

September 2008



# Action for Children briefing

## Action for Children's short breaks services for disabled children

Action for Children believes that short breaks services should be available to all disabled children and their families who need them.

Bringing up a disabled child can be very challenging, often putting significant strain on family life. Through our specialist short breaks services, Action for Children helps reduce the pressures that can cause significant stress within the family and, in some cases, cause family breakdown. We know, however, there are currently many families who cannot access these services and as a result are left to cope on their own.

Action for Children has welcomed the Government's Aiming High Strategy, which will deliver an extra £370 million for short breaks across England. The challenge is now for local authorities, providers of disability services and other organisations to grasp this opportunity to make a real difference to the services offered to disabled children and their families.

There is still a need for further investment, open and transparent eligibility criteria and processes, and a greater emphasis on assessing the requirements of each disabled child and their family, rather than simply slotting children into existing services.

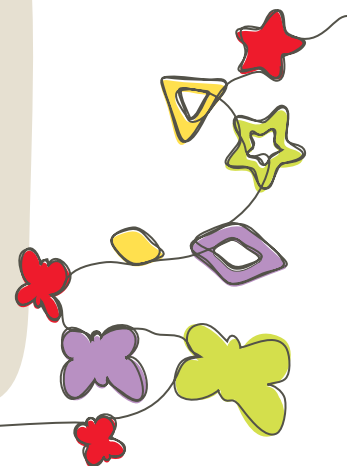
This briefing paper looks specifically at Action for Children's short breaks services for disabled children, young people and their families. It describes the importance of responsive, flexible, high-quality services and contains a number of case studies outlining the benefits of short breaks to the disabled child, their family and society.

### Action for Children

Action for Children is one of the UK's leading children's charities, helping children and young people achieve their full potential. Through our services, we support some of the UK's most vulnerable and excluded children, young people and their families.

We run nearly 450 services and work with nearly 170,000 children, young people and their families across the UK.

*as long as it takes*



## Why short breaks services are an issue for Action for Children

Action for Children has been providing short breaks to disabled children for over 20 years. A significant number of the children using our services have multiple and complex needs, which are often with associated healthcare needs or life-limiting

illnesses. Action for Children believes that short breaks can greatly improve the quality of life of both the disabled child and their family, and that they should be made more widely available.

## What are Action for Children short break services?

Action for Children short breaks services are developed with statutory partners such as local authorities, primary care trusts in England or local health boards or health trusts in Wales. We run a number of residential and family-based short breaks services that are used by over 1,000 disabled children and young people. We also run holiday and weekend activity services, children's resource centres with an early years emphasis and community short break services.

These services vary widely depending on the demand of local parents and service user involvement and engagement is a priority to ensure that each child gets the support they need.

Our services support children and young people with a wide range of needs, including children with multiple and complex impairments such as severe learning difficulties, and mobility and communication needs, sometimes combined with long-term health issues. Approximately 30 per cent of the children and young people using our residential short breaks services are on the autistic spectrum disorder.

Partnerships with parents and key professionals such as social workers, psychologists, schools and health services are an essential part of our services, and wherever possible services develop a 'team around the child' approach, meeting regularly to discuss how best to meet the child's needs.

It is important to note that not all children and young people feel positive about overnight breaks away from home. Most enjoyed the short breaks available to them but some children were very homesick and worried about their families. It is therefore vital that there are a range of options available to families, including home-based and community service short breaks that facilitate access to play, leisure, sport and childcare services.

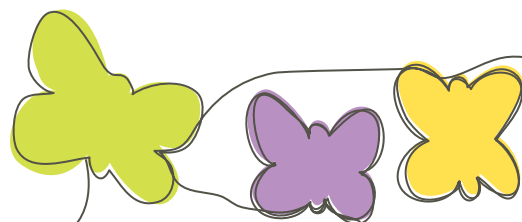
We stress the importance of designing short breaks around the needs of the child and balancing them with the wider support needs of families. This means good assessments of need and a range of choices are essential.

## Government policy

*Aiming High for Disabled Children: better support for families* was published in May 2007, following a joint review of disabled children's services by the Department of Children, Schools and Families and HM Treasury.

Aiming High will deliver a total funding package for short breaks of £370 million allocated by the Department for Children, Schools and Families from 2008–2011. This comprises £280 million in revenue funding announced in May 2007, along with £90 million in capital funding announced with the Children's Plan in December 2008.

We understand that Administrations in Scotland, Wales and Northern Ireland will also be receiving proportionate allocations.



