

**Evidence review on models of support for families with disabled children**

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**|**

#  1. Introduction

## 1.1 Description of search:

This literature review looks at the evidence available on the models of support within local councils for families of disabled children, including evaluations of the different models. The purpose is to review accessibility of services, types of services, cost effectiveness.
This to take into account the severity of the disability, age of chid, number of disabled or other children in family, single parent families and socio economic group.

## 1.2 Databases searched:

Date range: 2015-2020.

Social Care online, LAPH database, Google site

## 1.3 Key terms:

short breaks, respite care, befriending schemes, awareness of services, access to services

## 1.4 Key findings:

**Access to services**- Councils have different requirements for access to targeted support service. Some require an assessment whereas others do not. Assessments are used to tailor support to the needs of the child. Although the literature shows that ease of access to service is important to parents, it is also found that assessments which lead to tailored needs can be more cost effective for councils.

**Control of access**- Local authorities use eligibility criteria and assessments to control who has access to short breaks services.

**Continued assessment**- Many councils have different methods to continually (often annually) make an assessment to ensure that the child and family are accessing the services appropriately.

**Alternative care**- Some councils included different types of care including community-based care and ‘transition’ support. The literature tells us that there is not enough information gathered about these types of services.

**Parent and carer involvement**- A key theme throughout the short breaks statements was the involvement of parents and carers in the evaluation and adaptation of services.

**Level of disability**- Specialist services may be required depending on the effects of the disability. Somerset Council offer a more tiered model than the usual targeted and specialist service, to identify and meet the needs of severely disabled children. The literature shows that for children who are severely disabled or have challenging behaviour, specialist services as well as targeted interventions may be the best way to support the family.

**Payments**- Direct payments are offered across all eight councils. Some councils offer further financial support to help disabled children attend universal services.

**Meet the needs of child and family**- Over all the literature outlines that a flexible approach to services and support, which consider the needs of the whole family are required. Many councils aim to offer a flexible model of service to support this.

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#  2. Short Breaks

## 1.2 Background:

Most Councils offer universal services which include a wide range of activities for all children. These can include: Scouts, Brownies, sporting clubs and youth clubs. Councils also offer **targeted services** or **specialist services** for children and families who need extra support due to a disability. Councils often follow an assessment criterion for these additional services to ensure that families get the support they need. Specialist services are for families with a child with challenging or complex behaviour and multiple disabilities. Recent models of short breaks and respite care offer a flexible approach and consider the needs of the whole family.

Short Breaks provide the families of children with disabilities or health conditions a break from their caring responsibilities. Short Breaks “*give children and young people who have a disability the opportunity to join in with an enjoyable activity away from their parents/carers.  Short Breaks allow children and young people to take part in activities, make friends, develop independence and have fun. Short Breaks also provide parents/carers a break from caring responsibilities.”.*1

## 1.3 Accessing to services

Local Authorities have a legal responsibility to assess the needs of any disabled child whose family may want or need services above the level of universal services and to provide short breaks to children where an assessment shows that they are necessary to meet their needs, taking into account of the family context.[[1]](#footnote-1)

Evidence from the council Short Breaks service statements shows that some councils have easier access to the targeted services than others ([see Appendix 1](#_Appendix_1) for table). Two of the eight councils state that no assessment is required to access targeted services. Others claim that targeted services are open access, but an assessment is required. Somerset Council require the child to have a statement of special educational need and receiving disability allowance to access targeted services including short breaks. ([see Appendix 2](#_Appendix_2) for Luton Council care pathway example).

A 2019 scoping review of the evidence of short breaks found that carers regularly cite access to breaks as one of three factors that could make a positive difference to their lives and help them achieve personal wellbeing outcomes, such as maintaining contact with friends and pursuing interests and hobbies (Seddon, D., Prendergast, L; 2019). Further evidence in the literature outlines how families have historically reported accessing short breaks services to be a challenge (Spruin, E., Abbott, N., Hold, N. 2018).

The models of services for both targeted and specialist support are similar across the councils involved in the review. **Targeted services** are for children who needed extra support. Targeted services include youth clubs, arts and sports activities, weekend activities, day care and holiday activities for the child and the family. Many activities are facilitated by an outside provider.

