

The effectiveness of short breaks in families where there are children with disabilities: A Systematic Review of the Evidence

Prepared for the Health and Social Care Board on behalf of the Social Work and Social Care Research Advisory Group

Summary

2017

Foreword

The Health and Social Care Board (HSCB) is responsible for arranging health and social care services across Northern Ireland. Some services are commissioned directly by the HSCB and some indirectly through Health and Social Care Trust procurement. In 2017 the Health and Social Care Board, responded to a concern raised by the regional Social Work and Social Care Research Advisory Group relating to the extent to which it is possible to demonstrate if short breaks are an effective intervention in the management of crisis situations in families where there are children with disabilities.

It was considered that a more systematic approach to the evaluation of short breaks is required to improve how future services are delivered. The aim of this review is to summarise the existing evidence base around the outcomes and impacts of short breaks on children with disabilities and their families.

This call for evidence was designed with the Social Work Research and Continuous Improvement Strategy (2015-2020) in mind. The purpose of the research strategy is to increase the quantity and quality of research and evidence, relevant to Northern Ireland, to inform policy, commissioning and practice.

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<http://www.hscboard.hscni.net/swresearch/> under Evidence Reviews
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Executive Summary

What is the aim of this review?

The Health and Social Care Board, on behalf of the Social Work and Social Care Research Advisory Group, has identified a concern relating to the extent to which we can demonstrate if short breaks are an effective intervention in the management of crisis situations in families where there are children with disabilities. A more systematic approach to the evaluation of short breaks is required to improve how future services are delivered.

The aim of this review is to summarise the existing evidence base around the outcomes and impacts of short breaks on children with disabilities and their families.

What is respite?

According to the Department of Health, Social Services and Public Safety (DHSSPS)ⁱ, 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 and break from their caring responsibilities.”

What is the gap in our knowledge?

Robertson et al. (2011)ⁱⁱ undertook an international literature review of the impacts of short break provision on disabled children and families. They found that although progress had been made since the previous systematic reviews, important gaps remain in our understanding of what families want and need, as well as what is the most effective way to provide support to them.

The aim of the current review is to summarise what is known about providing this type of short break and respite provision effectively to young people with disabilities and their families.

What did we learn from this review?

There have been very few robust evaluations undertaken of respite and short breaks provision where the impact is compared to families who have not received the same support. More than half of the studies eligible for inclusion in this review used qualitative techniques. Although they provide useful insights into the lived experiences of families caring for children with disabilities, their findings cannot be easily generalised to relate to other families.

There is some promising evidence of the effectiveness of short breaks and respite provision for families with children with disabilities. It is certainly very highly valued by families as a useful support in helping them cope. Families using respite tend to be those who are experiencing the highest levels of parenting stress and distress.

Overall one may conclude that short respite breaks positively impact on the wellbeing of carers (although these effects do not tend to be maintained over time). There is some evidence that family relationships and stress levels improve. In the child, increased independence, social skills, social awareness, interests and confidence are noted in some studies. A smaller number of studies (albeit more methodologically rigorous) that attempted to objectively measure change identified no significant differences in social outings, friends, or child behaviour problems. Although some studies explore the views of both parents, less is known about the effects of respite care on fathers, siblings, the synergistic effect of other interventions, and long-term effects.

Respite in an out-of-home setting for a short period of time may reduce immediate levels of parenting stress, but for more long-term effects on family functioning and improvements in child outcomes, other elements of effective interventions specifically targeting these outcomes may also need to be included.

There is not currently sufficient robust evidence to fully assess the effectiveness of in-home respite provision, although there is some promising evidence. Respite in the home setting appears to be preferred by carers of younger children and it may reduce immediate levels of parenting stress, but more robust evidence is required.

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. There are several multicomponent initiatives which offer flexibility to parents and families in order to better meet individual needs. These tend to be evaluated as single group studies. Although these can useful insight into changes over time, more robust evaluations including the use of comparison groups are required to examine whether the added value of providing support in this way. Currently there is not sufficient robust evidence to fully assess the effectiveness of this type of multi-component support to families with different needs.

