

“Holidays or Isolation?”

Research into holiday activity provision for disabled children and young people in Scotland

APRIL 2020



1. Background

In May 2019, Shared Care Scotland¹ commissioned Simon Jaquet Consultancy Services Ltd² to undertake research into holiday activity provision for disabled children and young people in Scotland.

The purpose was to explore the experiences of disabled children, young people and their families of accessing suitable activities over holiday periods, in order to better understand what would improve both the anticipation and enjoyment of holidays. The research also looked at the experience of providers and those planning and commissioning services, to find out ‘what works?’

In summary, the research was commissioned to:

1. Understand the scale, nature, and delivery of holiday activity provision for disabled children and young people in Scotland
2. Support future efforts to improve the quality, choice, and availability of this provision

2. Methodology

The research employed a mixed methods approach to data collection including: 1.1 interviews, observation of practice, focus groups and online surveys. An informal literature overview was also completed, and case studies were developed to help illustrate different aspects of holiday activity provision.

3. Findings

Findings from disabled children and young people

The 162 responses received to the online survey, and qualitative data from focus groups, and observation of practice in six local authority areas, provided good evidence across a wide spread of geography, age, disability, and experience of holiday activity provision.

Key findings:

- ▶ Disabled children and young people described a focus on mainly family orientated activities, both at home and outside, including day trips and holidays
- ▶ They acknowledged the low level of contact with their peers and expressed concerns about becoming bored and losing contact with their friends
- ▶ They were aware of losing their term-time routine and struggling to settle back into school after the holidays

- ▶ They were particularly keen to be included and to take part in activities (formal and informal) with other young people and 'just wanted to be like everyone else'
- ▶ They also acknowledged the need for activities that meet the requirements of a range of conditions
- ▶ The reality of longer holidays spent mainly with family contrasts with the aspiration of being a young person in the company of their friends

Findings from parent carers

There were 480 responses to the online survey from across 30 of Scotland's 32 local authority areas, and representing a wide range of disabilities. This was combined with qualitative data from six local authorities.

Key findings:

- ▶ From the responses received, the main carer (99%) during the holidays is overwhelmingly the mother
- ▶ Parent carers placed a high value on spending time with family, and undertaking family activities (specifically including non-disabled siblings)
- ▶ They recognised that many disabled children and young people lack a wider network of peer relationships, and this is particularly evident during the longer break
- ▶ Parents reported significant difficulties in finding suitable holiday activities (and information about them) for their disabled child
- ▶ Parent carers experienced two main challenges over the longer summer holiday:
 - The continuous demands on their time negatively impacted their own mental health;
 - many had to reconsider their employment status in order to care for their child, often with knock-on financial consequences
- ▶ Parents perceived a lack of continuity between what takes place in the school, and leisure activities in the community during holidays. Many would value a more integrated approach which would also support their child's transition back to school
- ▶ There are strong parent carer networks, but the main source of practical support remains the family
- ▶ There is agreement that the cornerstones of good holiday provision are:
 - child-centred service delivery
 - consistent staff and volunteers
 - appropriate staff training
 - adequate facilities and equipment
 - close collaboration between the school and the holiday service provider
- ▶ Most parents were sceptical about the extent to which their child can participate in local activities, with only 2% responding that their child is 'completely involved' in their 'local community'

Findings from service providers

71 organisations from across Scotland responded. The majority had recent (2019) experience of directly delivering holiday activity programmes.

Key findings:

- ▶ Most service providers are third sector bodies, including many smaller local organisations
- ▶ There is a tension between the third sector’s service delivery role, and its advocacy and campaigning role on behalf of parents and young people
- ▶ Service providers were aware of the needs of disabled children and their families during the holiday periods, and were frustrated at their inability to meet these adequately, mainly due to capacity and funding arrangements
- ▶ The short-term nature of funding for holiday activity provision was a frustration, and there is a strong desire for longer term funding
- ▶ Respondents felt there was a need for better commissioning arrangements as these vary in duration and effectiveness

Findings from local authorities

Fourteen local authorities responded to the consultation, representing a range of size, geography, and location.

Key findings:

- ▶ Local authorities rely substantially on the third sector for service delivery, making use of a variety of commissioning and contracting arrangements
- ▶ In most cases, the strategic management of holiday activity provision is the responsibility of the local authority. In others, the role is taken by the Health & Social Care Partnership
- ▶ The volume and variety of holiday activity provision had been significantly affected by the impact of austerity on local authority budgets
- ▶ Local authorities vary in their approach to funding and staffing of programmes. There was mixed evidence of local authorities adopting strategic approaches to planning, with programmes frequently being reactive to current circumstances, and constrained by available funding
- ▶ Local authorities acknowledged that services often fall ‘short of the mark’. Roughly half of the provision is described as meeting the needs of disabled children and young people ‘to a significant extent’; the remainder ‘to a limited extent’
- ▶ Local authorities have a potential role in building the capacity of smaller third sector organisations

4. Conclusions

Availability of holiday activity programmes

There is inconsistent provision of holiday activity programmes across Scotland, and rural areas seem to be more adversely affected, largely as a result of geographical isolation and related transport difficulties.