**Specialist services** are described in the statements as being for children who need specialist provision, and the child needs to be referred by an assessment with a social worker/ social care provider or health professional. Specialist services include overnight residential care or overnight family-based care and “sitting services”. Seven of the eight councils also included ‘direct payments’ within their list of special care services.

Somerset County Council provided a slightly different support model service although it is heavily based on the targeted and specialist support model. Their service is split into three: ‘Additional Assessment and support’, ‘Complex More Support’ and ‘Acute Specialist Support’ depending on the needs of the child. Additional Assessment and support are what would be described as targeted support. The other two categories are specialist services which has been split into two. The Acute Specialist Support is for children who have a severe impairment and may need overnight/ foster care.

### How to ensure the right children/families are accessing the right support?

The courts have upheld the use of eligibility criteria by local authorities to control access to short breaks. However, it is essential that any eligibility criteria are (1) published, including as part of the short breaks services statement and (2) consistent with the duties owed to individual children and families, particularly the duties to (a) assess all children ‘in need’ and (b) meet children’s assessed needs where it is ‘necessary’ to do so.1

Due to local authority finite budgets and a high demand in short break services, courts have upheld the use of eligibility criteria by local authorities to control access to short breaks. The fundamental principles of the lawful use of eligibility criteria are that:

• Short breaks are provided to first to children and families with higher levels of need before children and families with lower levels of need; and

• Children whose needs are assessed to meet the ‘specific’ statutory duties receive a level of service (or direct payments) sufficient to meet those needs.1

The High Court have made clear that eligibility criteria can only be used after an assessment of the child’s needs, not in place of an assessment at the appropriate level for the child, in accordance with the local assessment protocol.[[2]](#footnote-2) There is usually a list of criteria provided by the council for eligibility for Short Breaks access. Eligibility is often reviewed to ensure the correct support is being accessed.

Rutland County Council provide a step-by-step process of access to the short breaks scheme. This includes checking the eligibility criteria to see if the scheme is suitable for the child:

Children/young people aged 5-25 who are resident in Rutland and:-

* Have a place that is funded to Rutland County Council at a special school are in receipt of mid-rate Disability Living Allowance/PIP
* Are in receipt of higher level Disability Living Allowance/ PIP[[3]](#footnote-3)

If a family does not meet the criteria, they are encouraged to contact the council to find out what other support is available. Step two is applying to the scheme via an application form. Step three is choosing how your family would like to access short breaks.

Rutland County Council require families to complete a monitoring record twice per year showing how they spend the money and showing what difference this has made to the family. 1

Coventry Council offer short breaks through the provision of a support worker. In these circumstances, the relevant professional involved with the family (e.g. a social worker, early help worker or school representative) will complete an assessment to consider the child and family’s needs and what package of support would meet these needs.2

Targeted Short Breaks packages are approved at a [Short Breaks Panel](https://www.coventry.gov.uk/info/156/special_educational_needs_and_disabilities/1812/short_breaks/6). The Panel meets monthly and is chaired by the Operational Lead for the Children's Disability Team.

The Short Breaks Panel is specifically for children and young people who require consideration for [Targeted](https://www.coventry.gov.uk/info/156/special_educational_needs_and_disabilities/1812/short_breaks/4) and [Specialist Short Breaks](http://www.coventry.gov.uk/info/156/special_educational_needs_and_disabilities/1812/short_breaks/5). The panel aims to ensure equity and transparency in the allocation of resources to children/young people and their families. Those in the greatest need will receive the highest allocation of resources. The Panel ensures that services are needs led and that the provision is routinely monitored and reviewed. The Panel is open to all Social Care, Education and Health professionals.2

If a child or young person does not have a professional worker, their school can complete an assessment and request to attend the Short Breaks Panel. A parent can also refer their child or young person via the Multi-Agency Safeguarding Hub ([MASH](https://www.coventry.gov.uk/info/31/children_and_families/2186/coventrys_multi_agency_safeguarding_hub_mash)) for an assessment to consider support needs.[[4]](#footnote-4)

Durham Woodland Primary school outline a graduated approach to assessing and reviewing support. This takes the form of cycles of “Access, plan, do , review”:

* **Assess** a child’s special educational needs – This would include assessment by teachers supported by the SENCO, Observations and assessments carried out by the educational psychologist and advice from outside agencies.
* **Plan** the provision to meet your child’s aspirations and agreed outcomes – Additional or different provision is planned by the class teacher with support from the SENCO and external advice where it has been requested. Targets are set and formalized in a short note, a support plan or an EHCP and are discussed with parents/carers and the child.
* **Do** put the provision in place to meet those outcomes – Interventions are out in place and time and support is allocated for them to be carried out.
* **Review** the support and progress – The impact of any intervention is reviewed with teachers, parents/carers and the child looking at progress towards targets and next steps.

