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Short breaks (respite): families of children with disabilities

1. Introduction

This paper provides an overview of short breaks (also known as respite services) for families of children with disabilities in Northern Ireland and the rest of the United Kingdom (UK).

2. What are short breaks?

The vast majority of children with disabilities in Northern Ireland live at home and are supported by their own families. Children with disabilities can also live with foster or adoptive parents, and a small number are living in residential settings.¹

Unpaid carers are people who provide help and support to a family member or friend. Support for carers is vital as they provide invaluable care and support, often over long periods of time.² Short breaks or respite services provide opportunities for disabled

¹ RQIA (2013) Baseline Assessment and Review of Community Services for Children with a Disability, http://www.rqia.org.uk/cms_resources/Community%20Services%20for%20Children%20with%20a%20Disability.pdf p7.

² Ibid

children and young people to spend time away from their primary carers.³ The purpose of the respite is to give carers a much needed break from their caring responsibilities.⁴

There are several ways a carer of a child with disabilities can get a break, whether through families or friends, or voluntary organisations who may offer a few hours of support each week. Alternatively, health care trusts (or local authorities as they are known in the rest of the UK) also provide services to enable carers to have a break. Breaks may, or may not, be repeated at regular intervals.

In terms of costs, respite care is not always free. It can be paid for by several means for example, by Direct Payments, government grants, charitable sources and by families through private means.⁵

The provision of short breaks differs across the UK, and this issue is considered further in the next sections of this paper.

3. Northern Ireland

According to the Department of Health, Social Services and Public Safety (DHSSPS), a short break service can broadly be described as “*any service which allows a disabled child to have enjoyable planned experiences away from his/her primary carers and gives carers a break from their caring responsibilities*”.⁶

Short break services are described as an integral component of family support initiatives designed to meet the needs of disabled children and their families.⁷ In Northern Ireland, they are delivered by Health and Social Care (HSC) Trusts in partnership with the community and voluntary sector. These services are intended to complement other forms of family support - such as assisting parents and families with the child’s personal care needs, or helping the family to engage the child in play or leisure experiences.

Short break care provision in Northern Ireland includes for example:

- day or overnight periods of care in the home of an approved carer;
- overnight periods of care in a residential children’s home;
- sitting and care services provided in the child’s home to allow the family to do other things;
- overnight care in the child’s home (in particular for children with complex physical healthcare needs to enable parents to have a night’s rest);

³ Every disabled child matters website <http://www.edcm.org.uk/campaigns-and-policy/short-breaks>. Website accessed 21.11.13.

⁴ NI Direct website: An overview of carers’ rights. Website accessed 21.11.13.

⁵ NHS Choices website getting a break from caring

<http://www.nhs.uk/CarersDirect/yourself/timeoff/Pages/Accessingrespitecare.aspx> Website accessed 21.11.13.

⁶ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

⁷ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

- befriending services aimed at undertaking specific activities with the child;
- community activities, including after-school, evening and weekend group activities; day trips and holidays.⁸

3.1 The legislative basis for short breaks

The main legislation in relation to disabled children is in the *Children (Northern Ireland) Order 1995*⁹ and the *Chronically Sick and Disabled Persons (Northern Ireland) Act 1978* (CSDP).¹⁰ The DHSSPS has made the following comments in relation to the legislation:

- Disabled children, by virtue of their disability, are defined as “children in need” under Article 17(C) of the Children Order. It is the duty of each Health and Social Care (HSC) Trust to promote the welfare of disabled children by developing a range of personal social services relevant to their needs (under Article 18 of the Children Order);
- Where a carer who has parental responsibility for a disabled child requests an assessment of his/her ability to provide care for the child, the HSC Trust must carry out an assessment and take account of this in deciding what, if any, services to provide (Article 18A of the Children Order);
- The HSC Trust is empowered to provide direct payments to persons who have parental responsibility for a disabled child, or the child if they are aged 16 or 17 years, if the child’s needs call for the provision of services under Article 18 of the Children Order (Article 18C of the Children Order);
- The HSC Trust is empowered to provide: inter alia assistance for a disabled child in his home (including adaptations); assistance in obtaining television, library or similar recreational facilities and games and outings or other recreational facilities outside his home; assistance in travelling to and from his home for the purpose of participating in any services provided to promote his social welfare; and to facilitate the taking of holidays by the child, whether at holiday homes or otherwise (Section 2 of the CSDP Act).¹¹

The DHSSPS has also published *guidance and regulations* in relation to respite care and the Children Order (1995) which is presented in Appendix 1.¹²

⁸ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

⁹ Legislation.gov.uk website: Children (Northern Ireland) Order 1995

<http://www.legislation.gov.uk/nisi/1995/755/contents/made> Website accessed 21.11.13.

