
Cerebra
Local Authority
Short Breaks Statements:
Accessibility and Accuracy

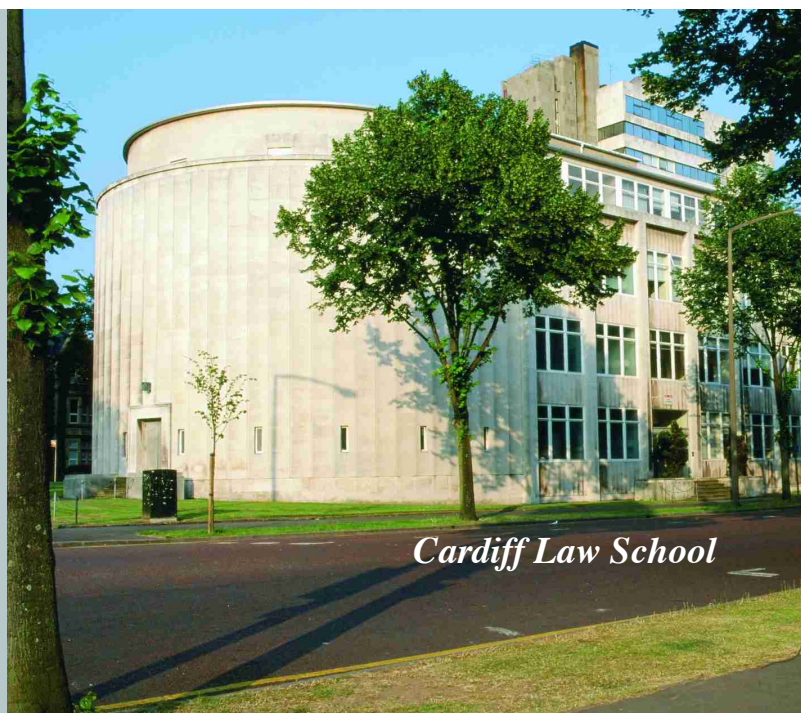
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Cardiff Law School

LOCAL AUTHORITY SHORT BREAKS STATEMENTS: ACCESSIBILITY AND ACCURACY

Cardiff University Cerebra Legal Entitlement Research Project

In 2013 an innovative research programme commenced at Cardiff Law School with funding and technical support from Cerebra, a unique charity set up to help improve the lives of children with neurological conditions.

The research programme was founded on the work of Cardiff Law School's pioneering Law Clinic. The Clinic is run by volunteer undergraduate and postgraduate students, assisted by practising solicitors, barristers and the Law School's own academic staff. The Clinic provides legal advice on a diverse range of issues and comprises a number of specialist schemes.

The Cerebra Legal Entitlements Research Project is one of these schemes and provides support for disabled children, their families and advisers, who are encountering difficulties with the statutory agencies in relation to the provision of health, social care and education.

In 2013 and 2014 selected Opinions produced by the Project were published as 'Digests' and these are accessible from the Cerebra website.¹ In 2015 it was decided that the focus of the student research should move to tackling generic problems that had been highlighted by families approaching Cerebra for assistance. Although a number of subject areas were considered as suitable for this new programme it was ultimately decided that the research would address the accessibility and suitability of information provided by councils responsible for social services concerning the entitlement of disabled children and their families to 'short breaks' support.

Without the funding and technical support provided by Cerebra, this new programme (as with the wider Legal Entitlements Research Project) could not have been developed. Its practical success owes much to the many Cerebra colleagues who have helped us overcome teething problems; have managed the referrals; and throughout been wonderfully positive and imaginative.

We are immensely grateful to the student advisers for their freely given support and dedication. Very special thanks are also due to:

Sharon Howley

Co-ordinator of Cerebra Legal Entitlements Research Project.

Brian Thorne

Solicitor (retired) and expert adviser to the programme.

Luke Clements

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For further information on the programme see

www.law.cf.ac.uk/probono/

For access to the programme see

www.cerebra.org.uk/english/gethelp/legalhelp/pages/default.aspx

Copies of earlier Digests can be accessed at

www.law.cf.ac.uk/probono/cerebra_opinions.html

¹ <https://w3.cerebra.org.uk/help-and-information/legal-entitlements-research-project/>

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INTRODUCTION

Case work from the Cerebra Legal Entitlements Research Project at Cardiff Law School has highlighted an apparent lack of understanding by disabled children and their families concerning their entitlement to short breaks, how to get them and what to do if they are not happy about them.²

As a result of these findings, it was decided that the student researchers would endeavour to assess the accessibility and suitability of information provided by local authorities concerning the entitlement of disabled children and their families to 'short breaks' support.

Background

Respite care or 'short breaks' provision is of vital importance to families with disabled children.³ Short breaks give families and the disabled child the chance to have time apart – or at least time when the family is not providing care or supervision. It is identified in policy documents as well as by families themselves as one of the most important support services that can be provided.⁴ As a 2015 report noted:⁵

The fundamental importance of short breaks to families with disabled children is beyond doubt. Short breaks are vital to improving the lives of disabled children and helping them reach their potential. They provide parent carers with essential support to help them cope with their caring responsibilities. It is no exaggeration to say that by increasing family resilience, short breaks help keep families with disabled children together. This has been recognised by successive governments, who have established a legal framework and committed funding to ensure families with disabled children have access to the short breaks they need.

In recognition of the particular importance of short breaks support for such families, in 2008 the Children Act 1989⁶ was amended to require local authorities to provide services designed to assist family carers of disabled children 'to continue to [provide care], or to do so more effectively, by giving them breaks from caring'. The legal obligations on local authorities are described below and are distinct in England and Wales (see in Annex I (England) and Annex II (Wales)). However Regulations in force at the time of the research (and continuing in England) require that local authorities (among other things) provide a range of daytime care, overnight care and leisure activities and that these be detailed in a 'short breaks services statement' which must include any criteria by which eligibility for these services is to be assessed.

Despite these legal obligations the referrals received by the Legal Entitlements Research Project in 2013–14 suggested that information concerning the availability and short breaks support (and the actual support itself) was often difficult to access. These findings were buttressed by research⁷ that found that 53% of parent carers said they had never accessed any form of short breaks service.

The Cerebra Legal Entitlements Research Project research was designed therefore to analyse the accessibility and accuracy of local authority 'short breaks service statements'.

² See for example, Ron's story, and Alice's story in the 2013 digest and Kumar's story and Peter's story in the 2014 digest accessible at <https://w3.cerebra.org.uk/help-and-information/legal-entitlements-research-project/>

³ For example: C Hatton, M Collins, V Welch, J Robertson, E Emerson, S Langer and E Wells, *The Impact of Short Term Breaks on Families with a Disabled Child Over Time*, Department for Education, DFE-RR173, 2011; Contact a Family, *What makes my family stronger*, 2009; Contact a Family, *No time for us: relationships between parents who have a disabled child – a survey of over 2,000 parents in the UK*, 2004; Mencap, *Breaking point: families still need a break*, 2006; Shared Care Network, *Still waiting*, 2006.

⁴ HM Treasury/Department for Education and Skills, *Aiming high for disabled children*, 2007 and see HM Government, *The Children Act 1989 Guidance and Regulations. Volume 2: Care Planning, Placement and Case Review*, DCSF Publications, 2015, chapter 6.

⁵ Every Disabled Child Matters: *Short breaks in 2015: An uncertain future* (2015).

⁶ By the Children and Young Persons Act 2008, s25 which amended Schedule 2 para 6(1)(c) of the 1989 Act.

⁷ Every Disabled Child Matters: *Short breaks in 2015: An uncertain future* (2015).

EXECUTIVE SUMMARY

The short breaks statements of 63 councils responsible for social services in England were analysed (in November / December 2015), chosen at random to include all parts of the country. Welsh Authorities were not surveyed given imminent the change in the law in 2016.

Councils are required to provide such statements as part of their duty to assist family carers of disabled children 'to continue to [provide care], or to do so more effectively, by giving them breaks from caring'.

A questionnaire was drafted to obtain quantitative and qualitative data as to whether the short breaks services statements:

- were accessible for parents;
- explained in simple terms how entitlement was determined;
- informed carers of the right to an assessment, and how to challenge a decision on their eligibility or entitlement;
- dealt with the benefits to the carer of having transport provided; and
- included reference to Disability Living Allowance (DLA).

Positive findings included

Once the short breaks statement had been found 79% were considered to be easy to read.