The result of this approach means that every child with SEN will have an individualised SEN support plan which describes the child’s needs, outcomes and provision to meet those needs. Durham states that parents/carers and child/ young persons views are integral to this process.

## 1.4 Alternative respite

Alternative respite care is described in the literature as “*alternative breaks provided by host family support arrangements, supported holidays (taken together and apart), access to leisure and arts facilities, the provision of equipment (for example, a bicycle), the provision of space (for example, a shed) and technologies (for example, telecare).”* (Seddon, D., Prendergast, L; 2019). Much of the literature on the impact of short breaks focuses on traditional models of short breaks rather than alternative types of support. This highlights significant gaps in knowledge of the role of alternative models of short breaks, particularly the impact of alternative short breaks that more away from traditional models. (Seddon, D., Prendergast, L; 2019).

Evidence shows that home-based care is preferred by many families, although for some parents, this does not give them a complete break for their daily routine. A flexible approach is required to meet the needs of the parent and child. By taking part in activities in the local community disabled children are helped to feel that they are living ‘ordinary lives’ (Stanley, K. 2008). Coventry Council offer a ‘Community short breaks’ service with emphasis on engagement with community-based activities. “*Community short breaks provide group activities for children and young people with disabilities to relax, have fun, make new friends and develop independence skills. Activities last up to 2 hours during term time and school holidays. Our aim is to ensure that all children accessing the service have the support they need to engage in community-based activities. To see the latest term-time and school holiday activity timetables, go to our What’s On page*.”[[5]](#footnote-5)

Haringey Council was the only council to mention support for ‘transition’ from childhood to adulthood in their Short Breaks statement. At Haringey Council short breaks are provided jointly with colleagues in Adult Services. Their statement states that they ensure that short breaks address the ’transition’ needs of people moving from childhood to adulthood. Opportunities to develop the following life skills are provided:

* Employment
* Independent Living
* Friends, Relationships and Community
* Good Health

The short breaks on offer support young people to:

* Manage risk, whilst keeping themselves safe in the community
* Develop decision making skills
* Manage money
* Travel independently
* Improve social interaction skills though modelling with peers
* Lead ordinary lives, enjoying and contributing to everyday activities

## 1.5 Payments

All eight of the council short breaks service statements offered a personal budget through direct payments. Coventry Council outline that the direct payment is based the number of hours, days, weeks and nights that is requested to meet the needs of the child which are determined by their assessment with a social worker. 1 Similarly, Luton council outline that the decision on the allocation of the amount of the direct payment is decided by a multi-agency panel, based on the outcome of the assessment.[[6]](#footnote-6)

As well as direct payments, Oxfordshire County Council provide a Max Card Discount Scheme to support parents and carers. “*The Max Card is a discount card for families of disabled children and children with additional needs. Families simply show their Max Card upon entry to a venue to obtain free or discounted admission. It is designed to help families save money on great days out at castles, zoos, bowling alleys and lots more.”[[7]](#footnote-7)* The Max card is free to families in Oxfordshire and  it has been funded by Oxfordshire County Council working in partnership with Action for Carers Oxfordshire.

Shropshire Council offer an additional ‘participation fund’ which is managed by the councils Disabled Children’s Team. The fund is designed to make local universal services more accessible to children with disabilities. It may be used to purchase specialist equipment so that a disabled child can attend local clubs or groups; to pay for additional hours for a support worker or fund attendance to an activity.[[8]](#footnote-8)

## 1.6 Evidence of impact of Short Breaks

A 2020 report by children’s charity ‘Together for Short Lives’ evidences the positive impacts that short breaks for respite have on families of children with life limiting conditions. The report ‘*Give me a break’* estimates that 11 percent of parents of children who need respite would experience significantly less stress and improved mental and physical health if they could access them. The report also highlights that providers of short breaks need to provide the service to meet the needs of a diverse range of families, including those from all ethnic backgrounds and socio-economic groups (Together for Short Lives, 2020).