¹⁰ Chronically Sick and Disabled Persons (Northern Ireland) Act 1978 <http://www.legislation.gov.uk/ukpga/1978/53> Website accessed 22.11.13.

¹¹ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

¹² Children Order 1995 (Guidance and Regulations) Volume 5 Children with a Disability: Short-term or respite care. <http://www.dhsspsni.gov.uk/co-volume5-children-with-disability.pdf>, p50-54 Website accessed 21.11.13.

Other legislation relevant to respite services includes the *Carers and Direct Payments Act (Northern Ireland) 2002*¹³ which made amendments to the Children Order in the areas that referred to children, particularly children with disabilities and their carers. This Act gives carers the right to request an assessment of their individual needs and places an obligation on Trusts to meet the needs of carers as assessed, including the need for respite care.¹⁴

3.2 Assessment of need

In Northern Ireland, the statutory duties are based on the assessment of need, and each arrangement reflects individual circumstances. The key assessment framework is the *Understanding of the Needs of Children in Northern Ireland* (UNOCINI).¹⁵ This framework allows for assessment and for the planning and review of services to children. It also includes a specific 'Child in Need' and family support pathway.

3.3 Number of children in receipt of short breaks

The DHSSPS has advised that figures which accurately capture the number of children receiving short break services, or the amount of provision received are not readily available.¹⁶ As the range of short break services are diverse, it is difficult to compare 'like with like'. In some cases, the service includes discretely measurable factors, such as the number of overnight stays in a short break care children's home, but in other cases, there are less measurable factors, such as the hours spent by children in summer schemes. Further complexity is added in that services are delivered in the following ways:

- directly by the Trust which manages and provides the service;
- indirectly whereby the Trust has a service level agreement with a voluntary organisation to provide the service; or
- through Direct Payments¹⁷ (cash payments made instead of providing services directly) to parents, or to young people aged 16 and over.

3.4 Costs

The DHSSPS has been unable to provide a breakdown of respite costs or funding, and there does not appear to be a ring-fenced budget in Northern Ireland for this purpose.¹⁸ Despite the requirement for an assessment, there have been issues with Trusts having insufficient resources to meet the level of need identified.

¹³ Carers and Direct Payments Act (Northern Ireland) 2002

¹⁴ Law Centre NI website. Respite care <http://www.lawcentreni.org/publications/frontline-magazine/392.html>
Website accessed 22.11.13.

¹⁵ DHSSPS (2011) *Understanding of the Needs of Children in Northern Ireland* Guidance.

¹⁶ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

¹⁷ NI Direct website: Direct Payments for Carers <http://www.nidirect.gov.uk/direct-payments-for-carers> Website accessed 21.11.13.

¹⁸ BBC NI news website. Respite care under threat. (2011) <http://www.bbc.co.uk/news/uk-northern-ireland-12250245> Website accessed 4.12.13.

Nevertheless, the DHSSPS states that there is a considerable variation in the costs involved in supporting arrangements, particularly where a continuum of services are needed to provide support to the child and carers.¹⁹ For example, the DHSSPS states that “one current support arrangement, which includes short breaks, is in excess of £162,000.²⁰ In other cases, one off payments, such as to support access to a summer scheme may be less than £50 and, while the sums may vary, the benefit in outcomes for the child have to be considered in the context of the child and family. In addition, while services may be provided, the HSC may not be the funder, as is the case where summer schemes are provided by local councils or sporting groups”.²¹

3.5 Input from other sources

The DHSSPS acknowledges the contribution of other sectors in the provision of short breaks services such as the voluntary and community sector, some of whom do not receive HSC Trust funding. Some examples of these other sources of respite support include:

Northern Ireland Children’s Hospice

The Northern Ireland Children’s Hospice²² is currently supporting over 250 families through either community-based support (hospice at home and Saturday day care) or through short stays within Horizon House. It is the largest provider of support to children with the most complex of needs, with a significant element of its funding coming through charitable sources, in addition to allocations under a formal contract with HSC Board. Some HSC Trusts have a contract with the Hospice to deliver ‘Hospice at Home’ but this represents only a small contribution in the overall amount of support which the Hospice requires to deliver Short Break care services.²³

Shared care schemes

Shared Care Schemes offer regular planned short breaks with approved host families to give primary carers a break and enhance the quality of children’s lives by offering new opportunities and new relationships outside the immediate family circle. These schemes can be provided by a range of providers including HSC Trusts, the community and voluntary sector and/or a combination of both under either contracted services or funding from a range of sources such as Big Lottery.

