup>1</sup> 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<sup>2</sup> ('the 2000 Act') places local authorities under a duty to carry out an assessment of a carer's needs in certain circumstances. 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.

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

 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 (Statutory Duties) (Wales) Regulations 2011 to extend to the schools and other public authorities that are referred to in Part 2 of Schedule 19 to the Equality Act 2010.

<sup>&</sup>lt;sup>1</sup> Safeguarding Children: Working Together guidance under the Children Act 2004

<sup>&</sup>lt;sup>2</sup> Practitioners Guide to Carers' Assessment – guidance Carers and Disabled Children Act 2000. 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.

• 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<sup>3</sup>.

#### 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.

#### 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.

<sup>&</sup>lt;sup>3</sup> Section 22 of the Chldcare Act 2006

- 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.
- 1.8 Any short break must offer a positive experience to the disabled child or young person whilst also providing their family with a break from caring. As local authorities have a duty to provide a range of short break services including access to universal services, it will be important to have an explicit agreement between the local authority and the family that any activity provided as a short break meets the assessed needs of both the disabled child and their family.

#### 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 or another setting, 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 or another setting.
  - (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<sup>4</sup>.
- 2.3 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

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<sup>&</sup>lt;sup>4</sup> Safeguarding Children: Working Together Under the Children Act 2004

experience of the *Aiming High for Disabled Children* programme<sup>5</sup> in England and an alliance of voluntary organisations in Wales that certain guidelines are important to follow:

- families, children and young people 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

2.4 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, 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

2.5 Local authorities may find that when developing a broad range of short break activities there engagement of local parents in service design can be key to getting the right balance. Parents can support local authorities to identify the best ways to provide personalised packages of care to meet individual family need.

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

2.6 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.

<sup>&</sup>lt;sup>5</sup> The Aiming High for Disabled Children was set up as a transformation programme for disabled children's services in England.

- 2.7 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.
- 2.8 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.

# 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

- 2.9 The Carers Strategies (Wales) Measure 2010<sup>6</sup> requires Local health Boards and local authority social services to produce strategies setting out how they will consult with and provide information and advice to carers to assist them in their caring role. This Measure, for the first time, places a legislative duty on the NHS in relation to services for Carers in Wales. The Welsh Government has committed to extending the duties with the Carers Strategies (Wales) Measure 2010 to other local authority functions, such as Education and Housing.
- 2.10 The Social Services (Wales) Bill proposes to impose duties on local authorities to publish information on carers' rights and the services offered to carers in their local areas. It will ensure that carers can easily identify themselves as carers and having done so, become aware of their rights and of the services available locally that will support them in their caring role. It will also support the implementation of the new Carers Strategies (Wales) Measure by building on the requirement for Local Health Boards and Local Authorities to publish strategies setting out how they will provide information and advice to carers, and requiring them to provide and publish this proposals information.
- 2.11 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.

<sup>&</sup>lt;sup>6</sup> Carers Strategies (Wales) Measure 2010 and relevant guidance issued to LHB's and LA's

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

- 2.12 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<sup>7</sup>.
- 2.13 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.
- 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 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.

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

2.16 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.

#### 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

<sup>&</sup>lt;sup>7</sup> The Community Care, Services for Carers and Children's Services (Direct Payments) (Wales) Regulations 2011

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 any 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 reviewed annually 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.

# 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.

- 3.4 It is essential to consider how partners from local health services should be involved, as well as partners from the third sector and local parent groups.
- 3.5 Local authorities may wish to consider, when 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

3.6 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 must keep their short breaks statement under review

3.7 The local authority must review its short breaks services statement annually 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.

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

3.8 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.

#### 4 Eligibility

# As part of their short breaks service statement, details of any eligibility criteria they apply to short breaks services

- 4.1 The application of any 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.
- 4.5 Local authorities should refer to the statutory guidance *Framework for the Assessment of Children in Need and their Families*, 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.
- 4.6 In order to meets 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.
- 4.7 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.