A 2017 Health and Social Care Board (Northern Ireland) review of the evidence on short breaks found that respite care for short periods of time can reduce immediate stress for the family. However, more long-term effects on family functioning and improvements in child outcomes are improved by effective interventions specifically targeting these outcomes. “*One randomised control trial shows the additional benefit of including more components of family support alongside respite and short breaks provision and this results in the longest effect on parental outcomes assessed in any of the studies*” (Health and Social Care Board, 2017).

2. Evaluation/ Outcomes

Several of the council short break statements highlighted the importance of consulting with parents and families with regards to developing and evaluating the short break services. Coventry Council develop their short breaks offer in partnership with children, young people and their parents and carers via their engagement platform ‘Lets talk’. Ongoing feedback is gathered from users of the services via regular surveys, feedback opportunities and consulatations.1

Luton Council emphasise and importance of outcomes in their service statement. “The outcomes help us identify targets and link them to our service plan. Through regular parent consultation we endeavour to deliver what parents need and this process has resulted in the provision of parent led services including mentoring for parents, representation on our local authority strategic boards.”3

Haringey Council outlined in their statement that consultation with parents and carers, children and young people about the type of short break on offer is an important aspect of their service development. “*Ongoing consultation and co-production with parents tell us that parents and children want us to consider the following when planning and commissioning short breaks for their children:*

* *Age and ability appropriate activities/support*
* *Wide variety of activities to choose from e.g. sports, art, music, dance, cooking*
* *Appropriately trained staff who are empathetic and understand the needs of the children and young people, and can build real relationships*
* *Suitable levels of support*
* *Appropriate sensory environments where necessary*
* *Ability to provide feedback*
* *Choice and flexible delivery*
* *Opportunity to access short breaks at key times, including weekends and holidays*
* *The needs of the whole family to be taken into account*
* *The ‘basics’- all staff DBS-checked, facilities safe and clean etc*.”[[9]](#footnote-9)

A 2017 evaluation of the evidence on the outcomes and impacts of short breaks for children and young people with disabilities and their families found few robust evaluations of respite and short breaks provision, where the impact is compared to families who do not receive the service. However it found evidence that short breaks and respite care are highly valued by families and that they positively impact wellbeing of carers; that family relationships and stress levels improve; and some studies noted an increase in children’s independence, social skills, social awareness, interests and confidence (Sneddon, H. 2017).

None of the council short breaks service statements mentioned long-term outcome measures of the services.

3. Cost

According to the UK care guide, respite care costs on average £700-800 a week. It can be as much as £1,500 a week, for emergency respite care, live-in care, or staying in a care home.

There are 2 main ways of getting help with the costs of respite care:

* from the council
* from a charity

Or, you can pay for it yourself.[[10]](#footnote-10)

In 2009, it was estimated that the UK could make an estimated saving of £174 million if short breaks were effectively delivered to all those eligible to receive them (Health and Social Care Board, 2017). Some of the short break statements did outline that an assessment is required for targeted and specialist services so that support is distributed fairly to those that need it more. This would support a more economically effective service.

4. Severely Challenging Behaviour

A 2015 rapid review by the Institute of Public Care evaluated the role of residential respite care as a preventative intervention. The review was commissioned by Hampshire County Council to form part of their Innovation Fund ‘Active Agents for Change’ Evaluation and support for children at “The edge of care”. Children at the edge of care typically include children at risk of out-of-home placement due to abuse or neglect, children who are in high conflict with their families, children who have offended and children with poor mental health (Asmussen et al, 2012). However, the Institute of Public Care suggest that additional groups of young people are at risk of late entry into care. These include: Young people with a disability/ learning disability including those on the autistic spectrum who have been previously adequately care for by their families. (Institute of Public Care, 2015)

The review included a 2007 study which found some positive of respite care for young people and their families “*periods of respite not only relieved pressure but gave young people and parent’s time to reflect and to respond to the interventions by the professionals involved*” (Dixon and Biehal, 2007, p.74). The study included children with multiple and complex needs. Overall, the impact of a combined respite care/community support intervention seemed more likely to be successful in families where parenting was “inconsistent” or “weak” (Dixon and Bieham, 2007, p76. Sited in Institute of Public Care, 2015).