¹⁹ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

²⁰ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

²¹ Ibid

²² Northern Ireland Children’s Hospice website http://www.nihospicecare.com/childrens_hospice Website accessed 1.12.13.

²³ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

Community Outreach Care Services

Community Outreach Care Services involve outreach workers who are employed by an HSC Trust,²⁴ or by the community and voluntary sector, to provide short break care in an alternative form. The care can be provided either in the child's own home, or in the local community on a one-to-one basis or in small groups. Children referred to the service can engage in a wide range of activities, swimming, bowling, badminton, soft play centres, library and meals out which are based around the interests and wishes of the children. Services are provided primarily in the evenings and at weekends however staff can work flexibly during school holidays to meet the needs of each individual child. It is noted that such services can also be provided by local councils, Sporting Organisations, Youth Service, etc and while not funded by the HSC, referral can be supported by HSC.

There are also Community Development Models where Trusts have a worker dedicated to identifying and securing funding to support relevant voluntary and community sector programmes designed to offer short breaks. Such schemes also enhance the social opportunities for disabled children and young people.

Family Fund

In addition, the Family Fund²⁵ is a charitable body established in 1973 to manage an inter-territorial fund to provide financial assistance and information to families that have a child or children with a severe disability. The Fund is resourced by government departments in England, Scotland, Wales and Northern Ireland to undertake this function. The Fund offers a wide range of goods and services which may be focused on directly supporting the needs of the child with a disability but are equally aimed at improving the overall lot of the family adversely affected by a disability. The Department's allocation of £1.57m in 2012/13 allowed the Family Fund to support approximately 2,900 families with disabled children in Northern Ireland. Holidays/family breaks continue to be the Fund's biggest request – 918 were awarded in 12/13 with a total value of £502,927.²⁶

3.6 Review of Short Breaks

However, despite the various types of respite, a recent report by the Regulation, Quality and Improvement Authority (RQIA) into community services for children with disabilities illustrates high levels of unmet need and a lack of joined up and flexible respite services in Northern Ireland.²⁷ One of the report's recommendations is that:

Services should be based on assessed need, including domiciliary care; host

²⁴ Ibid

²⁵ Family fund website <http://www.familyfund.org.uk/news/news-and-announcements/northern-ireland-funding> Website accessed 1.12.13.

²⁶ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

²⁷ RQIA (2013) Baseline Assessment and Review of Community Services for Children with a Disability, http://www.rqia.org.uk/cms_resources/Community%20Services%20for%20Children%20with%20a%20Disability.pdf p 39. Website accessed 4.12.13.

*family schemes with trained and approved carers; social and recreational activities provided by volunteer and paid staff; and a range of short breaks and respite care services.*²⁸

Likewise, a previous report by the Patient and Client Council about respite for people with learning disabilities (including carers of those both under and over 18 years of age) shows that more respite places are needed for families in Northern Ireland, and that many families were unaware of the carers assessment process.²⁹

The DHSSPS have advised that the RQIA is undertaking a review of short breaks/respite provision for both adults and children in Northern Ireland.³⁰ This will consider current arrangements to develop such services; consider arrangements in place for taking account of the views of service users, families and carers; and address issues of access and quality of provision. It aims to publish their findings in the Spring of 2014.³¹

4. England

In England, short breaks for disabled children and their families are the responsibility of the Department of Education. The Department of Education has produced *Short Breaks Statutory Guidance*³² which states that:

*“Short breaks are part of a continuum of services which support children in need and their families. They include the provision of day, evening, overnight and weekend activities and can take place in the child’s own home, the home of an approved carer, or in a residential or community setting. Most users of short breaks are disabled children and their families but non-disabled children in need may also receive short breaks.”*³³

The statutory guidance seeks to improve outcomes for disabled children by providing guidance on how to safeguard and promote their welfare. The guidance also considers the vulnerability of the child, appropriate assessments and care planning. It is aimed at managers of services for looked after children, commissioners, social workers and families of disabled children.

²⁸ Ibid, p42.

²⁹ Patient and Client Council 2011 Respite (Short breaks), p20
http://www.patientclientcouncil.hscni.net/uploads/research/Bamford_-_respite.pdf Website accessed 29.11.13

³⁰ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

³¹ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13

³² Department for Education website: Short Breaks Statutory Guidance. Available online at:
<http://www.education.gov.uk/childrenandyoungpeople/send/g00222840/short-breaks-statutory-guidance> Website accessed 25.11.13.

³³ Department for Education website Short Breaks Statutory Guidance. Available online at:
<http://www.education.gov.uk/childrenandyoungpeople/send/g00222840/short-breaks-statutory-guidance-website> accessed 25.11.13, p7. Website accessed 21.11.13.