On entitlement to services 95% had clear general categories, usually being 'Universal' (available for all children and young persons), 'Targeted' (for children with additional needs) and 'Specialist' (for those with severe and complex disabilities).

79% set no restrictions on availability of universal services and of those that did, these were largely based on the capacity of the short break service and the needs of the child.

Half explained eligibility for targeted and specialist services in easy to understand terms. 68% didn't include any 'impairment specific' restrictions on access to short breaks support, other than for specialist services where the disability was often required to be 'severe'.

Negative findings

In just over half of the authorities finding the statement was time consuming and confusing.

A fifth of short breaks statements were considered to be either overly-legalistic, lacking in detail or overly-complicated.

85% of the statements gave no clear explanation on how the amount of support was decided and those that did said it would be by an assessment.

Only 9% of authorities provided information on other sources of help where someone was assessed as ineligible.

The survey looked at limits imposed on the level of support (as in general, once a need has been identified the authority is under a duty to provide the support needed regardless of resources). 26% specified limits to the level of support and only 4% gave an explanation as to how support above the maximum could be obtained.

Short break services are, as a matter of law, aimed at providing support for carers: to enable them to provide care more effectively. While it is of course essential that the support provided to the disabled child is of high quality and enjoyable, many sites focused on this aspect almost exclusively and failed to reflect the fact that the legal obligation is 'carer' focused.

Only 6% provided information on how a parent carer could be assessed and some suggested it was discretionary not mandatory. Likewise only 6% referred to child carers and none made any mention of their right to an assessment.

The ability to challenge a decision is clearly of fundamental importance if carers are to receive the support they need. Yet 81% of the statements contained no mention of the legal right to challenge an assessment or how families could challenge a decision on the level of support provided.

If carers have to transport their disabled child to the activity then this will seriously reduce the amount of short break they receive. Again this issue was inadequately or not dealt with in the statements. 63% made no mention of transport and those that did mainly referred to the prohibitive cost of providing it and limited funding.

The survey concluded:

- finding the short break statement was in half the authorities surveyed difficult and would be especially so for parent carers not familiar with the term 'short breaks' - the students were familiar with this term;
- if the websites had clearer headings and more helpful links this would make the short break statement more accessible. In particular it was considered helpful for sites to have a logical point to start a search (ie a home page with an entry such as 'social care' or 'carers');
- that statements were in general visually appealing but could be improved with clearer headings and language, be more focused on the needs of the carers and cover gaps such as contact points, the right to challenge decisions and transport need;
- many short breaks statements appeared not to have been updated since being posted in 2011 / 2012: several had broken hyperlinks and most failed to reflect the legal changes to carers resulting from the Care Act 2014 and the Children and Families Act 2014;
- a standard format or template for all authorities to use would overcome many of the shortcomings identified as well as end certain legally questionable practices/policies identified in a few of the websites;
- of the authorities surveyed, the Isle of Wight was considered the best and capable of acting as a good template - see www.iwight.com/azservices/documents/2832-2181CS-Short-Break-service-statement-November-2014.pdf. Other sites that attracted 'honourable mentions' included those for Camden, Hampshire, Liverpool and Cheshire West and Chester.

Methodology

The research focused on English social services authorities. Welsh authorities were not analysed since at the time of the survey the relevant law in Wales was about to undergo significant change – with the Social Services and Well-being (Wales) Act 2014 coming into force on the 6th April 2016. The applicable law in England and in Wales (post April 2016) is detailed in Annex I and II to this report (pages 17 and 21).

The web-based short breaks information provided by 63 English social services authorities were analysed – representing slightly more than 40% of such authorities (152). Authorities were selected to ensure that there was an even geographical coverage and a mix of Unitary Authorities, County Councils, Metropolitan and London boroughs – but otherwise the choice was random. The same questionnaire was used on each authority.

The questionnaire largely consisted of a series of closed-ended dichotomous questions. Where relevant these questions were followed by a supplementary open-format question enabling the students to express an opinion and capture qualitative data. There was also provision for the students to detail the hyperlink pathway they followed in order to find the short break statement. A copy of the questionnaire is at Annex III.

The local authority websites were analysed by 13 law students (12 undergraduate and one postgraduate), each of whom reviewed four or five short break service statements. Two of the students have English as their second language. The review took place in November - December 2015.

Restricting students to four or five authority searches was designed to limit their ability to develop expertise in navigating these websites: to test (so far as possible) how accessible / informative the sites were to the relatively 'uninitiated'. However, the students have had two training sessions: one explaining the relevant law and one familiarising them with the questionnaire. The training was done to ensure a consistency of approach to the use of the questionnaire – but it had the inevitable distorting effect of familiarising the students with the law and the required information resources. Accordingly it is reasonable to assume that they would have had more training than many families: ie a greater awareness of what information authorities should provide (and the format in which it should be made available).

The questionnaire was informed by the range of issues that the Legal Entitlements Research Project had encountered concerning short breaks services statements over the previous two years and in particular it was designed to obtain qualitative and quantitative data as to whether these statements:

- were accessible for parent carers;
- explained in simple terms how entitlement to short breaks support was determined;
- informed parent carers of the right to challenge/ make a complaint;
- informed parent carers and young carers of their right to an assessment;
- explained in simple terms how assistance with transport to short break services was provided; and
- included references to Disability Living Allowance (DLA), and if so, the contexts in which these references arose.

Legal Overview

As noted above social services authorities in England are under a duty to provide services designed to assist family carers of disabled children 'to continue to [provide care], or to do so more effectively, by giving them breaks from caring'.

A detailed note concerning the duty is provided at Annex I to this report (together with a note concerning the legal position in Wales – Annex II). However, in summary, regulations⁸ require that authorities, when discharging this duty, have regard to a number of important factors concerning the needs of family carers and that a range of services be made available which is sufficient to assist carers to continue to provide care or to do so more effectively. Authorities are required to provide a 'Short Breaks Services Statement' that describes (among other things) the services that are available and how they can be accessed.

Survey Findings

Are the 'short break service statements' accessible to parents and carers?

The provision of information concerning the availability and accessibility of short breaks statements is a core statutory function of social services authorities. Notwithstanding the wide range of functions discharged by social services authorities, categorisation studies suggest that large scale websites can (and should) have a navigation structure that limits the number of levels that site visitors have to work their way through;⁹ that if 'users are forced to click through more than four or five levels, they may simply give up'.¹⁰ Students were not instructed on the intricacies of website hierarchical navigation systems, or the various mechanisms that can be used to make sites accessible (such as drop-down menus, cascading menus and the like) or inaccessible labyrinths. The questionnaire simply posed a series of questions designed to obtain their objective and subjective views on site accessibility.

General accessibility

On the basis that requiring users to follow more than four or five hyperlinks ('clicks') is likely to increase the number of visitors giving up their search, students were asked how many 'clicks' it took for them before they found the relevant short breaks statement (but to abandon the search once they had made 20 clicks). In those cases where the use of hyperlinks failed to identify the Short Break Statement the students resorted to a 'Google' search. It took an average of 8 hyperlink clicks to find the short breaks statements. The range was 5 clicks to 20 (in 4 local authorities the students were unable to identify the statement at all – ie 6% of the surveyed authorities). Amongst the difficulties searching the research students reported:-

- No logical place to start the search;
- The website focused on other council services;
- False trails, eg Children and Families- Special Educational Needs, Local Offer, information on EHC Plan but nothing on short breaks.

The students' considered that finding the short breaks statement was, for 32 of the 63 of local authorities (51%), time consuming and confusing. Students' comments on some of the searches:

- Approximately 20 hyperlink clicks – the process was quite long. Information was relatively confusing if you didn't know exactly what you were looking for.
- 12 clicks – search wasn't successful; there was nowhere a mention of short breaks. Nowhere was there an option of an A-Z search.
- It took me a long time to find anything on disability, and when I did, the short breaks services document on the side of the page was not obvious or easy to spot at all.
- Short Breaks statement "hidden" amongst 130 results for short breaks.
- Short breaks statement is under adult care.
- [named local authority] – this page is very helpful and efficient.
- [named local authority] 5 clicks- a very well organised webpage from a first point of view, coherent headings, very efficient search.

⁸ The Breaks for Carers of Disabled Children Regulations 2011, SI 707.

⁹ See for example Lou Rosenfeld and Peter Morville Information Architecture for the World Wide Web: Designing Large-scale Web Sites (O'Reilly Media 1998).

¹⁰ Peter Morville Information Architecture on the World Wide Web (1998) p35

Although for half of the local authority sites the route to the short break statement proved to be a time consuming and confusing process, in most cases (49 authorities / 78%) the journey ended in success with identification of the statement. However in a fifth of cases (22%) it did not.