Parenting programmes can offer support for parents and families of children with learning disabilities, by helping the parents to acquire adequate parenting skills to provide sufficient and safe care. Such parents will also require long-term support to adapt to new challenges (Institute of Public Care, 2015). The review identified a number of practice pilots and linked evaluations ‘reframing’ the role of respite care as part of a positive intervention at the ‘edge of care’.

The 2015 review concluded that intensive, multi-faceted and integrated interventions for families with complex needs are more effective than routine services. The offer or short breaks and respite care can provide a break for the family or carer and prevent a child being placed into long-term care.

# 5. References

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Staley, K. (2008) Having a break: good practice in short breaks for families with children who have complex health needs and disabilities. Social Care Institute for Excellence

Together for Short Lives (2020) Give me a break: How the UK Government can improve parental health and reduce health inequalities by allocating short break funding for seriously ill children in England at the Comprehensive Spending Review; Together for Short Lives and Julia’s House Children’s Hospice.

# Appendix 1

|  |  |  |
| --- | --- | --- |
|  | **Targeted Service** | **Specialist service** |
| **Rutland County Council** | **Access:** Activities open to any disabled child/young person who lives in Rutland. Access to short breaks does not require an assessment to take part in universal or Aiming High targeted provision**Includes:** Aiming High Activities (youth clubs, art, dance, sports, music, weekend activities). Aiming High Short Breaks Scheme. | **Access:** Needs assessed by a social worker.**Includes:** Overnight residential or family-based care, sitting services, or access to Direct Payments |
| **Coventry City Council** | **Access:** In these circumstances, the relevant professional involved with the family (e.g. a social worker, early help worker or school representative) will complete an assessment to consider the child and family’s needs and what package of support would meet these needs.**Includes**: Does not outline what targeted service includes in short breaks statement. | **Access:** An assessment of need is required to access this service. This is through a Child and Family Assessment, undertaken by a social worker. **Includes:** Overnight short breaks |
| **Luton Borough Council** | Referred to as ‘Personalisation’ of the short breaks service. This is when an assessment is used to meet the needs of the child/family and the short breaks service is adapted to meet those needs. | **Access:** Short breaks packages are tailored to suit the needs of your family. Needs are identified via an assessment**Include:** * ­shared care
* ­residential care
* ­day care
* ­overnight care
* ­weekend care ­
* direct payments
 |
| **Oxfordshire County** | **Access:** Open Access services; children are assessed by the provider.**Includes:** Specialist holiday play schemes; group-based day care; individual day care. Open access after school, holiday and youth activities | **Access:** Allocated on the basis of a child and family assessment which is prepared by a social worker in accordance with the Assessment Framework for the assessment of children in need and their families. **Includes:** Direct payments, family based short breaks, overnight stays in residential units, short break provision for disabled young people with complex health care needs |
| **Somerset County Council** | In Somersets 2020 short breaks statement, they have tiered their support offer in the following way:**Additional Assessment and support:****Access:** Child must have a diagnosed disability, in receipt of disability living allowance (DLA)/ personal independence payments (PIP) or an Education Health and Care Plan (EHCP).**Includes:** Time limited support from the community Inclusion Activity Team, 1:1 support from a Somerset Supporter, Direct Payments and Specialist Club Provision**Complex More Support:****Access**: For children with a diagnosed disability, in receipt of DLA or PIP, or an EHCP.**Includes:** Same as ‘Additional Assessment and Support’ plus overnight short breaks through direct payments and Occupational Therapy Assessment and ongoing support if needed.**Acute Specialist Support:****Access:** This is for children who have had a medical diagnosis of severe physical impairments, learning impairment or autism Or has needs arising from their impairment that cannot be met by services within the universal or targeted service.**Includes:** Direct payments, overnight short breaks/ foster care and Occupational Therapy assessment and ongoing support if needed. |
| **Croydon Council** | **Access:** Direct access or following an assessment of need by the Children With Disabilities team**Includes:** After school clubs, holiday clubs and community groups • Early Help (supplied by third party organisation) Specialist after-school and Saturday schemes and clubs • Specialist sports activities • Summer holiday facilities (accessed by direct contact with provider) | **Access:** Via a relevant social care and provider assessment with a social worker or childcare team**Includes:** Specialist school, home support, domiciliary care enablers, family based short breaks, direct payment, overnights, sessional support, various other |
| **Shropshire Council** | **Access:** Accessing All-in Short Breaks does not require an Early Help or social worker assessment. However, it requires that • A child meets the eligibility (under age of 18, live in Shropshire Council area and have a disability that prevents them from accessing universal services without additional support). • A child becomes a member of All-in**Includes:** “All-in” Short Breaks programme. youth clubs, holiday schemes, swimming, horse riding, cycling, forest school, drama, football and also a log cabin for overnight stays. | **Access:** Eligibility is determined through an assessment by a social worker. It takes into account and considers; • The complexity and severity of the disability, • Family circumstances, • Other issues affecting the whole family,**Includes:** A range of Specialist Short Breaks are available such as specialist after school clubs, Family Based Shared Care, outreach, childminding, overnight care or Direct Payments |
| **Haringey Council** | **Haringey Council did not distinguish between targeted services and specialist services in their short breaks statement. The state that children and young people are eligible for short break services if they are aged between 0-17, live in Haringey and are eligible for services from the Disabled Children’s Team. Direct payments are available.** **Access:** Assessment with Special Educational Needs Co-ordinator (SENCO) or other professional.**Includes:** Holiday playschemes, family fun days and help in the home. Can vary from a few hours to a few days including nights and weekends. Family Link Scheme is available which has a number of carers who provide a range of both day and overnight stays to disabled children specifically under 10 years and under. Breaks are offered in the carers home or in the community. |