4.1 The legislative basis for short breaks

In England, part 3 of the *Children Act 1989*³⁴ sets out local authorities' powers and duties to provide support services for children in need and their families.³⁵ Short breaks can be provided by local authorities through the use of their powers under either Section 17(6) or under section 20(4) of the *Children Act 1989* as follows:

- Section 17(6) of the 1989 Act: this concerns children who are not 'looked after'. It grants local authorities a power to provide accommodation as part of a range of services in order to discharge their general duty to safeguard and promote the welfare of children in need; and
- Section 20(4) of the 1989 Act: this concerns children who are 'looked after'. It grants local authorities a power to provide accommodation 'for any child within their area (even though a person who has parental responsibility for him is able to provide him with accommodation) if they consider that to do so would safeguard or promote the child's welfare'.³⁶

4.2 Related legislation

Two other pieces of legislation also relate to the provision of short breaks in England namely:

- Section 10 of the *Children Act 2004*.³⁷ This provides the legal basis for partnership 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*.³⁸ This 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 *Children Act 1989*.

4.3 Departmental Regulations

Since 2011, the government in England has also introduced a duty on local authorities to provide a range of short break services for disabled children and young people, and to publish a short break statement that explains what is available locally and how it can

³⁴ Children Act 1989. Available online at <http://www.legislation.gov.uk/ukpga/1989/41/contents> Website accessed 21.11.13.

³⁵ Department for Education website Short breaks statutory guidance. Available online at: <http://www.education.gov.uk/childrenandyoungpeople/send/g00222840/short-breaks-statutory-guidance-website-accessed-25.11.13>, p7. Website accessed 25.11.13.

³⁶ Department for Education website Short breaks statutory guidance. Available online at: <http://www.education.gov.uk/childrenandyoungpeople/send/g00222840/short-breaks-statutory-guidance-website-accessed-25.11.13>, p7. Website accessed 25.11.13.

³⁷ The Children Act (2004) <http://www.legislation.gov.uk/ukpga/2004/31/section/10> Website accessed 21.11.13.

³⁸ The Carers and Disabled Children's Act <http://www.legislation.gov.uk/ukpga/2000/16/section/6> Website accessed 29.11.13.

be accessed.³⁹ The *Short Breaks for Carers of Disabled Children Regulations*⁴⁰ provide further detail on how local authorities must perform their duty in the *Children Act 1989* to provide breaks for carers of disabled children - to help them continue to care for their children at home and allow them to do so more effectively.⁴¹ In addition, the government also published advice for local authorities in terms of the Regulations.⁴² This advice states that the Regulations require local authorities to do three things, namely:

- 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.

Local authorities are also required to publish these statements on their websites and to review them on a regular basis.

4.4 Government funding for short breaks

In terms of government funding, £800 million has been made available to local authorities in England for short breaks through non-ringfenced (early intervention) grants between 2011 and 2015.⁴³ Increased funding for short breaks was originally identified in the Department of Education's *Aiming high for disabled children: better support for families (2007)* publication which sought to affirm the government's commitment to making disabled children and their families a priority.⁴⁴ In 2011-12 and 2012-13 an additional £40 million per annum was made available in capital funds for respite breaks.⁴⁵

The Department of education has advised that it is, however, for each individual local authority, in collaboration with local NHS services, to determine how it wishes to use

³⁹ Gov.uk website: Short break duty <https://www.gov.uk/government/publications/short-breaks-for-carers-of-disabled-children> Website accessed 21.11.13.

⁴⁰ Short breaks for carers of disabled children: Departmental advice for local authorities, Available online at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Breaks_for_Carers_of_Disabled_Children.pdf Website accessed 27.11.13

⁴¹ Legislation.gov.uk website: The Breaks for Carers of Disabled Children regulations. <http://www.legislation.gov.uk/ukSI/2011/707/made> Website accessed 25.11.13.

⁴² Short breaks for carers of disabled children: Departmental advice for local authorities, Available online at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Breaks_for_Carers_of_Disabled_Children.pdf Website accessed 27.11.13 p10. Website accessed 25.11.13.

⁴³ Short breaks for carers of disabled children: Departmental advice for local authorities, Available online at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Breaks_for_Carers_of_Disabled_Children.pdf Website accessed 27.11.13 p3. Website accessed 21.11.13.

⁴⁴ Department of Education (2007) *Aiming high for disabled children: better support for families* <http://webarchive.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/publications/eOrderingDownload/PU213.pdf> Website accessed 3.12.13.