## Short breaks – a legal duty

The Government earlier this year tabled an amendment to the Children and Young Persons Bill that would create a new duty on local authorities in England to help parents caring for disabled children by giving them breaks from their caring responsibilities.

Local authorities already have the ability to provide short breaks under the Children Act 1989 but, due to the great importance disabled children and their families place on these services, the government has now ensured that a specific requirement for short-break provision will be put into place.

### Non-residential short breaks services

Non-residential services may include support workers enabling disabled children to participate in community-based activities or volunteers supporting disabled children in befriending schemes. One example of an Action for Children non-residential service is the Re:d Centre.

### Re:d Centre, Bury

The Re:d Centre in Bury currently works with around 110 disabled children and young people each week, providing short breaks, play activities and social opportunities, as well as offering support, information and advice to families and professionals.

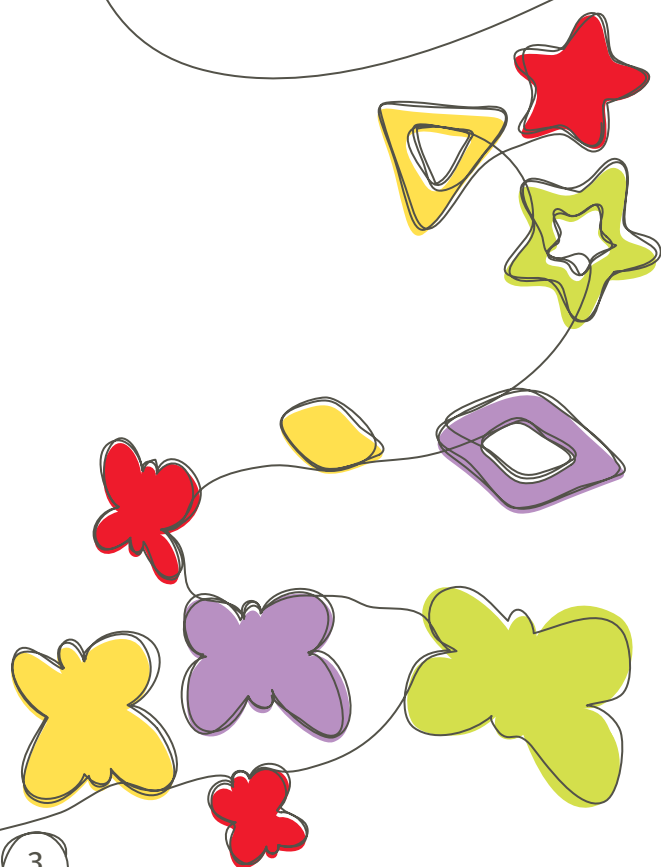
The centre provides community-based short breaks such as after-school short breaks where children are collected from their school and spend the afternoon in the centre, or weekend short breaks where children enjoy a range of activities, trips and visits during a morning or an afternoon session.

Parents can drop in to the centre at any time for support and information. They can also access a resource library to find more information on their child's impairment and associated needs.

The centre also provides services for siblings of disabled children, including drop-in sessions and holiday workshops where they can talk about their feelings and experiences in a safe and non-judgmental environment.

### Shared care family-based short breaks

Action for Children runs a number of family-based shared care services that provide short breaks for families with a disabled child or young person. Foster carers are recruited to have a disabled child stay with them on a regular basis – breaks can be a few hours, overnight stays, weekends or longer periods. A key aspect of this service is partnership with parents and the development of an effective working relationship between the foster carer and the family.



## Residential short breaks services

Residential breaks are the best option for some children, but this needs to be in settings as much like an ordinary home as possible, with specialist equipment unobtrusively available to maximise independence. Only small numbers of children or young people will stay at any one time, creating the feeling

of a sleepover. While parents and siblings have a break from caring, disabled children and young people can enjoy new activities, experiences and a wider social network, helping them to develop social and life skills, and enjoy independence from their families.

### Action for Children Warren Park, London

**Action for Children's Warren Park service works with children and young people aged between 8 and 18 who experience a wide range of impairments, including severe learning difficulties – 50 per cent are on the autistic spectrum.**

Warren Park is a purpose-built centre offering residential short break services and day activities. The short break service provides regular overnight support for 30 children and young people. The level of care is agreed through an assessment process and varies depending on individual need.

The Day Activity Unit includes a large play area with specific play/activity rooms such as a computer room, a sensory room, a soft play and ball pool, and a large garden with specialist play equipment. The After School Club provides social and learning opportunities for disabled children while also supporting parents with their work arrangements or other commitments, and the Holiday Club provides activities during the school holidays.