Based on the available evidence, it is premature to make robust claims regarding the psychosocial impact of camp as a therapeutic intervention. Camps are widely used in America and usually comprise of overnight stays of several nights and day activities, often outdoor or adventure type activities. Some camp programmes aimed at young people with disabilities may include an element of psychoeducation about their particular conditions. Theoretically informed camp programs, long-term follow-up, and incorporating camp-based messaging into routine hospital care, may enhance the utility of camp as a potential psychosocial intervention in paediatrics. There is some evidence that regularly planned overnight clubs, participation in schemes such as the Duke of Edinburgh and befriending schemes may be useful in terms of improving outcomes for young people, but the available evidence is methodologically weak.

Several studies on the cost-effectiveness and cost-benefits of short breaks provision have been undertaken but many of these are now 7 or 8 years old. In 2009, it was estimated that the UK State could make an estimated saving of £174 million if short breaks were effectively delivered to all those eligible to receive them.

What are the recommendations for support in N. Ireland?

In terms of using this evidence review to inform practice in N. Ireland, an important next step is to understand what the local needs are of families here. This will involve listening to families (parents and other carers, young people and other family members such as siblings) about what they want and need, as well as understanding their strengths and assets. Staff working in services and professionals providing support to families will also yield important insights. Co-production that is sensitively and meaningfully undertaken will be helpful: the evidence highlights the importance of parental choice and flexibility, as well as active involvement of the young person and their carer in planning services. This needs to go beyond consultation and examples of good practice in this regard can be found locally as well as elsewhere in the UK. A specific example of coproduction in action that might be helpful to learn from can be seen in the Welsh experience of developing children's budgets (where children and families actively engage in prioritising which services and projects should be funded). They have developed a useful guide for planning and running workshops in this area that can be freely accessed at <https://pbnetwork.org.uk/wp-content/uploads/2015/04/Welsh-Govt-PB-toolkit.pdf> and this approach could be used for the community of families with children with disabilities (either locally or regionally). One also needs to better understand the

current provision both locally and regionally in terms of strengths and areas that require development, and gaps in provision, so that any changes can be integrated in an effective and sustainable way.

It would be useful to systematically review the evidence relating to the most effective ways to reduce parenting stress in families with children with disabilities. This would highlight the most effective components to include in any wrap-around support offered (including respite care) to families in the future.

Once the local context has been examined in this way, we would suggest that any changes to services are piloted and evaluated before being scaled up regionally. Although more robust research is needed into all the types of respite care provision, we have identified two areas in which it would be beneficial to prioritise undertaking further robust evaluations:

- the evidence suggests that short breaks may be most effective if it is delivered in a way that takes account of what each family wants and needs from it, and if additional support focusing on alleviating parental stress is offered alongside (offering respite by itself may improve short-term pressure but not have longer term effects on parental wellbeing or child outcomes). Including elements of intervention alongside the respite or short breaks aimed specifically at reducing parental stress and improve parental coping may be particularly beneficial.
- providing the young person with opportunities to undertake new activities through befriending, summer schemes or youth activities positively benefits both the young person and the family. This may be particularly important in developing life skills and supporting progress towards independence.

Finally, it should be noted that this review did not include the families of children with acquired care brain injuries, palliative end-of-life care or very complex healthcare needs. Further investigation needs to be undertaken to examine what is the most effective type of support to provide to these families.

ⁱ Personal correspondence cited by Black, L. A. (2013) in *Short breaks (respite): families of children with disabilities. Research and Information Service Briefing paper*. NIAR 825-13. Northern Ireland Assembly: Belfast.

ⁱⁱ Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V. & Emerson, E. (2011). The impacts of short break provision on families with a disabled child: an international literature review. *Health & Social Care in the Community*, 19 (4): 337-371.