

ESSENCE SUMMARY 12

Short breaks for adults with learning disabilities and behaviour that challenges: economic evidence

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BACKGROUND

Around 1.5 million people in the UK have a learning disability and challenging behaviour. The National Institute for Health and Care Excellence (NICE) developed a guideline on services for this population focusing on prevention, early intervention and minimising inpatient admissions.

A summary of the economic evidence from the NICE guideline is presented in this case study. Although respite care is intended to provide short-term and temporary relief for caregivers, it has unintentionally become a long-term placement for some individuals with developmental disability.

KEY POINTS

- Although short breaks (respite care) are intended to give time off caring to carers for adults with learning disabilities and challenging behaviour, it is commonly provided as residential care intervention for the service users (rather than for the carers).
- In evaluating short breaks, the work that fed into the NICE guideline did not find any robust evidence on their effectiveness or cost-effectiveness. Other information was available to suggest that the Guideline Committee should make a recommendation for short breaks that is potentially resource-intensive.
- Additional economic analyses from a public sector perspective demonstrated that short breaks at various intensities can be considered cost-effective and potentially cost-saving.
- Since the analyses were based on assumptions rather than evidence, NICE is very cautious about using the results to guide commissioning and provision decisions. Beyond the certainty of the potential cost range of short breaks, the economic analyses produced are speculative and their validity cannot be confirmed.
- A variety of national charities currently provide short breaks and other services for those with intellectual disabilities and challenging behaviour as well as their carers.

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CONTEXT

In the UK around 1.5 million people have a learning disability and challenging behaviour, and around 350,000 people have a severe learning disability (1). According to the National Institute for Health and Care Excellence (NICE), an individual with a learning disability has lower intellectual ability and significant social or adaptive functioning since childhood (2). Of those with learning disabilities and challenging behaviour in the UK, 148,000 adults accessed social care support in England in 2016/17 (3).

Social care can be crucial in assisting adults with learning disabilities and challenging behaviour. Support can include helping individuals to get up and get dressed, to develop friendships and relationships or to do meaningful activities. NICE

has developed a guideline which covers support services for adults with a learning disability and behaviour that challenges (4). The guideline aims to promote a lifelong approach to supporting this population, their families and their carers. Overall, the guideline focuses on prevention, early intervention and reducing inpatient admissions. In particular, it asserts that 'short breaks should be reliably available on a regular and continuing basis'.

NICE created an economic model to show the levels of quality of life improvements and the levels of cost savings that have to occur in order to make various short break intensities cost-effective. The findings are presented below.

WHAT IS THE INTERVENTION?

Short breaks (i.e. respite care) provide adults with learning disabilities and behaviour that challenges the opportunity to do something different. The intervention involves a person with care and support needs spending regular, short periods away from their main carer. These care recipients may spend the break in their own home, in the home of an approved carer or in a residential placement. According to NICE (2), short breaks should be:

- community-based and close to home;
- available on short notice (both in crisis and to prevent a crisis);
- tailored to the needs and preferences of the person and their family or carers;
- able to deliver what is agreed in the plans for education, health and care, care and support, carer's assessment or behaviour support;
- planned in advance wherever possible, involving care recipients and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it;
- provided by staff who understand and respect the care recipient's cultural norms and values about personal care, private life and lifestyle.

IS THE INTERVENTION EFFECTIVE?

NICE did not find robust evidence on effectiveness of short breaks for adults with learning disabilities and behaviour that challenges. Because of this lack of evidence, the Guideline Committee considered information from other sources. For example, they used views and experiences of people who used short breaks. They also used

other research that found associations between the lack of short breaks and negative outcomes, such as placement breakdown, placement of children in residential care or out of area placement. For this reason, the Guideline Committee made a recommendation for short breaks that is potentially resource-intensive.

IS THE INTERVENTION COST-EFFECTIVE?

NICE did not identify any cost-effectiveness studies relating to short breaks. Because of this, they conducted additional economic analyses to identify when different intensities and costs of short breaks would be cost-effective based on assumptions on costs and outcomes (in this case measured in terms of quality-adjusted life years) for the adult with learning disabilities and behaviour that challenges.

Despite the fact that there are a variety of types and intensities of short breaks (able to cater for lower-level needs up to intensive, complex or fluctuating needs), NICE did not analyse every possible configuration of these options. Instead, they illustrated a range of short break intensities and approximated when a certain intensity of short break may be cost-effective.