### James – Action for Children Caring Together Shared Care Service

James is autistic and needs intensive support and supervision. The stress this placed on his mother Andrea and her husband was compounded by the fact that she felt her other three sons were not getting the attention they needed because of the increasing amount of care that James required.

Finally, after years of waiting for an appropriate carer for James, James' teacher and her husband offered to become his short-break carers and registered with Action for Children to undergo assessment and receive training and support. James stayed with Judy and Norman for a long weekend

every six weeks for over 10 years. Andrea says, 'We could do all sorts of things that we could not normally do. We've been so lucky. Short breaks are very important.' Although James is no longer supported by Action for Children, he still sometimes stays with Judy and Norman, and Andrea is still very involved with Action for Children.

Despite having initial doubts about leaving her child with somebody else, Andrea is very satisfied with the outcome. She considers the impact of the short breaks service in her life as 'invaluable', especially as James 'was happy because he was getting the attention he needed from the people that he went to'.

## Benefits of short breaks

Although it is difficult to put a cost on the benefits of short breaks services, it is easy to see the positive impact for a disabled child, their parents or carer and society.

Not having access to short breaks services can put significant stress on a family – short breaks were cited as the key factor that helped or could have helped relationships and prevented family breakdown.<sup>1</sup> The Parliamentary Hearings report on services for disabled children states that for parents ‘the lack of short breaks was the biggest single cause of unhappiness with service provision’.<sup>2</sup>

## Benefits to the child or young person

Short breaks offer significant benefits to a disabled child, particularly the opportunity to interact with others in a different environment. There is also evidence of giving increased independence – one surveyed parent said ‘[It] teaches him to do things better for himself.’<sup>3</sup>

A mother of one of our service users described the positive impact the short breaks service has made on her son’s life: ‘Although Liam cannot speak, he is very happy to go there [Action for Children project] and he expresses it.’



## Benefits

## Wider benefits

There are also benefits to society as a whole. The ability to access short breaks can reduce the strain on families, thus reducing the chances of family break up, stress-related illnesses and the impact upon the employment and education of the family, which has a cost to society as well as the family.

## Benefits to the parents or carers

Short breaks can alleviate carer stress, which can be acute where the child has multiple and complex needs. They provide parents with a break from the sometimes 24-hour care, giving them time to relax, sleep, catch up with family and friends etc. Parents also value the opportunity to spend time with their other children, often doing activities together that may be difficult when the disabled child is present. Research suggests that some parents feel able to give better care on the child’s return from a short break.

<sup>1</sup> *No time for use – relationships between parents with a disabled child*, Contact a Family, 2004; ‘Are You Listening?’ Barnardo’s Cymru and Action for Children-Gweithredu dros Blant for the Welsh Assembly, 2003

<sup>2</sup> Parliamentary hearings on services for disabled children, summary report, Pg 6

<sup>3</sup> ‘Respite Care for Children with Severe Intellectual Disability and their Families: Who needs it? Who receives it?’, *Child and Adolescent Mental Health* Vol 7, 2002, pp 66–72

## Geraint – Action for Children Blackwood Resource Centre

Geraint is 14 and has been using Action for Children’s Blackwood Resource Centre for seven years, where he spends two nights a month in short break care. He also used Action for Children’s Caerphilly Children’s Centre between the ages of two and four, following his diagnosis with an autistic spectrum disorder.

Action for Children’s short breaks service has opened up a wealth of new experiences for Geraint, says his mother Ann: ‘Using the service has given Geraint different experiences, like going swimming and meeting different people. I would say that getting used to being supported by other people, and not being totally reliant on me as his sole carer, has been the greatest benefit.’

Geraint has severe communication difficulties. His mother Ann stresses the positive impact that accessing the service has had for her son: ‘He doesn’t speak but you can tell he is happy, he is now very well balanced. He has improved his social skills as well.’

## Conclusions

This briefing paper has described the difference short breaks services can make to the lives of disabled children and their parents or carers. However, for many families accessing such support is still a distant dream. It is pleasing that all the main political parties are making improving the life chances of disabled children a main priority and this offers a real opportunity to transform services for disabled children and make them more responsive to their needs.

Aiming High offers a real chance to start that much-needed journey by making available short breaks provision for disabled children with high care needs. However, Action for Children believes that such provision should eventually be available to all disabled children and their families who would benefit from these kinds of services.

For more information about Action for Children’s short breaks services, please contact the Action for Children Public Affairs team on **020 7704 7132** or at **publicaffairs@actionforchildren.org.uk**