# Appendix 2



Luton Council: Care pathway for short breaks service

Disclaimer

We hope that you find the evidence search service useful. Whilst care has been taken in the selection of the materials included in this evidence search, the Library and Knowledge Service is not responsible for the content or the accuracy of the enclosed research information. Accordingly, whilst every endeavour has been undertaken to execute a comprehensive search of the literature, the Library and Knowledge Service is not and will not be held responsible or liable for any omissions to pertinent research information not included as part of the results of the enclosed evidence search. Requestors are welcome to discuss the evidence search findings with the librarian responsible for executing the search. We welcome suggestions on additional search strategies / use of other information resources for further exploration. You must not use the results of this search for commercial purposes. Any usage or reproduction of the search output should acknowledge the Library and Knowledge Service that produced it.

1. Council for Disabled Children (2017) *‘Short Breaks for Disabled Children: A legal guide for local authorities’* <https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Shortbreaks%20legal%20duty%20guide%20for%20LAs.pdf> [↑](#footnote-ref-1)
2. See R (JL) v Islington LBC [2009] EWHC 458 (Admin) at [98]-[99]. Short break care in the child’s home is provided under section 2(6)(a), while the provision of ‘recreational facilities outside the home’ is covered by section 2(6)(c). [↑](#footnote-ref-2)
3. Rutland County Council (2018) *Rutland Aiming High: Short Breaks Scheme 2018-2019* Rutland County Council [↑](#footnote-ref-3)
4. <https://www.coventry.gov.uk/info/156/special_educational_needs_and_disabilities/1812/short_breaks/4> [↑](#footnote-ref-4)
5. <https://www.coventry.gov.uk/downloads/file/31080/coventry_city_council_short_breaks_statement> [↑](#footnote-ref-5)
6. <https://www.luton.gov.uk/Health_and_social_care/Lists/LutonDocuments/PDF/ISCAN/short-breaks-2018-2019.pdf> [↑](#footnote-ref-6)
7. <https://www.oxfordshire.gov.uk/residents/children-education-and-families/information-parents/breaks-disabled-children> [↑](#footnote-ref-7)
8. <https://shropshire.gov.uk/media/12641/shropshire-statement.pdf> [↑](#footnote-ref-8)
9. <https://www.haringey.gov.uk/sites/haringeygovuk/files/send_short-breaks-statement-local-offer_final_jan_2019.pdf> [↑](#footnote-ref-9)
10. <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/> [↑](#footnote-ref-10)