⁴⁵ Personal correspondence with author and Adriana Sarjant, Special Educational Needs and Disability Division, Department of Education (England). Response dated 22.11.13.

available funding in the light of local circumstances, its own assessment of individual needs, and the appropriate provision to be offered against any agreed local eligibility criteria. It is important that, whatever decision is reached, the local authority and local NHS services continue to assess the individual needs of disabled children and their families, and that appropriate care packages continue to be put in place.⁴⁶

4.5 Charges for respite provision

Under the *1989 Children Act*, it is possible for local authorities to make a reasonable charge for short breaks services. However, it is not lawful to levy charges if someone is on income-related benefits such as Income Support, Child or Working Tax Credits, Job Seekers' Allowance or Employment and Support allowance.⁴⁷ Provided that they operate within the legal framework described above, decisions about how much to spend on short breaks, what sort of break they want to provide and how much, if anything - to charge, are a matter for each local authority.⁴⁸

5. Wales

5.1 The legislative basis for short breaks

In Wales, short breaks are provided for in *The Breaks for Carers of Disabled Children (Wales) Regulations 2012*⁴⁹ which are made under paragraph 6 of schedule 2 to the *Children Act 1989* used in England. The Regulations imposes duties on the 22 Welsh local authorities, as part of the range of services they provide to families, to provide breaks from caring, in order to assist parents and others who provide care for disabled children. Sub-paragraphs (1)(c) and (2) of paragraph 6 of schedule 2 were inserted by the *Children and Young Persons Act 2008* (section 25).

There is a requirement for each local authority to prepare a statement setting out the range of services provided, any criteria by which eligibility for those services will be assessed and the range of services is designed to meet the needs of carers in its area. The Welsh Government is also providing a small amount of funding to Short Breaks Network⁵⁰ - a charitable organisation - to undertake a review of local authority statements.

Short breaks are not "defined" as such, but according to the Department for Health and Social Services in Wales, regulation 4 requires that they should include, as appropriate, a range of a) daytime care in the homes of disabled children or elsewhere, (b) overnight care in the homes of disabled children or elsewhere (c) education or

⁴⁶ Personal correspondence with author and Special Educational Needs and Disability Division, Department of Education, response dated 22.11.13.

⁴⁷ Personal correspondence with author and Adriana Sarjant, Special Educational Needs and Disability Division, Department of Education (England). Response dated 22.11.13.

⁴⁸ Personal correspondence with author and Adriana Sarjant, Special Educational Needs and Disability Division, Department of Education, response dated 22.11.13.

⁴⁹ Legislation.gov website *The Breaks for Carers of Disabled Children (Wales) Regulations 2012*

<http://www.legislation.gov.uk/wsi/2012/1674/made> Website accessed 21.11.13.

⁵⁰ Short Breaks Network Wales <http://www.shortbreaksnetwork.org.uk/wales> Website accessed 3.12.13.

leisure activities for disabled children outside their homes, and (d) services available to assist carers in the evenings, at weekends and during the school holidays.⁵¹

5.2 Costs

The cost of short breaks is met by each local authority in Wales. The Welsh Government has advised that it does not provide any additional funding to local authorities specifically for this purpose.⁵² Nevertheless, it has not been possible to contact all authorities for this research request because of the variety of forms of support and variable costs.

6. Scotland

In Scotland, as elsewhere in the UK, there are many kinds of respite arrangements to help children with disabilities and their families. Each local authority (of which there are 32 in Scotland)⁵³ and health board (of which there are 14) will decide on their priorities and how best to address the need for respite.⁵⁴ They may provide respite services directly, jointly, or commission them from other service providers, although the majority of such services are likely to be delivered by the local authority.⁵⁵

6.1 The legislative basis for short breaks

Local authorities in Scotland have duties under *The Children (Scotland) Act 1995*⁵⁶ regarding assessment, services and support to children with disabilities, children affected by disability, and their families. The local authority has a duty to carry out an assessment of the child, or of any other person in his or her family, in order to ascertain the child's needs and the effect of disability on them, if asked to do so by the child's parent or guardian (Section 23:3).⁵⁷

The *Children (Scotland) Act 1995* also requires the local authority to assess the carer's capacity to provide, or to continue to provide care, during their assessment of the disabled child (Section 24). These services should be designed to minimise the adverse effects of disability and enable the child to lead lives which are as normal as possible.⁵⁸

⁵¹ Personal correspondence with author and Penny Hall, Social Services and Integration Directorate, Department of Health and Social Services, Welsh Government. Response dated 3.12.13.

⁵² Personal correspondence with author and Penny Hall, Social Services and Integration Directorate, Department of Health and Social Services, Welsh Government. Response dated 3.12.13.

