



Executive Summary

Short Breaks User Engagement Report

Bedford Borough Council

Evaluation carried out by Autism Bedfordshire and Bedford and District Cerebral Palsy Society.

Having a child with a disability has a major impact on family life. Children with Disabilities do not have the same opportunities as other children to develop socially or emotionally or have a chance to develop their life and independent skills. Without the range of short breaks, including clubs and social groups, many do not see other children outside school increasing isolation and family stress levels. This is further emphasised through adolescence and transition to adult services.

There are a range of short breaks services provided by two main respite care homes, domiciliary care agencies, local voluntary sector, Family Link, National Childminding Association, and carers through direct payments. The overall findings of the of the evaluation is that;

- the current choice and variety of short breaks should be maintained;
- provision increased where possible to meet the identified needs and gaps by families;
- information and access to short breaks is improved for families; and
- communication and coordination is improved between short break service providers to ensure that services are not offered at the same time.

Context

Local authorities are required to provide services designed to assist carers of disabled children by giving them breaks from caring under the Children Act 1989. As set out in the Breaks for Carers of Disabled Children Regulations 2011 local authorities have the duty to ensure they have regard to the needs of those carers who would be unable to continue to provide care unless breaks from caring were given to them; and have regard to the needs of those carers who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to undertake education, training or any regular leisure activity, meet the needs of other children in the family more effectively, or carry out day to day tasks which they must perform in order to run their household. Bedford Borough Council commissioned Autism Bedfordshire and Bedford and District Cerebral Palsy to carry out a User Engagement Project to gather the wishes and views of children, young people, their families and associated professionals in the Borough. The findings highlighted in the full report aim to assist Bedford Borough Council in the shaping of services for families.

Methodology

A series of interviews were undertaken with children and young people with disabilities, short break providers and associated professionals in Bedford Borough and focus groups with parent/carers were held. A total of 508 questionnaires were distributed comprising of 260 families on Bedford Borough's disability register and 248 distributed through Bedford Borough's special schools. A total of 66 were completed which equates to 13% of the distribution, and 17% of the 400 believed numbers of children with disabilities within Bedford Borough.

Headline findings and recommendations

In order to fully understand the issues relating to the short break needs of children with disabilities and their families in Bedford Borough, it imperative that the report is read in full. Feedback from the children, young people and their families identified the following areas for consideration:-

- **Information, support groups and training for parents/carers.** A number of parents/carers were not aware of the short breaks and the different options available to them. Providing information to parents/carers is a vital element of the support needed for families with disabled children.
- **Access to short breaks.** Families expressed frustration that they feel they have to 'fight' for short breaks. A lack of trust between families and the local authorities generally was evident and documented.
- **Duration and regularity of short breaks.** There was evidence of waiting lists for places on the voluntary sector social clubs, and parents stated that the groups were not frequent enough. Additional concerns were raised regarding the reduction of availability of support during the summer holidays. Families wanted groups to last for a minimum of 3 hours, with 5 hours being a reasonable length of time and 7 hours making a real difference. Families wanted weekly groups during the weekends and evenings, with weekends and holidays being a greater priority for most.

Feedback on all the different models of short breaks in Bedford Borough are as follows:-

- **One to one support** Parents who had found a good carer and were able to organise when they had short breaks were mostly satisfied with their service. However, there were not enough trained carers available and parents needed support with direct payments. Potential to develop a Home Support Team similar to Central Bedfordshire was identified which would include the one to one support in the community with a base to return to when needed.
- **Specialist clubs** There was a high level of satisfaction with specialist social groups and clubs provided by the voluntary sector and after school clubs. However, there were concerns about the quantity and parents/carers highlighted a need to increase holiday clubs, evening and weekend clubs, as well as a return of the Foxgloves Social Group. The provision of transport would not only increase the length of the short break, but make the breaks more accessible.
- **Mainstream access** 35% of families said they wanted their child to access mainstream activity groups. Families whose children have autism, behaviours that challenge, severe learning disabilities or physical disabilities, and/or complex needs did not feel that mainstream activity groups were appropriate for their children. They felt that their children could only be supported successfully in specialist activity groups for children with special needs, and professionals strongly agreed. In addition, concerns were noted for those children who find it difficult to stay for long periods at a mainstream group or community facility.
- **Community Access** Families stated that they like their children to access the community from the specialist social groups, or individually with a one to one carer, but need a safe base other than the child's home to return to should the child need to.
- **Overnight Residential.** Those wanting and needing overnight short breaks were a minority, but these are the families whose children need intensive support and the families are therefore in need of overnight breaks in order to be able to continue to provide care for their child with a disability. It was considered beneficial for children to stay for more than one night so that the child and staff can get to know each other adequately and build up confidence in managing complex care needs.
- **Whole family activity groups at safe venues and in the community** Parents expressed a need for these short breaks for the whole family and stressed that they are vital for parents to share information, support each other, and be able to go out and enjoy their children with support from trained staff and volunteers.
- **Siblings support and activity groups** Parent/carers said that these are essential to continue and function to give the siblings short breaks, as well as the attention and support that they need.
- **The activities** The children identified a range of indoor and community activities that they like to do, and these are reported in pages 34 – 42 of the full report. All short breaks should provide a range of indoor and community activities. The children said that they like to go to clubs and be with their friends.
- **Transition** This remains a real challenge and concern for parents. All services end when their child leaves school and there are fewer options available. Short breaks that bridge the gap, and teach life skills are very important. Providing information and support for parents leading up to transition is also essential.
- **Behaviours that challenge** Parent/carers were very keen for additional support to reduce the behaviours that challenge, but felt that they would still need short breaks as their children will still have complex needs and severe learning difficulties and still need round the clock care.
- **The cost of short breaks** Parents who meet the criteria have their short breaks funded, so cost is not an issue. For other parents the issue of cost varies greatly and some are very happy to pay and others don't book places on schemes because they cannot afford it. The cost of short breaks for all organisations is expensive and most parents could not afford the true costs. They will always need to be subsidised and funded.