The majority of the short breaks statements were labelled as such and clearly identified as of relevance to families with disabled children. If parent carers have prior knowledge that that the place to find information about social care for their disabled child is contained within the 'short breaks statement' then searching their council's website will generally (and eventually) be successful. Some examples of the difficulties students encountered in identifying 'the end of the maze' included:

- A very brief document entitled short break care services which is part of Family support Team information
- Not clear as called Break Time.
- It doesn't seem to offer much practical information to parents. It reads very much like a report to Council, rather than a document aimed at parents. In one section it refers to itself as a 'report':

Of the short breaks statements that were identified, the majority (79%) explained in easy to understand language who was entitled to short break support. However in a fifth of cases this was not the case and examples of comments students made, include:

- Reference is made to the law, but it is broken down and examples are provided.
- The language is fairly complex but it is well explained and gives interpretations of what certain words mean under certain legislation.
- The use of statute makes it rather confusing; by avoiding the legal jargon I consider that the statement would have been far more comprehensive.
- Just says that they are for disabled children and that they will need to be assessed but no specific detail is provided. No definition of disability is provided. Lack of detail could lead to confusion as to whether you would be entitled.
- Long sentence structures are used and simple ideas are written in an over-complicated manner [eg] "adopted a multi-agency approach in the assessment",

Eligibility

Of the statements analysed by the students, 95% had clear categories of entitlement – almost invariably differentiating

between Universal Services (ie for all children and young people); Targeted Services (for children with additional needs) and Specialist Services for children with severe and complex disabilities.

Universal Services:

79% of the statements analysed by the students contained no restrictions on who could access universal short breaks and no statement limiting the amount of universal short break provision available. Of those that did refer to restrictions / limits to provision, the general tenor was to condition family expectations / manage demand and in this context students noted:

- [named local authority] 'Short Breaks Funding provides opportunities for disabled children and young people to spend time away from their families and have fun. The priority of this scheme is to support disabled children of families on a low income to access short break opportunities on out of school activities and or holiday activities which otherwise they would not be able to attend. Funding is limited and will be assessed on a need basis as applications are received.' Parent carers are advised to consult the Local Offer or Family Information Services for further information.
- [named local authority] 'Whether the children can attend depends on the capacity of the short break, and the needs of the child.'
- [named local authority] 'Some children may not be able to access these services for a variety of reasons and we are committed to overcoming these barriers wherever resources allow. These may relate to the need for someone to accompany the child or the level of skill and training required for staff to care for the child safely'.
- 'Whether a disabled child can attend will depend on capacity of the short break and needs of the child/ young person.'

The statements do not always make it clear what exactly some local authorities are offering parent carers in terms of a service in the universal category. Some of the statements surveyed suggested that universal services were those which were used by and benefit all children and families – namely mainstream activities such as youth clubs, after school clubs, swimming pools, Cub Scouts and Brownies. Some councils signposted parent carers to the Family Information service, an information directory, or to their 'Local Offer'. Some statements gave no 'onward' link (in terms of a hyperlink or website address) and merely advised parents to contact the service directly.

Charging and universal services

Of the statements surveyed 28% mentioned charging for universal short break support. In these cases the charges were for the activity (rather than for the associated care costs). Examples of the way this was dealt with include 'you will be expected to pay a small charge in the same way all families do'; 'you should contact the service provider directly about fees' and 'No charges for now, but it is currently under review'. A few councils mentioned the possibility of financial support (the research did not quantify this element), stating for example, 'Some services offer discounts for families on a low income and it's always worth discussing any difficulties with the individual provider as some offer bursaries and reduced rates' and another mentioned the existence of a 'small grants fund to support children to access community groups'.

Of the statements surveyed, the students found that 54% clearly explained how families could access universal services. These contained, for example, links and contact details for the relevant services / organisations. However for the remainder (46%) this was not the case. Problems identified in this respect included 'No links or phone numbers' and 'The link for additional information is broken'.

Targeted and Specialist support.

Restrictions on who is able to access Targeted or Specialist support?

Of the statements surveyed half (50%) specified in easy to understand terms how eligibility for targeted and specialist provision was determined. 68% of the statements contained no mention of restrictions and in most cases no categories of impairment were excluded – save only that in order to access specialist services a child or young person must have disabilities considered to be severe. Frequently the statement contained a list of impairments considered to be eligible, eg:

- [named local authority] The 'proposed' eligibility criteria for specialist services are:
 - CYP with severe or profound learning difficulties.
 - CYP with severe or profound physical disability.
 - CYP with severe and profound sensory impairment.
 - CYP with a life limiting illness or complex medical condition.
 - CYP with an autistic spectrum disorder with another profound or complex disability.
- 'Only for parents whose child requires substantial additional support as a result of their disability and additional needs in order to achieve their age appropriate potential – and this support cannot be provided within your family.'
- 'Specialist Services – Generally, children are eligible for help from these teams if they have a moderate to severe learning disability and/or a significant physical disability. Children with particularly complex chronic health conditions (e.g. uncontrollable epilepsy) which are substantially disabling can also be eligible for support from these teams.'

One council had named conditions it did not consider eligible for assessment for specialist services. The statement took no account of the impact of the impairment on the family and must be of questionable legality.¹¹ The list comprised:

- ADHD, Emotional & Behavioural difficulties, Dyslexia, Dyspraxia, Mild Autistic Spectrum Conditions including Asperger's Syndrome, Obsessive / Compulsive Disorder, Mild physical disabilities, Speech and Language difficulties, Oppositional Defiance Disorder, Mental Health Conditions, Mild Global Developmental Delay, Mild Learning Disability, Mild sensory impairment.

Eligibility criteria for targeted services were seen to vary significantly as councils categorise targeted services differently. In some cases these were similar to universal services – in that parent carers were able to approach the provider directly and no assessment was required. In other authorities an assessment was a pre-requisite to accessing a service. Students recorded the following comments:

- Some local authorities deny access to targeted services to younger children. Some it's under 5's some under 8's.
- 'Available to children and young people assessed by health or social care as needing targeted services to meet their needs. An assessment will look at a child's developmental needs, the parent or carer's capacity and wider family and environmental factors.'
- Targeted services are 'non-assessed services' and are open to 'A child or young person with disabilities or additional needs aged 0 - 18 years who lives in the local authority and has difficulty accessing universal services.'
- Targeted services are available for all children with needs but where there is high demand, it will prioritise children that do not receive any other service. They may also be subject to assessments by the specific organisation that manages the service.

¹¹ See in this respect, S Broach, L Clements and J Read *Disabled Children: A Legal Handbook* (Legal Action Group 2016) para 3.15.

The research found that in 9% of the statements surveyed there was an explanation as to how assistance could be obtained where the assessment had resulted in an ineligibility determination – for example:

- Some families receive professional support following their assessment whilst others might be offered practical support, or are signposted to other services / support systems that might be helpful e.g. specialist parenting programmes, holiday play schemes.

As noted in the legal overview below (Annex I) where an assessment has identified an eligible need for short breaks support, there is in general a duty on the local authority to meet that need, regardless of resources constraints – which means that local authorities are not lawfully able to impose rigid limits on the amount of support that can be provided. The survey analysed whether councils' short break statements were imposing limits to the amount of support that can be obtained as targeted/specialist provision.

Although the majority of statements surveyed made no mention as to the amount of provision that could be provided, a quarter (26%) specified limits to the level of support available (and only 4% of the statements surveyed gave an explanation as to how support above maximum could be obtained). Provisions imposing limits on support included:

- The local offer provides up to 104 hours/2 hours per week.
- 'Resources are finite and specialist short breaks are limited. Thus we are working with parents, carers and providers to establish ways of improving capacity and opportunity. Options are: providers working together, sharing resources to increase capacity – providers levying a reasonable discretionary charge so they can invest in providing more short breaks for more children.'
- 'However the range and amount of such breaks is governed by the availability of resources, in times of financial restraint targeted resources may not be as freely available on a 'first come, first served' basis, and services may be focused on those who meet the criteria for a specialist assessment, or who are assessed through the integrated teams in the localities.'
- 2-5 year olds maximum 78 hours for one year - 5-18 year olds maximum 156 hours for one year.

85% of the statements surveyed contained no clear statement explaining how the council decided how much short break support would be provided. In those that did, it was explained that the amount of support needed would be determined by the assessment process.