It is hard to quantify the scale and scope of provision as there is no single system that supports and measures it. Services are supplied mainly by the third sector through contracting arrangements with the local authority, however many larger authorities also provide programmes themselves. There is no nationally agreed framework, structure, or process to act as a 'model' for what this could look like in practice at local level.

Young people's view

Disabled children and young people of all ages value both the social and the activity aspects of being with other young people during the holiday period. Above all, they just want to have things to do and to enjoy, as well as be more independent and spend time with their friends.

While this may be the aspiration, for many disabled children and young people the reality is that being with family tends to be what they experience most.

Parent carers' view

Holiday breaks for children also provide much needed breaks for parent carers, at a time where the caring responsibility is often at its most intense. Parents (especially mothers) provide most of the care for disabled children and young people over the holiday period. As a result, they take on significant caring duties which can impact on their health, employment opportunities, and financial security.

Siblings are an important (and frequently side-lined) aspect of the overall picture. They are often young carers with their own needs for support, including short breaks from their caring responsibilities.

Parents fund their child's activities in a range of ways, including the use of benefits and their own resources. Little use is currently made of Self-directed Support as a means of accessing holiday activities.

Good practice

Over and above what might be described as the 'core' childcare competences in the organisations they use, families of disabled children and young people also look for the following to be in place:

- ▶ A longer lead-in period prior to the start of the holiday activity provision in order to allow for effective planning
- ▶ Closer links with schools, so that what happens over the summer is seen as relevant to, and supports, what takes place in school

- ▶ Consistent and well-trained staff who can build positive and trusting relationships with the disabled children and young people
- ▶ Specialist provision for young people with complex needs, but inclusive provision for most children and young people
- ▶ Effective engagement and regular communication between providers and families
- ▶ Commissioning of services over a significantly longer period in order to provide continuity for both children and parents

Challenges and solutions

According to many respondents, there is still limited understanding and awareness of disability in society, and many disabled children and young people may feel excluded or are treated differently. Consequently, holiday activity providers may miss opportunities to build in simple adjustments that would make their provision more inclusive and accessible. There is scope for broad based education and engagement initiatives, especially ones that value the talents, insights, and voices of disabled children and young people themselves.

Patterns of short-term funding lead to real limitations on planning, fundraising, recruitment and retention of staff. Longer term funding to build the capacity of smaller third sector provider organisations would put holiday activity provision on a firmer footing.

Self-directed Support (SDS) also has the potential to provide eligible families with more choice and control over how they spend their time during the holiday period. Currently, there is little evidence of families using SDS as a source of funding for holiday activity provision. The biggest barrier is that many families do not know about it.

Across Scotland different services employ different programmes, staffing models, managing agency, and funding arrangements. Where there is formal holiday provision available, the eligibility criteria for children and young people is not always clear. Integrated services, where disabled children and their non-disabled peers can play together, are also hard to find. Sharing practical tools, innovative approaches, and experience across local authorities, and between the sectors, would help promote learning and the development of new provision.

Disabled children and young people face significant social isolation from their peers during the holiday period. This is magnified in more rural areas, where transport difficulties compound the problem. There is a need to highlight the vital importance of holiday activity provision for both child and parental health and well-being. There is an important role for youth work and children's work organisations to support disabled children and young people in a range of inclusive activities, and there is also a need for an effective national 'youth voice' which could advocate on their behalf.

5. Recommendations

Building on existing relationships, Shared Care Scotland (with statutory bodies, other national carer organisations and wider stakeholders) should foster bi-lateral partnerships which will:

- ▶ Use the findings of this research to raise awareness of the importance of accessible, inclusive and affordable holiday activity provision
- ▶ Advocate for the interests of disabled children, young people and parent carers, and work with national and local government to find ways to improve the choice and availability of holiday activity provision
- ▶ Create links between frontline practice and national and local policy development, particularly developments in out of school care
- ▶ Play an active role in developing and piloting new initiatives, potentially through targeted use of the third sector Short Breaks Fund
- ▶ Work with the independent funding organisations to secure and target funding towards more capacity building within third sector holiday providers

A detailed list of recommendations can be found in the main report. A separate publication containing 16 case studies illustrating a range of different approaches to holiday activity provision, is also available.

The main report and associated papers will be published on our website:

www.sharedcarescotland.org.uk

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