⁵³ COSLA Scottish local Government <http://www.cosla.gov.uk/scottish-local-government> Website accessed 2.12.13.

⁵⁴ Scottish Government: Health Board <http://www.scotland.gov.uk/Topics/Health/NHS-Workforce/NHS-Boards> Website accessed 29.11.13.

⁵⁵ Local authorities are autonomous bodies which are entirely separate from the Scottish Government. They are responsible for managing their own day-to-day business. They must use resources as efficiently as possible and deliver services effectively to ensure taxpayers get the best possible value.

⁵⁶ Legislation.gov.uk. The Children (Scotland) Act 1995. <http://www.legislation.gov.uk/ukpga/1995/36/contents> Website accessed 2.12.13.

⁵⁷ Personal correspondence from author and Dawn Sungu, Carers Policy Unit, Adult Care and Support Division. Response dated 14/11/2013

⁵⁸ Personal correspondence from author and Dawn Sungu, Carers Policy Unit, Adult Care and Support Division. Scottish Government. Response dated 14/11/2013.

In addition to the *Children (Scotland) Act 1995*, the *Social Care (Self-directed Support) (Scotland) Act 2013*⁵⁹ makes a number of improvements to children's rights. For example, the Act concentrates on the provision of choice to children and families during their social care assessment. It provides a variety of options for the provision of support and it requires the statutory body to "give effect" to the child or family's choice/preferences.

6.2 Regulations

Children who are placed for respite in a residential or family setting in Scotland for more than twenty-four hours in any one period, that is, where the child remains away from his or her home overnight, are 'looked after' by the local authority. In turn, the *Looked After Children (Scotland) Regulations 2009*⁶⁰ apply to these children.

In order to safeguard and promote the welfare of children while they are placed for respite away from their own homes, a series of short planned placements (which include overnight stays) may be treated as a single placement, provided all the placements occur within a period which does not exceed one year, no single placement is of more than four weeks duration and, the total duration of the placement does not exceed 120 days. However, these regulations do not apply if the family arranges their child's respite using the direct payment option, within self-directed support.⁶¹

6.3 Policy

In addition to legislative provisions, a national programme in Scotland entitled *Getting it right for every child*⁶² aims to improve the wellbeing of children and young people through a personalised outcomes approach.⁶³ The *Getting it right for every child* approach ensures that *anyone* providing support puts the child or young person and their family at the centre.

Respite placements must be subject to a care plan. A first review of the care plan should take place within 6 weeks of the placement; a second within three months of the first review and every six months thereafter. Children should receive a medical before the series of placements commences.

The duration of the respite break must allow the carer a break from caring tasks; for this reason a minimum duration of one hour is required for the service episode to count as respite for the purposes of this performance indicator. The carer may use the break for any non-caring activity they choose.

⁵⁹ Legislation.gov.uk website. Social Care (Self-directed Support) (Scotland) Act 2013 <http://www.legislation.gov.uk/asp/2013/1/contents/enacted> Website accessed 21.11.13.

⁶⁰ Legislation.gov.uk website. Looked After Children (Scotland) Regulations 2009 <http://www.legislation.gov.uk/ssi/2009/210/made> Website accessed 21.11.13.

⁶¹ Personal correspondence from author and Dawn Sungu, Carers Policy Unit, Adult Care and Support Division. Scottish Government. Response dated 14/11/2013.

⁶² The Scottish Government. Getting it right for every child <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright/background> Website accessed 29.11.13.

⁶³ Personal correspondence from author and Dawn Sungu, Carers Policy Unit, Adult Care and Support Division. Scottish Government. Response dated 14/11/2013.

6.4 Budget

The Scottish Government is investing, through the voluntary sector, over £8 million between 2010-2015 in the provision of respite breaks.⁶⁴ This fund is being administered through *Shared Care Scotland's Better Breaks Programme*⁶⁵ and the Family Fund's *Take a Break Programme*.⁶⁶ The *Take a Break Programme* aims to support carers, (including kinship carers) and their families to take a break to improve their physical and emotional well-being, enabling them to enjoy life and opportunities outside of caring.