Assessment/entitlement

Of the statements surveyed almost 3 out of 10 (29%) contained no explanation as to who in the local authority decided whether the family had an eligible need for targeted or specialist services. In those councils where an explanation was provided (71%) parents were generally signposted to a 'short breaks team' or 'social services disabled children's team'. Only half (53%) of the statements surveyed provided a telephone number or email address to enable contact to be made with the decision making team.

Carers.

As noted in the legal overview below (Annex I) 'short breaks' services are primarily aimed at providing support for carers. The Children Act 1989¹² requires that councils provide services designed to assist family carers of disabled children 'to continue to [provide care], or to do so more effectively, by giving them breaks from caring'. The 2011 regulations¹³ require that local authorities, when discharging this duty, have regard to the needs of family carers 'who would be able to provide care for their disabled child more effectively if breaks from caring were given to them ...'. This duty was reinforced in April 2015 when authorities became subject to a duty to assess parent carers¹⁴ and young carers¹⁵ on the 'appearance of need' – ie a duty not predicated upon a request and triggered if it appears to the authority that they may have needs for support. The survey sought to ascertain whether short breaks statements: (1) reflected the fact that the support was primarily directed at sustaining carers; and (2) reflected the enhanced rights of parent carers and young carers to request an assessment or be given an assessment on the appearance of need.

¹² Schedule 2 para 6(1)(c).

¹³ The Breaks for Carers of Disabled Children Regulations 2011, SI 707.

¹⁴ Children Act 1989, sections 17ZD and 17ZE.

¹⁵ Children Act 1989 section 17ZA and 17B and *The Young Carers' (Needs Assessments) (England) Regulations 2015* SI 527.

Only 6% of the statements surveyed provided information to parents on how they can access a carers assessment – and even in such cases, the phrasing suggested that such assessments were discretionary – for example:

- For some short breaks we may need to assess your child and family to ensure that we provide the right level of support and short break services.

Likewise, of the short breaks statements surveyed only 6% mentioned young carers and none made any reference to the rights of young carers to an assessment. Although particularly troubling (given that about a third of young carers are caring for a disabled siblings¹⁶) this comes as little surprise. The Cerebra Legal Entitlements Research Project has consistently identified failures by councils to assess the needs of young carers (and indeed parent carers).¹⁷

Transport

The observed failure of the short break statements surveyed to highlight the central importance of 'giving carers' a break is also evident in their treatment of 'transport'. This again is an issue that has been prominent in referrals taken by the Cerebra Legal Entitlements Research Project.¹⁸ If a parent carer has to transport their disabled child to a short break activity it may impair or indeed entirely negate the value of the 'break' that would otherwise accrue. The survey sought to ascertain whether short breaks statements made reference to transport and what support was available to assist with it. 63% of the statements surveyed contained no reference to transport at all. Of those statements that made mention of transport, some acknowledged that a lack of transport could be a barrier to children attending a short break and some recognised that parents could spend much of their short break taking the disabled child to and from the short break provision. Comments made by students (and extracts they identified from statements) include:

- 'Short Breaks Transport provides support for children/young people who have the most complex needs and/or families on a low income, where there is no other alternative transport and without which the child/young person would otherwise be unable to access provision. Funding is limited and will be assessed on a needs basis as applications are received.'
- 'Transport can be a barrier to accessing short break services for some children and young people. Work is on-going to determine how we can resolve this issue whilst keeping costs to a minimum and ensuring that it is offered fairly but not unnecessarily'.
- 'Providing transport is very expensive, and we think that the money is better spent on providing as many short breaks as possible within the budget.'
- 'It is recognised that transport can be an issue for some families in terms of accessing short breaks. Many short break providers therefore have transport arrangements. This will need considering by parents when making choices'.
- 'Aiming High capital funds were used to buy an adapted vehicle for Mencap to increase the number of young people able to attend their services'.
- Reference is made to the fact that families may be entitled to claim 'appropriate benefits' and have access to info about local transport.
- 'We know that transport is needed by many families in order for their children to get to their short break. We also know that transport is expensive and time consuming, children can often be on buses for longer than an hour. We will therefore be working with our parent forums to ensure that we provide transport fairly but not unnecessarily. We will be looking at how we can reduce the costs without preventing any child from enjoying their break.'

¹⁶ A 2013 US study looking at the siblings of disabled children found that they were almost three times more likely to have significant levels of problems in interpersonal relationships, their psychological well-being, school performance, or use of leisure compared to other siblings – see Goudie, A., Havercamp, S., Jamieson, B., & Sahr, T., 'Assessing functional impairment in siblings living with children with disability' in *Pediatrics* Vol. 132 No. 2 August 1, 2013.

¹⁷ See for example The Cerebra Legal Entitlements Research Project Digest of Opinions 2013 Alice's Story page 1; Ron's Story page 3; and the Digest of Opinions 2014 Kumar's Story p20; and Peter's Story p24 accessible at <https://w3.cerebra.org.uk/help-and-information/legal-entitlements-research-project/>

¹⁸ See for example The Cerebra Legal Entitlements Research Project Digest of Opinions 2013 Harry's Story page 8 and the Digest of Opinions 2014 Claire's Story p38 and Tom's Story p43 accessible at <https://w3.cerebra.org.uk/help-and-information/legal-entitlements-research-project/>

Right to challenge

The decision to undertake research concerning short break statements arose from the volume of referrals taken by the Cerebra Legal Entitlements Research Project concerning contested 'short break' decisions. It is logical to assume that this is not an isolated problem and that significant numbers of families with disabled children may be dissatisfied with their short break support provision. The survey sought to ascertain whether short breaks statements contained advice as to what families who were dissatisfied could do. 81% of the statements surveyed contained no mention of the legal right to challenge an assessment; to challenge the amount of short break support, or indeed how or to whom families should complain if dissatisfied. Where information was provided concerning the right to challenge, it was 'variable'. An impressive example was as follows:

- 'If parents, carers or young people are not in agreement with the decision that panel has made they should initially discuss any concerns with the Social Worker who completed the care plan or the Duty Senior Social Worker. Please call the Disabled Children's Team. If the issues are not resolved at this first stage then you will need to officially appeal the panel decision within 14 days of the panel date. You can do this by contacting the manager of the Disabled Children's Team. The proposed short breaks care plan will be reconsidered by the next available panel. This panel will have at least one different member from the panel where the original decision was made. Parents, carers and young people are invited to attend and any further information will be considered. If the issue is not resolved at panel then the parent, carer or young person can follow the [named local authority] complaints procedure ...'

Other less impressive examples identified by the students (and extracts they identified from statements) include:

- There is a 'tell us what you think' section, but not clear if it is for response or for the actual statement and services they offer.
- There is an organisation which gives feedback to council for parents known as Our Voice Matters.

- 'If a service user or carer is unhappy with any aspect of short break activities, they should contact the organisation providing the service to raise their concerns. Each provider has a complaints procedure. If the response is unsatisfactory, in some circumstances CYPs complaints team can look into concerns raised'

Disability Living Allowance

A troubling factor that has arisen in relation to a few referrals taken by the Cerebra Legal Entitlements Research Project concerns the failure of local authorities to distinguish between an eligible need (for social care support purposes) and the fact that a disabled child may be receiving a particular social security benefit. So concerned was the Department of Health about this problem that in 2012 it issued policy guidance¹⁹ to address it. The guidance referred to evidence that 'some local authorities were taking the mobility component [of DLA] into account when considering what social services to be provided'. It then stated that the 'Department would like to make the position clear' that:

... local councils have a duty to assess the needs of any person for whom the authority may provide or arrange the provision of community care services and who may be in need of such services. They have a further duty to decide, having regard to the results of the assessment, what, if any, services they should provide to meet the individual's needs. This duty does not change because a particular individual is receiving the mobility component of Disability Living Allowance.

Students were asked to identify references to DLA in the short breaks statements so that the relevance of these statements could be ascertained.

¹⁹Department of Health (2012) Charging for Residential Accommodation and Non-Residential Care Services LAC(DH)(2012)03 paras 9-11.

In some cases, however, receipt of DLA can be used as a simple screening tool to fast track a disabled child for specialist support. This would appear administratively sensible – provided that disabled children who were not in receipt of DLA also had the opportunity to qualify for support. In this context 16% of authorities mentioned DLA (or referred to the child's special educational needs (SEN)) as an eligibility criteria for targeted or specialist services (ie without recourse to an assessment) and in half of these authorities it was made clear that not being in receipt of DLA or a Statement of SEN / Education, Health and Care Plan did not mean that the child was ineligible for support.