The range of short breaks costs between £5,011 and £33,229 per adult per year (at 2015/16 prices). NICE used these costs in each of the two cost-effective analyses they performed. The first analysis examined changes in quality-adjusted life years under the assumption that there were no changes in service use. This analysis demonstrated that there are many intensities of short breaks that are cost-effective if the threshold for cost-effectiveness is £20,000 per quality-adjusted life year. However, more costly and intensive short break packages may be cost-

effective under the assumptions that more people experience quality-adjusted life year gains (e.g. care recipient, their family members or other carers).

The second cost-effective analysis looked at changes in costs. NICE found that short breaks are cost-saving to the public sector when measured over 1-year or 5-year periods. These results assume that: adults with a learning disability and behaviour that challenges are likely to experience a breakdown in their family in 10% of the cases; short breaks are able to prevent a breakdown in 10% of the cases; the average cost of supported living and residential care is £73,040/year for adults (2015/16 prices); the average care package cost for living in the family home is £8,695 per year for adults.

Short breaks were still cost-saving assuming that residential care was cheaper (£57,747 per year for adults) and that short breaks were 1% effective in preventing a breakdown in the family home.

Overall, the analyses demonstrated that different intensities of short breaks can be cost-saving when compared to the possibility of a placement breakdown requiring residential placement. Specifically, when the care recipient lives at home the provision of additional short breaks can be cost-saving if residential care is avoided.

WHAT IS THE QUALITY OF EVIDENCE ON SHORT BREAKS?

The analyses are based on assumptions rather than evidence from prospective effectiveness studies. Because validity of any assumptions made is unknown, caution is needed in interpreting the results. However, this second-best

approach can help to identify key assumptions about costs and outcomes to determine which intensities of short breaks could be cost-effective or cost-saving.

HOW ARE SHORT BREAKS IMPLEMENTED?

NHS England provides information on the type of carers' breaks and support available in the country (5). They also offer an online tool to search for the nearest local carers' centre or short break service (6).

A number of national charities, such as Mencap¹ and Scope UK², provide short breaks and other services for disabled people and carers. The Carers Trust³ provides information on how to pay for short breaks and funding available to help.

Additionally, Revitalise⁴ is a national charity that offers holidays with care.

In the London area, the Kiloran Trust⁵ provides holidays and short breaks for all carers who are looking after someone at home. Also CarePlace⁶ is London's centralised source for care and community services which may provide additional information and guidance.

OTHER INFORMATION

The Government and NHS England have committed to reducing health inequalities for people with a learning disability and behaviour that challenges. Through this commitment, they have established national programmes to improve treatment and outcomes. The House of Commons Library recently published a briefing paper providing an overview of policies and services, such as short breaks, for people with a learning disability in England (7).

A National Audit Office 2017 report examines how the NHS in England and local authorities seek to improve the lives of the adults with learning disabilities and behaviour that challenges who use local authority learning disability support services (8).

Public Health England also offers guidance for NHS and local authorities on learning disabilities, including different options of services available (9).

More generally, the University of Birmingham has produced information on the latest guidance and evidence on health inequalities and learning disability (10).

¹ www.mencap.org.uk

² www.scope.org.uk/Support/Families/Guide/Finding-respite-care

³ <https://carers.org>

⁴ <http://revitalise.org.uk/respice-holidays/planning-break/care-at-our-centres>

⁵ www.careplace.org.uk/Services/9908/Kiloran-Trust

⁶ www.careplace.org.uk/Information/AboutUs

REFERENCES

1. NHS (2018) Learning disabilities.
2. National Institute for Health and Care Excellence (2018). Care and support of people growing older with learning disabilities. NICE Guidance [NG 96].
3. NHS Digital (2017) Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017.
4. National Institute for Health and Care Excellence (2018). Learning disabilities and behaviour that challenges: service design and delivery. NICE Guidance [NG 93].
5. NHS England (2018). Carers' breaks and respite care. NHS.
6. NHS England (2018). Find Carers services. NHS.
7. Parkin, E (2018). Learning Disability – policy and services. House of Commons Library.
8. National Audit Office (2017). Local support for people with a learning disability.
9. Public Health England (2018). Learning disabilities: applying All Our Health.
10. University of Birmingham (2017). Health inequalities & learning disability.

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SHORT BREAKS FOR ADULTS WITH LEARNING DISABILITIES AND BEHAVIOUR THAT CHALLENGES: ECONOMIC EVIDENCE

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