As the 'Take a Break' is a limited fund, the average grant is in the range of £200-£500 per family. To date, it is estimated that over 15,000 families have benefitted from both programmes.⁶⁷

In 2013-14, the Scottish Government is providing local government in Scotland with over £10.3 billion in funding. The vast majority of the funding, including the funding for disabled children, is being provided by means of a block grant. The Scottish Government has agreed with the Convention of Scottish Local Authorities (COSLA)⁶⁸ that there should be a presumption against any new ring fenced funding, as it is the responsibility of each local authority to allocate the total financial resources available on the basis of local needs and priorities.⁶⁹

6.5 Cost of breaks

The costs of a respite break in Scotland, like elsewhere, will vary depending on the needs of the child, type and duration of service available and possible travel, escort and professional care arrangements required to support the child's respite break. These costs are routinely met by the local authority and/or health board. Most, if not all local authorities and health boards do not charge families for these services. However some may expect families to contribute to, or undertake transport arrangements if they are out with routine school transport and/or at weekend/during holiday periods. This may be done by the family transporting their child, or using their Disability Living Allowance (mobility) component.

7. Bringing Northern Ireland 'into line'?

The research request also asked about how the provision that exists in England and Scotland could be made applicable to Northern Ireland; if new primary legislation would

⁶⁴ <http://www.sharedcarescotland.org.uk/>

⁶⁵ Shared Care Scotland website. Better breaks programme <http://www.sharedcarescotland.org.uk/short-breaks-fund/Better+Breaks.html> Website accessed 21.11.13.

⁶⁶ Shared Care Scotland website. Take a break programme <http://sharedcarescotland.org.uk/short-breaks-fund/Better+Breaks/Take+a+Break.html> Website accessed 2.12.13.

⁶⁷ Personal correspondence from author and Dawn Sungu, Carers Policy Unit, Adult Care and Support Division. Scottish Government. Response dated 14/11/2013.

⁶⁸ COSLA <http://www.cosla.gov.uk/> Website accessed 2.12.13.

⁶⁹ Personal correspondence from author and Dawn Sungu, Carers Policy Unit, Adult Care and Support Division. Scottish Government. Response dated 14/11/2013.

be required to do so, or through amending existing legislation. Unfortunately, to answer this question fully would require legal expertise.

As highlighted in the paper, respite provisions in Northern Ireland differ from across the UK in terms of guidance, regulations and funding levels.

Fundamentally, the *Children Act 1989* does not apply to Northern Ireland (see Section 108 of the 1989 Act). However, the DHSSPS has advised that primary legislative provisions contained in the *Children (Northern Ireland) Order 1995* mostly replicate those provided in the *Children Act 1989* except for the following provisions:

- Section 22 (1)(b) of the *Children Act 1989* states that a reference to a child who is looked after by a Local Authority does not include a child who is provided with accommodation under section 17. In the *Children (NI) Order 1995* there is not this distinction. Disabled children provided with accommodation lasting more than 24 hours for respite care purposes are considered to be ‘looked after’ children.
- Section 17b of the *Children Act 1989* provides for vouchers for persons with parental responsibility for disabled children. This provision means that a local authority may issue a voucher which, if they consider that it would help the person with parental responsibility for the disabled child care for him if he had a break from his caring responsibilities, may be used to secure the temporary provision of services for the child under section 17. There is not an equivalent provision to the Voucher Scheme in the *Children (NI) Order 1995*.⁷⁰

In addition, the timescales set out in Northern Ireland Regulations differ from those in England and Wales – in Northern Ireland, no single placement is to last for more than **4 weeks** and the total duration of the placements is not to exceed **90 days** in any period of 12 months (see Appendix 1).⁷¹ In England, no single placement is to last more than 17 days and short breaks must not exceed 75 days in a 12 month period.

Furthermore, the DHSSPS has stated that there is a funding disparity in terms of children’s services in Northern Ireland when compared to elsewhere in the UK.⁷²

The author of this paper also asked the Departments in England and Wales their view on the changes that might be needed in Northern Ireland regarding the legislation and if provision were to be changed, and their responses were as follows:

“Of course, as a general rule, health and social services are devolved competencies for the Northern Ireland Assembly, so any attempts to extend short breaks to Northern Ireland by Parliament would require a legislative consent motion”.

Adriana Sarjant, Department of Education, England.

⁷⁰ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13.

⁷¹ Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13.

⁷² Personal correspondence with author and DHSSPS DALO. Response dated 3.12.13.

“This question is probably one for lawyers but I would have thought that you would require primary legislation as the Children Act and Children and Young Persons Act apply to England and Wales only as far as I am aware.”

Penny Hall, Department of Health and Social Services, Welsh Government.

Appendix 1: Children Order 1995 (Guidance and Regulations)

Extract from Volume 5 Children with a Disability: Short-term or respite care (p50-54)

11.11 Respite care should be provided in the context of a package of care for families. Many children with a disability are cared for away from home or usual placement on a short-term basis as part of a planned programme or respite care. Respite or short-term care for families with a child with a disability has developed historically as an emergency service – frequently providing short-term care within a long-stay hospital or other institution in order to meet a family crisis.