In a few cases reference in the short breaks statements to DLA were troubling in that they either implied that receipt of the benefit disqualified families from support, or created a presumption against such support. Examples identified by the students (and extracts they identified from statements) include:

- 'Where families receive DLA Mobility allowances the onus will be on them to transport their child to short breaks other than in exceptional circumstances.'
- 'However, any cost for the activities will need to be covered by the family. Many families choose to use their disability living allowance (DLA) to fund activities or a support worker.'
- 'Options for travel expenses such as the DLA mobility element'.

Conclusions

See Executive summary – page 5 above.

ANNEX I

The Applicable Law - England

Short breaks for disabled children – legal overview²⁰

Disabled children

The principal Act that places duties on local authorities to care for disabled children in England is the Children Act 1989.²¹ A 'disabled child' is given a very wide definition by the Act²² - and this includes children with physical and sensory impairments as well as those with a 'mental disorder of any kind'.

The duty to assess disabled children

Local authorities are under a duty to assess the needs of disabled children²³ and their carers. The duty to assess parent carers and young carers is considered separately below.

The principal guidance concerning the assessment duty is found in a document known as Working Together (2015).²⁴ This requires that every assessment 'should be focused on outcomes, deciding which services and support to provide to deliver improved welfare for the child' (para 52). Once an assessment identifies a need for support, there is a duty on the authority to meet that need both under the Children Act 1989, section 17 and / or the Chronically Sick and Disabled Persons Act 1970 section 2.

²⁰ A detailed account of the duty to provide short break support can be found in S Broach, L Clements and J Read *Disabled Children: Legal Handbook* (2nd) LAG 2015.

²¹ Although the Chronically Sick and Disabled Persons Act 1970, section 2 is the provision by which most disabled children's support services are actually provided.

²² Section 17(11), namely a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and 'development' means physical, intellectual, emotional, social or behavioural development; and 'health' means physical or mental health.

²³ *R (G) v Barnet LBC and others* [2003] UKHL 57; (2003) 6 CCLR 500 and see also Children and Families Act 2014 s36 and the SEN and Disability Regulations 2014 regs 3-10.

²⁴ HM Government, *Working together to safeguard children* (2015) issued under section 7 of the Local Authority Social Services Act 1970, which requires authorities 'to act under' such guidance.

The duty to meet the needs of a disabled child under the 1970 Act is strict in the sense that it is non-resource dependent. Accordingly if the assessment identifies a need for (say) 10 hours of sitting services a week then this need must be met precisely and it is not something that the local authority can 'trim'²⁵ because it has to make cut backs due to resource shortages.²⁶

The support that can be provided under the 1970 and 1989 Acts include a very wide spectrum of services such as adaptations, equipment, transport, meals, talking books etc. One important category of support, however, concerns services which replace that provided by the child's usual carers – eg sitting services, after school / holiday clubs, placement in short-break centres or short term fostering support. These arrangements often have a dual benefit – in that they also provide a short-break for those caring for the disabled child: be they parents, or other family / friends (both adults and children).

In order to decide whether a disabled child and his or her carers are eligible for support (and of what kind / how much) local authorities are required to have written criteria that explain how entitlement is determined.

Short break services

Although the law is not always clear in relation to the process for determining eligibility for many of the support services a disabled child needs, it is much clearer in relation to the duty to provide short break support services. In this respect, the Children Act 1989 Schedule 2 para 6(1) (c) requires local authorities to provide services designed to assist family carers of disabled children 'to continue to [provide care], or to do so more effectively, by giving them breaks from caring'. 2011 regulations²⁷ require that local authorities, when discharging this duty, have regard to the needs of family carers 'who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to (i) undertake education, training or any regular leisure activity, (ii) meet the needs of other children in the family more effectively, or (iii) carry out day to day tasks which they must perform in order to run their household' (reg 3(b)).

Regulation 4 states that 'a local authority must provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or to do so more effectively'. These services must include a range of daytime care, overnight care and leisure activities (regulation 4(2)). This range of services must be set out in a 'Short Breaks Services Statement' (regulation 5).²⁸ This statement must include the range of services provided in accordance with regulation 4, any criteria by which eligibility for those services will be assessed, and how the range of services is designed to meet the needs of carers in the area.

The 2011 Regulations therefore impose a duty on local authorities to secure a sufficient supply of a wide range of short break services and to publish clear and transparent information about these services and how they can be accessed.

2011 practice guidance²⁹ provides a helpful summary for local authorities of the requirements imposed by the 2011 Regulations – including a requirement that local authorities must consider 'the legal implications of the eligibility criteria they apply to short breaks services' and suggests they should 'not apply any eligibility criteria mechanistically without consideration of a particular family's needs' (p4).

The 2011 practice guidance summarises the benefits of short breaks both for disabled children and parents (p7): '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'. The advice reiterates a central theme of the 2011 Regulations, being that 'short breaks should not just be there for those at crisis point' (p8). At p15, the advice correctly notes that 'local authorities must give families the choice to access short breaks services using a direct payment'.

²⁵ *In R v Islington LBC ex p Rixon* (1996) Times 17 April; 1 CCLR 119 Sedley J put it thus: 'The practice guidance ... counsels against trimming the assessment of need to fit the available provision'.

²⁶ Complaint 01/C/03521 against North Yorkshire 19th August 2002.

²⁷ The Breaks for Carers of Disabled Children Regulations 2011, SI 707.

²⁸ The SEN Code requires at para 4.44 that the Short Breaks Services Statement should be published with the 'local offer' for each local authority; see further para 3.XX on the local offer requirements relating to social care.

²⁹ DfE, *Short Breaks for Carers of Disabled Children: Departmental advice for local authorities*, (March 2011).

At 4.5-4.6, the advice describes the benefit of a 'local offer' of non-assessed short breaks to which families with disabled children can refer themselves. The advice notes the importance of having fair eligibility criteria for this kind of service but states that 'Local authorities can provide families with access to short breaks services without any assessment'.

Parent carers

In 2014 the Children Act 1989 was amended³⁰ to provide specific rights for 'parent carers'. The pre-existing law also provides for other adults (ie non-parents) who care for a disabled child.³² The 1989 Act³³ now obliges local authorities to assess parent carers on the 'appearance of need' – i.e. if it appears to a local authority that a parent carer may have needs for support (or is requested by the parent). Such assessments are referred to as 'parent carer's needs assessments'. Having undertaken such an assessment the authority must then determine whether the parent has needs for support and, if so, what those needs are.

Parent carers' needs assessments must include 'an assessment of whether it is appropriate for the parent carer to provide, or continue to provide, care for the disabled child, in the light of the parent carer's needs for support, other needs and wishes'³⁴ and must also have regard to:³⁵

- the well-being of the parent carer (see below³⁶), and
- the need to safeguard / promote the welfare of the disabled child and any other child for whom the parent carer has parental responsibility.

The requirement to consider 'well-being' brings with it the duty of the authority to consider a list of factors specified in the Care Act 2014 s1. These include such factors as (a) personal dignity; (b) physical and mental health and emotional well-being; (c) protection from abuse and neglect; (d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided); (e) participation in work, education, training or recreation; (f) social and economic well-being; (g) domestic, family and personal relationships; (h) suitability of living accommodation; (i) the individual's contribution to society.

Young carers

In 2014 the Children Act 1989 was also amended to strengthen local authority duties towards 'young carers' – namely people under 18 who provide or intend to provide care (unpaid) for another person.³⁷ Many young carers are providing care for a disabled sibling. The Act places a specific duty on local authorities to undertake assessments as to whether a young carer within their area has support needs (and if so, what those needs are) if—

- (a) it appears to the authority that the young carer may have needs for support, or
- (b) the authority receive a request from the young carer or a parent of the young carer to assess the young carer's needs for support.³⁸

The duty to assess is therefore a proactive obligation: one that is triggered by the 'appearance of need' (ie there is no requirement that a request is made). The Act and regulations³⁹ made under it provide considerable detail as to how 'young carer' assessment must be undertaken.

³⁰ Section 17ZD inserted by Children and Families Act 2014, section 97.

³¹ Adults who provide or intend to provide care for a disabled child for whom the person has parental responsibility Children Act 1989, section 17ZD(2) and see para 3.XX above for the definition of a 'disabled child'.

³² Carers (Recognition & Services) Act 1995 section 1.

³³ Sections 17ZD and 17ZE.

³⁴ Children Act 1989, section 17ZD(9).

³⁵ Children Act 1989, section 17ZD(10).

³⁶ Children Act 1989, section 17ZD(11); 'well-being' has the same meaning as the Care Act 2014 section 1.

³⁷ Children Act 1989 section 17ZA and 17B.

³⁸ Children Act 1989, s17ZA(1).

³⁹ The *Young Carers' (Needs Assessments) (England) Regulations 2015* SI 527 made pursuant to the Children Act 1989 17ZB(8).

ANNEX II

The Applicable Law - Wales

Short breaks for disabled children – legal overview - Wales

Disabled children

The principal Act that places duties on local authorities to provide social care support for disabled children and their families in Wales is (from the 6th April 2016) the Social Services and Well-being (Wales) Act 2014.

For most purposes the Welsh Act does not distinguish between a disabled child and any other child 'in need of care and support' (s21). However where the Act makes specific reference to a 'disabled child' (for example when referring to people caring for a 'disabled child') the Act gives 'disabled' the same meaning as in the Equality Act 2010.⁴⁰

The duty to assess disabled children

Section 21(1) of the 2014 Act places a duty on local authorities to assess children 'in need of care and support in addition to, or instead of, the care provided' by their family. The duty is triggered by the 'appearance of need': there is no need for a request. Accordingly if any employee of the local authority (eg a teacher, housing officer, social worker etc) is aware of the child having needs for support, an assessment should be undertaken. The same is true for the duty to assess carers (and is discussed below). Of great importance, section 21(7) states that the presumption is that disabled children have needs for such additional / substitute care and support.

The relevant guidance stresses that in undertaking the assessment, local authorities must:⁴¹

Identify all presenting needs including those which would be deemed as eligible if a carer was not meeting those needs. This is so that the local authority is able to respond appropriately and quickly where the carer or the child's family becomes unable or unwilling to meet some or all of the identified care and support needs.

Regulations⁴² and guidance flesh out the requirements of the Act. The relevant guidance is found in two statutory Codes: one under Part 3⁴³ of the Act (relating to the assessment process) and the other under Part 6⁴⁴ (which is concerned with the special position of 'looked after and accommodated' children). The regulations and guidance deal with such matters as the depth of assessments,⁴⁵ and the maximum timescale for completion of the assessment (namely 42 working days from the point of referral⁴⁶). Assessments must be sufficiently detailed in order to identify the needs of the disabled child and their families and carried out by a social worker or practitioner who is competent and with the requisite knowledge and skills to carry out an assessment. In this situation it will require knowledge and competence in relation to a disabled child and his/her family. Assessments of carers and disabled children may be combined – but only if it would be beneficial to do so⁴⁷ and the parties agree to this.⁴⁸

⁴⁰ Section 3(5) Social Services and Well-being (Wales) Act 2014. The Equality Act 2010 (section 6(1)) definition being a person who has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities – see also Equality Act 2010 (Disability) Regulations 2010 (SI 2128) reg 3.

⁴¹ Para 80 to the Part 3 Code.

⁴² The Care and Support (Assessment) (Wales) Regulations 2015 2015 No. 1305 (W. 111) – the ('assessment regulations').

⁴³ The Code of Practice on the exercise of social services functions in relation to Part 3 (Assessing the needs of individuals) of the Social Services and Well-being (Wales) Act 2014 – see www.assembly.wales/Laid%20Documents/sub-LD10410/sub-LD10410-e.pdf

⁴⁴ The Code of Practice on the exercise of social services functions in relation to Part 6 (Looked after and accommodated children) of the Social Services and Well-being (Wales) Act 2014 <http://www.assembly.wales/Laid%20Documents/SUB-LD10411/SUB-LD10411-e.pdf#search=LD10411>

⁴⁵ Regulation 3 of the assessment regulations and para 43 of the Part 3 code set out appropriate levels of qualification for those undertaking assessments which include **either** a registered social work or social care practitioner holding a professional qualification at level 5 or above or a person holding a social care qualification at level 4 or above.

⁴⁶ Para 78 of the Part 3 Code.

⁴⁷ Para 37 of the Part 3 Code.

⁴⁸ The Explanatory Notes to section 28 of the Act provide more detail on the meaning of valid consent and the circumstances in which the requirement for valid consent may be dispensed with.

In undertaking assessments the assessor must have regard to (among other things) the requirements of the UN Convention on the Rights of Children (section 7) and to the United Nation Convention on the Rights of Persons with Disabilities.⁴⁹ Assessments must record basic data (known as the 'Core Data Set')⁵⁰ and focus on five inter-related elements⁵¹ - namely the person's (1) circumstances; (2) their personal outcomes; (3) the barriers to achieving those outcomes; (4) the risks to the person/ others if the outcomes are not achieved; and (5) the person's strengths and capabilities.

The Part 3 Code at para 76 (and following) gives emphasis to the vital importance of assessments being child focused, advising that:

The process of assessment is about ensuring that the best interests and well-being of the child are met and children are safeguarded so that they reach or maintain a satisfactory level of health and development, or their health and development will not be significantly impaired. The central duty is to safeguard children and young people and to promote their well-being.

Eligibility

Regulations⁵² specify (in essence) that a disabled child is eligible for support provided by the local authority if, for a disability related or safeguarding reason, the child: (1) has a need relating to one of the eight factors listed below and (2) the need cannot realistically be met by the child or their family/ social circle. The eight factors are:

- ability to carry out self-care or domestic routines;
- ability to communicate;
- protection from abuse or neglect;
- involvement in work, education, learning or in leisure activities;
- maintenance or development of family or other significant personal relationships;

- development and maintenance of social relationships and involvement in the community; or
- achieving developmental goals;

If the local authority is of the opinion that it does not have to provide support because the need can be met by the child or their parents or by others who are willing to meet it or by support services to which they have access then the authority must identify this support and give its reasons for so thinking. The relevant Code⁵³ (para 32) explains:

The eligibility criteria must not be used as a tool to require individuals to demonstrate they have exhausted every other possible avenue of support before becoming eligible for local authority assistance.

Short break services

Unlike in England, there is no Welsh legislation (from April 2016) that is specifically labeled 'short breaks' or targeted on the rights of families with disabled children to 'short breaks'. The previous provisions were repealed by the 2014 Act and this has been the subject of adverse comment.⁵⁴ The Welsh Government has however undertaken to publish guidance (a 'technical briefing') concerning the continuation of the duties for provision of short breaks. The commitment to produce such guidance was noted in a 2014 Children's Commissioner for Wales report⁵⁵ concerning short breaks. It stated that the 'benefits of short breaks for children and young people cannot be underestimated' and that 'positive feedback from children and families about the value of their short breaks provision has been overwhelming' (p7). At page 11 of the report it was noted that:

Welsh Government has committed to ensuring that the continuing need for short break service provision is recognised in the regulations and codes of practice which will accompany the Social Services and Well-Being (Wales) Act.

⁴⁹ Para 67 of the Code of Practice on the exercise of social services functions in relation to Part 2 (General Functions) of the Social Services and Well-being (Wales) Act 2014 at <http://www.assembly.wales/Laid%20Documents/SUB-LD10420/SUB-LD10420-e.pdf#search=LD10420>

⁵⁰ Para 59 of the Part 3 Code.

⁵¹ Para 63 and Annex 1 of the Part 3 Code.

⁵² The Care and Support (Eligibility) (Wales) Regulations 2015 SI 1578 (W. 187) reg 4.

⁵³ The Code of Practice on the exercise of social services functions in relation to Part 4 (Meeting needs) of the Social Services and Well-being (Wales) Act 2014 at <http://www.assembly.wales/Laid%20Documents/SUB-LD10409/SUB-LD10409-e.pdf#search=LD10409> – and at para 33 it adds 'It is the responsibility of the local authority to identify and record on the assessment and eligibility tool how the personal outcomes will be achieved.'

⁵⁴ See for example Clements L *Why implementation of new Welsh social care legislation must be delayed* in Community Care 19th November 2015.

⁵⁵ Children's Commissioner for Wales Full Lives: A study of short breaks provision for children and young people with disabilities and their carers in Wales (2014) at <http://dera.ioe.ac.uk/20554/1/465.pdf>.

While such guidance will be a welcome addition, it is clear that the core provisions of the Act are designed to provide a range of support services for families with disabled children and (although not specifically named) 'short breaks' are one of these essential support services.