11.12 Some children still receive such care in a hospital setting. This may be appropriate where the child has substantial medical, therapy and nursing needs. It is clear government policy that children with a learning disability should no longer live in long stay mental handicap hospitals. Instead, if a hospital setting is required, the aim should be to provide care in small homely, locally-based units. However for most children care provided by Trusts or voluntary organisations will be appropriate with an input from child care services if required. There are examples of community facilities run by Trusts and voluntary organisations, sometimes working in partnership, which achieve high standards of respite care.

11.13 A number of evaluations of respite care schemes have shown varied patterns of use by families, with some a few hours a week with occasional overnight stays while others opted for shared care arrangements in which the child spent regular periods away from home. It is important to acknowledge the stresses associated with the child using respite care for the first time and sensitive introductions are required.

Application of regulations

11.14 The Children Order regulations relating to placements make special provision for short-term placements within schemes which are variously known as respite care, phased care or family link schemes. Under such schemes, a Trust or voluntary agency makes arrangements for a child who normally lives with his family – and whose family continues to exercise full parental responsibility – to spend short or sometimes longer periods of time with an approved foster parent or in a residential home. These regulations apply to all placements for more than 24 hours. The arrangements for respite care vary greatly and many schemes only make provision for day-time or occasional over-night stay. In these cases, if the provision of services to the family does not include accommodating the child for a period of more than 24 hours, then the regulations relating to placements do not apply. However, good practice requires that all such provision is properly planned.

11.15 It is important to note that, in respect of arrangements which do not involve a Trust initially, that under the Children Order the private fostering provisions come into force after a child has been, or it is intended that he will be, living with a foster parent for more than 27 days. Up until then, the registration system regulating child minders

applies. This requires the Trust to register a person who, for reward, cares for children aged under twelve on domestic premises, provided they are satisfied that the person is fit to care for such children. The Order requires Trusts to impose requirements on a registered person about the number of children he may care for, safety of the premises and equipment, records to be kept and notification of changes. In cases where parents make their own arrangements for respite care for their child by contracting with a child minder, they are responsible for ensuring that these are satisfactory although the Trust's responsibilities in respect of child minding will apply. It is important that Trusts' registration officers find out about child minders who intend to offer a respite care service so that the appropriate requirements are imposed on the person's registration. In such cases attention needs to be paid to the sleeping arrangements, the type of equipment available, training needs and information about other resources in the community.

11.16 Some children may spend longer periods of time away from home and it is necessary from the start to clarify the purpose of the respite care, to plan for the child's use of a particular service and to acknowledge that respite care may or not meet all the needs of the child and family. Respite care may be only one component of a package of services.

11.17 Regulation 13 of the Arrangements for Placement of Children (General) regulations allows for a pre-planned respite care arrangement involving a series of placements at the same place to be treated as a single placement. The length and timing of the individual placements within this arrangement need not be specified in advance, but all the placements should occur within a period which does not exceed one year, no single placement should exceed four weeks and the total time spent by a child in respite care should not exceed 90 days. The purpose of this provision is to allow the regulations to be applied once in relation to a series of placements if the conditions above are met.

11.18 Under the Arrangements for Placement of Children Regulations. Trusts or voluntary organisations are required to have a plan for each child setting out the proposed respite care arrangements as required under these regulations. The Foster Placement (Children) Regulations apply in all other respects for family placements. Children may only be placed with an approved foster parent – but a foster parent may be approved if desired for a respite care scheme only and the chosen name of the scheme and the carers may be used within the agreement. Regulations require medical examination of the child at stated intervals, but do not set out the form the examination should take nor whether it should be a child's GP or a consultant who should carry it out. The matter should be discussed with the parents, the child, the carers, the consultant responsible for the child and the GP if doubt exists about the most appropriate person to carry out the medical examination. It is envisaged that these examinations will be part of the usual health care arrangements for the child.

11.19 The formalisation of previously more informal arrangements is to safeguard the welfare of the child. Some parents perceive regulated foster care arrangements as relating to care proceedings and inadequate or uncaring parenting. Equally some of the families recruited for family-based respite care have never seen themselves as foster parents and may be alarmed at the prospect of a more regulated service. In practice all good family-based respite care schemes have always operated upon a firm principle of written agency and parent agreements and planning around the individual needs of children. The recruitment and training procedures for respite carers should now include opportunities to explain the new basis of regulating respite care and the mutual advantages to children, parents and respite carers of having greater accountability for the service provided. Positive publicity should emphasise the advantages of working within a planned framework which supports both parents and carers.