Once a local authority has determined that a disabled child (or her/his carers') have eligible needs, then the authority must prepare a plan⁵⁶ that explains the 'operational detail' - the 'how, who, what and when'.⁵⁷ The plan must describe how the need is to be met, by whom, in what way and when this will be done. As the Ombudsman has stressed, an assessment must result in a care plan that identifies the child's needs, what is to be done about these needs, by whom and when. If a direct payment is made, it must specify precisely what need these payments are intended to meet, why this level of payment is considered appropriate, or what outcome this will result in.⁵⁸ A copy of the assessment record must be offered to the disabled child and their parent(s).⁵⁹

The guidance gives considerable emphasis to the provision of timely support for families, stressing for example that it is 'important to identify early on what needs the family has and provide appropriate support and/or make appropriate referrals'.⁶⁰

The duty to meet the needs of the child and/or his/her carers is strict in the sense that it is non-resource dependent. Accordingly if the assessment identifies a need for (say) 10 hours of sitting services a week, or of one weekend a month for the child to be accommodated away from the home – then this need must be met precisely and it is not something that the local authority can 'trim'⁶¹ because it has to make cut backs due to resource shortages.⁶²

The need for short breaks support may arise either from a disabled child's assessment or that of his/her carers: as section 34(1) of the 2014 Act explains, a local authority may meet a person's needs by arranging for 'something to be provided to a person other than the person with [the assessed needs]'. Section 34(2) provides examples of what can be provided in such cases and this includes the three most common mechanisms for facilitating short breaks – namely (a) accommodation in a care home, children's home or premises of some other type; (b) care and support at home or in the community; (g) direct payments. Examples of (b) would include sitting service (including a night sitting service) as well as a day centre and an after-school (or summer holiday) club. Where the need has been assessed as eligible, the Act (section 51) and the relevant regulations⁶³ and guidance⁶⁴ enable the parent to require the local authority to make them a direct payment rather than arrange the necessary care.

Short breaks and 'looked after' children

Short breaks can also be provided by the child spending time in an overnight placement: for example, a foster home or respite care centre. These arrangements are covered by separate regulations⁶⁵ and a Code⁶⁶ to Part 6 of the 2014 Act. Paras 288 – 301 of the Part 6 code provide advice on the legal obligations relating to such children (under the heading 'Short breaks'). While it emphasises (at para 289) that 'short breaks will often be provided as part of a disabled child's care and support plan' (ie under Parts 3 and 4 of the Act) it states (para 288):

Sometimes it will be appropriate to place a child with a foster carer or in a residential setting for a short period of time only – for example, if the child is disabled and it is necessary to place the child away from home temporarily while the parents have a break from caring.

⁵⁶ Section 54 Social Services and Well-being (Wales) Act 2014

⁵⁷ *R (J) v Caerphilly CBC* [2005] EWHC 586 (Admin); (2005) 8 CCLR 255.

⁵⁸ Local Government Ombudsman complaint number 13 002 982 against Birmingham City Council 12 March 2014.

⁵⁹ Reg 6 The Care and Support (Assessment) (Wales) Regulations 2015 SI 1305 (W.111) and para 116 to the Part 3 Code.

⁶⁰ Para 70 of the Part 3 Code.

⁶¹ *In R v Islington LBC ex p Rixon* (1996) Times 17 April; 1 CCLR 119 Sedley J put it thus: 'The practice guidance ... counsels against trimming the assessment of need to fit the available provision'.

⁶² Complaint 01/C/03521 against North Yorkshire 19th August 2002.

⁶³ Care and Support (Direct Payments) (Wales) Regulations 2015 SI 1815 (W. 260) at <http://www.assembly.wales/Laid%20Documents/SUB-LD10414/SUB-LD10414-e.pdf#search=Care%20and%20Support%20%28Direct%20Payments%29%20%28Wales%29%20Regulations%202015>

⁶⁴ The Code of Practice on the exercise of social services functions in relation to Part 4 (Meeting needs) of the Social Services and Well-being (Wales) Act 2014 at <http://www.assembly.wales/Laid%20Documents/SUB-LD10409/SUB-LD10409-e.pdf#search=LD10409>

⁶⁵ The Care Planning, Placement and Case Review (Wales) Regulations 2015 SI 1818 (W.261).

⁶⁶ Code of Practice on the exercise of social services functions in relation to Part 6 (looked after and accommodated children) of the Social Services and Well-being (Wales) Act 2014 at <http://www.assembly.wales/Laid%20Documents/SUB-LD10411/SUB-LD10411-e.pdf#search=LD10411>.

Unfortunately the guidance in the Part 6 Code is far from helpful as to the legal position in such cases.⁶⁷ It suggests (para 290) that where such a placement occurs 'the local authority may decide' that the short break support is provided under section 76(1)(c) of the Act.⁶⁸ The guidance provides a list of factors that should be considered in determining whether the care is provided under section 76(1)(c) or under the general duty to meet the needs of the child under section 37 of the Act (at para 292). Where it is decided that the child is accommodated under section 76(1)(c) then the placement must comply with the relevant 'looked after' children regulations⁶⁹ - however these will generally be of a lighter touch in terms of administrative record keeping⁷⁰ - provided that the child is not subject to a care order and is receiving a pre-planned series of short breaks in the same setting, and where (a) no single placement lasts for more than 4 weeks; (b) at the end of the placement the child returns home to the care of the parents; and (c) the short breaks don't exceed 120 days in a year.

Carers

Section 24(1) of the 2014 Act places a duty to assess the needs of people who provide or intend to provide care for a disabled child. As noted above 'disabled' has the same broad meaning as in the Equality Act 2010.⁷¹

The same principles that apply to assessments of disabled children apply to assessments of carers – ie assessments of carers and disabled children may be combined (but only if it would be beneficial to do so;⁷² and the parties agree to this⁷³) and a copy of the assessment record must be offered to the carer.⁷⁴ The duty is, again, a proactive one (ie not dependent upon a request). As the guidance notes:⁷⁵

The duty is triggered if it appears to the local authority that a carer may have needs for support. The duty to assess applies regardless of the authority's view of the level of support the carer needs or the financial resources he or she has or the financial resources of the person needing care.

Section 24 requires that carers must be fully involved in their assessments. It places substantial duties on local authorities and contains a powerful list of rights for carers. These include:

- The duty to assess applies regardless of the authority's view of the level of the carer's needs for support, or their financial situation (s24(3));
- Specific consideration of
- the extent to which the carer is able, and will continue to be able, to provide care, and the extent to which the carer is willing, and will continue to be willing, to do so (s24(4));
- whether the carer works or wishes to do so (s24(5));
- whether the carer is participating in or wishes to participate in education, training or any leisure activity (s24(5));

⁶⁷The Code, for example, at para 291 suggests that the obligation under this section is a 'power' when it is clearly a 'duty'. The difficulty arises because section 76 has no 'power' to accommodate (unlike section 20(4) of the Children Act 1989) – ie in cases where the child does not meet the strict requirements of s76(1) but nevertheless the authority considers it necessary to treat the child as 'accommodated' to safeguard or promote their welfare.

⁶⁸This is broadly equivalent to the duty under section 20(1) Children Act 1989 in England.

⁶⁹The Care Planning, Placement and Case Review (Wales) Regulations 2015 SI 1818 (W.261).

⁷⁰Regulation 62(3) – and see paras 295-301 of the Part 6 Code.

⁷¹Defined by section 6(1) Equality Act 2010 as a person who has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities – see also Equality Act 2010 (Disability) Regulations 2010 (SI 2128) reg 3.

⁷²Para 37 of the Part 3 Code.

⁷³The Explanatory Notes to section 28 of the Act provide more detail on the meaning of valid consent and the circumstances in which the requirement for valid consent may be dispensed with.

⁷⁴Reg 6 The Care and Support (Assessment) (Wales) Regulations 2015 si 1305 (W.111) and para 116 to the Part 3 Code.

⁷⁵Page 5 of the Part 3 Code.

Young carers

In general the 2014 Act does not distinguish between the rights of adult carers and those of young carers although there are minor differences in relation to the assessment duty. Although the local authority must, for both adult (s24(4)(c)) and young carers (s24(4)(d)), seek to identify the outcomes that they wish to achieve, for young carers this is qualified by it being 'to the extent' that it is 'appropriate having regard to the carer's age and understanding', and the views the parents of the young carer on this question and their well-being generally (24(4)(d)). Young carer assessments must also pay particular regard to the developmental needs of the child, and whether it is appropriate for the child to be providing the care at all (24(5)(c)).

As with the assessment duty owed to disabled children (s21(6)) the way a carers assessment is undertaken should be 'proportionate in the circumstances' (s24(7)). Proportionality goes to the scope and depth of an assessment – and not (of course) to the question of whether one is undertaken: the duty to assess (where a need may exist) is obligatory.

Summary of the carer assessment duty

Stage 1

There is a pro-active duty on local authorities to offer assessments to all carers where it 'appears' to the authority (ie who appear to any arm of the authority) that they 'may' have needs for support.

Stage 2

The Act (section 24) requires an assessment of all such carers. Frequently the nature of the need will not be clear until such an assessment has been undertaken.

Stage 3

When undertaking an assessment, section 24 and the regulations require the local authority to have regard to a wide range of factors and s24(7) states that provided these are considered the 'nature of the needs assessment ... is one that the local authority considers proportionate in the circumstances'. This means that the local authority must look at the need for such things as: support, preventative services, information, advice or assistance, and also whether the carer works or wishes to do so; whether they want to participate in education, training or any leisure activity etc. Although the authority must consider these factors – it is up to the authority how it does this: it is for the authority to decide what is 'proportionate'.

Stage 4

Having completed the assessment, if the authority is satisfied that the person has needs for 'support' then it must decide if any of these needs meet the eligibility criteria: it is the need for 'support' that is the triggering issue, requiring that the authority take the assessment to the next stage.

Stage 5

Section 32 states that where an authority has done an assessment which has revealed that the person has needs for care / support then it must decide if these needs meet the eligibility criteria and if they do then it must meet those needs by providing assistance in a variety of ways (listed in section 34). The support may be provided to the carer – although more commonly it will be provided to the disabled child as a form of replacement care. The range of supports include (for example): (a) accommodation in a care home, children's home or premises of some other type; (b) care and support at home or in the community; (c) services, goods and facilities; (d) information and advice; (e) counselling and advocacy; (f) social work; (g) direct payments; (h) aids and adaptations; and so on (s34(2)).

ANNEX III QUESTIONNAIRE

Legal Entitlements Research Project October 2015

Survey - Local Authority disabled children's "Short breaks statements"

Name of relevant body/local authority

Q.1 Without using the search engine write down in the box below the names of the hyperlink options you used in order to find the short breaks statement (including the false trails).

How many clicks did it take? _____

Q.2 *Do you consider this was an easy process to follow?*

Yes ☐

No ☐

If No – give your reasons (prompt – did the first page of the website have a logical point to start: were the headings specific (eg disabled child / carer – rather than nebulous – eg ‘well-being’ etc)

Q.3 *Using the authority's search facility which of the following words / phrases give a result that takes you to details concerning Disabled Children's 'Short Breaks Statements'.*

NB Limit the search to the first 5 pages of 'search results'

- | | | |
|---------------------------|------------------------------|-----------------------------|
| a) Respite | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| b) Services for families | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| c) Health and Social Care | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| d) Breaks for Carers | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| e) Short breaks | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| f) Local Offer | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

Comments (if any)

The statement

Q.4 *Is the statement clearly identifiable?* Yes ☐ No ☐

Q.5 *Does the statement explain in easy to understand language who is entitled to short break support (ie it is it written in simple English and avoid jargon and does not presume an understanding of the law, etc.)?* Yes ☐ No ☐

If 'No' – give your reasons (prompt – the language is not simple; jargon words are used [if so name these]; it refers to the law [if so identify the phrases used]; it refers to other documents / policies which need to be read, etc.)

Q.6 Does the short break statement identify different categories of provision (prompt – ie Universal, Targeted and Specialist etc)

Yes ☐

No ☐

If 'Yes' - what are these categories?

Q.7 If the short break statement identifies a basic or 'universal' category of provision, are there any restrictions on who is able to access this support? (prompt – does it exclude children with Attention Deficit Hyperactive Disorders (ADHD) or is restricted to groups /activities that would not be suitable for a child requiring a high level of support etc.)

Yes ☐

No ☐

If 'Yes' what are the restrictions?

Q.8 If the short break statement identifies a basic or 'universal' category of provision, are there limits to the amount of support that can be obtained (prompt – does it limit the support to a maximum number of hours or to specific days etc.)

Yes ☐

No ☐

If 'Yes' what are these limits?

Q.9 Does the statement clarify if the universal services are subject to a charge?

Yes ☐

No ☐

Q.10 If universal services are subject to a charge, does the statement explain clearly how a reduction or waiver of the fee can be obtained?

Yes ☐

No ☐

Any comments – write here

Q.11 Universal services: is it clear how to access this support (prompt – does it give simple links – eg to the websites / telephone numbers the name of the organisation etc)

Yes ☐

No ☐

If 'No' what are the problems?

Targeted / specialist services

Q.12 If the short break statement identifies support that is not 'universal access' (eg specialist provision) are there any restrictions on who is able to access this support? (prompt – eg children with ADHD might be excluded etc.

Yes ☐

No ☐

Note – if there is a filter system that suggests that children with Special Educational Needs or DLA are automatically eligible – deal with this under Qs 15 and 16 below)

If 'Yes' what are the restrictions?

Q.13 *If certain children are excluded, does the statement explain how they can get help?* Yes ☐ No ☐ n/a ☐

Q.14 *Does the statement specify clearly (ie in easy to understand terms) how eligibility for targeted / specialist provision is determined?* Yes ☐ No ☐

Any comments – write here

Q.15 *Does the statement refer to the disabled child being in receipt of Disability Living Allowance (DLA) as a criteria for eligibility for targeted / specialist provision?* Yes ☐ No ☐

Q.16 *Does the statement refer to the disabled child having ‘special educational needs’ as a criteria for eligibility for targeted / specialist provision (prompt – ie the child is in a specialist school; is in receipt of a Statement of Special Educational Needs (SEN) or an Education Health and Care (EHC) Plan)?* Yes ☐ No ☐

Q.17 *If the eligibility criteria for targeted / specialist provision includes reference to the child having ‘special educational needs’ and/or DLA – does the statement make it clear that children without either DLA or ‘special educational needs’ may still qualify for support?* Yes ☐ No ☐ n/a ☐

Q.18 *Are there limits to the amount of support that can be obtained as targeted / specialist provision (prompt – does it limit the support to a maximum number of hours etc.)* Yes ☐ No ☐

If ‘Yes’ what are these limits?

Q.19 *If the answer to Q.18 is ‘yes’ – is there an explanation as to how support above the maximum can be obtained?* Yes ☐ No ☐

Q.20 *Is there a clear statement which explains how it is decided how much 'short-break' support is provided?*

Yes ☐

No ☐

Assessment/entitlement

Q.21 *Does the statement explain who decides whether the disabled child is eligible for targeted / specialist provision (prompt eg a social worker, panel, short break service provider).*

Yes ☐

No ☐

Q.22 *Does the statement explain clearly how to get an assessment of eligibility for targeted / specialist provision (prompt – ie does it give an email or telephone number to be used to make such a request, etc.)?*

Yes ☐

No ☐

Any comments – write here

Carers

Q.23 *Is there a clear statement that adult carers (ie parents, family members etc.) are entitled to an assessment*

Yes ☐

No ☐

Q.24 *If reference is made to adult carers having an entitlement to an assessment is there a clear explanation as to how to get such an assessment*

Yes ☐

No ☐

Q.25 *Is there a clear statement that young carers (ie siblings of the disabled child who are undertaking inappropriate care or suffering as a consequence of the disabled child's needs not being properly met) are entitled to an assessment?*

Yes ☐

No ☐

Any comments – write here

Q.26 *If reference is made to young carers having an entitlement to an assessment is there a clear explanation as to how to get such an assessment* Yes ☐ No ☐ n/a ☐

Q.27 *Are there any restrictions on parents/carers or young carers requesting an assessment (prompt e.g. only for those who care for a child with a severe disability).* Yes ☐ No ☐ n/a ☐

Transport

Q.28 *Does the short break statement explain how help with transport can be obtained (prompt – eg if the short break care would involve the family in travelling to a centre etc.)* Yes ☐ No ☐

Any comments – write here

Right to challenge

Q.29 *Does the short breaks statement explain what a family should do if unhappy with the local authority response to its request for help?* Yes ☐ No ☐

Any comment – write here (eg if there is a statement but it is unclear)

DLA

If during the survey you come across references to DLA (apart from in relation to the specific questions 15 and 17 above) please make a note of these in the box below. Such references might include that if the child is in receipt of DLA mobility component, no help is available for transport or that “many families use their DLA to pay for activities of this kind’ and so on).

Relevant references to DLA
