

Website Content Good Practice Template

AREA TITLE

About... **Family support**

Families of children on the autism spectrum can face considerable stress. Some children can require constant supervision, help with self-care skills, may eat a limited range of foods, be very resistant to change, and can spend many hours awake when others of the same age would be asleep. The lives of siblings can be severely affected. Family life is constrained, belongings may get damaged and parents are often worn out having to give constant care to the child.

In such cases what is required is a thorough assessment of the child's and their family's needs and the development of a greater variety of support for families with life at home outside school hours and during the school holidays. In addition, parents require up-to-date information about autism spectrum disorders and local services and agencies. Parent partnership services provide neutral and factual advice and information to the parents of children with special educational needs (SEN), information about what provision for children on the autism spectrum is available within a local authority's area and beyond. They should also be able to refer parents to voluntary agencies for further advice.

Early Support Programme

The Early Support Programme is the Government programme which aims to achieve better co-ordinated, family-focused services for young disabled children and their families. It is a national programme being introduced and used in local authorities, hospitals and community-based health services across England.

See the Early Years section for more information on Early Support

Short Breaks

What is a short break?

Short break provision varies widely in format. Some breaks take place in residential or community settings, some in the home of an approved carer, and some in the child's own home. They can last from a few hours to several days, and include day, evening, overnight and weekend activities.

Together for Disabled Children's (TDC) Definition of Short Breaks (below) gives a useful summary of the different types of short breaks available.

SCIE (Social Care Institute for Excellence) has produced a new good practice guide on short breaks. Rather than the traditional model of break focusing on residential care solely for the disabled child, the guide describes new types of short breaks which offer the following positive characteristics:

- Flexible and responsive to the whole family's needs
- Based at home if preferred or in the community.
- Ensuring continuity of care, allowing good relationships to be built with staff.
- Offering stimulating and educational activities so that the children benefit as much from the break as parents.
- Family-centred, developed with input from the families using the services.
- Supporting and working with parents
- Distinct from healthcare services

Certain types of short breaks are more effective for specific groups of children. For instance, family-based short breaks are sometimes less successful at placing teenagers, particularly boys with autism. Whereas, contract carer services have expanded in recent years, offering a family-based option of short-breaks to groups of children, including those on the autism spectrum, who had previously used residential short breaks.

The benefits

Such breaks give parents a necessary break from their caring responsibilities, allowing them to spend time with partners and other children, as well as giving time to do the things that are difficult when caring for a child on the autistic spectrum. They also give the child an opportunity to make new relationships and experience enjoyable activities.

The Shared Care Network (SCN) which represents short break services for disabled children and young people, conducted a survey of families of children on the autism spectrum getting short breaks. It found that such breaks helped children develop their social skills, giving opportunities to make friends and take part in social activities. Short breaks helped children learn independence and made them happier, and all parents surveyed said that getting short breaks helped their families cope.

A [report](#) by PriceWaterhouseCoopers for the DCSF, *Market for Disabled Children's Services, a Review* (p80, para 277), found that in some instances short breaks can reduce the long term costs of interventions. Other research studies show short break services may lead to significant savings to residential care budgets as they enable parents to continue caring for their disabled child at home and reduce family stress (Beresford, 1994; Chan and Sigafos, 2001 - see 'Get help from...' section for full references).

The National Service Framework For Children, Young People and Maternity Services states that "Good short-term break services are associated with reductions in maternal stress and a reduction in marital problems and break down." In a survey of parents of disabled children, a break from caring to be with their partner and/or other children was identified by parents as the single most important factor in helping their relationship. (No time for us. Relationships between parents who have a Disabled Child. Contact a Family 2004.)

A lack of short break services

The Shared Care Network survey "Still Waiting" (2006) found that over 90% of short break schemes reported have waiting lists, with families commonly waiting up to a year for services. Children on the autism spectrum are among those who wait the longest for short breaks; a previous SCN survey showed that a third of disabled children on waiting lists are on the autism spectrum.

The foreword to Aiming High for Disabled Children, Short Breaks Implementation Guidance, describes how "Children who have the greatest need for breaks often seem unable to access provision because of the challenges posed by their disability." The report cites evidence that current short break provision is particularly inadequate for children and young people most at risk of social exclusion, including those on the autism spectrum and/or with challenging behaviour. In fact, the latter are the most likely to be on waiting lists for family-based short break services, with autism spectrum teenage boys likely to wait longest.

A lack of such services was the biggest single cause of unhappiness with service provision and the single greatest unmet need in parental submissions to the 2006 Parliamentary Hearings on Services for Disabled Children.

Changes to short break provision

Aiming High for Disabled Children (AHDC)

A transformation in the local authority provision of short breaks for disabled children is currently underway, with a doubling of expenditure by 2011. In May 2007 the Government published Aiming High for Disabled Children, a report setting out a transformation of disabled children's services, with the lion's share of resources allocated to a substantial overhaul of short break provision. In addition to the £90 million of short break capital funding set out in the Children's Plan in December 2008, ADHC provides for £269 million to be issued to local authorities, and aims to transform short break services over the next two years. Further investment through PCTs has recently been announced in the [Child Health Strategy](#).

- **Funding for local authorities**

As part of AHDC, the children's services departments of 21 local authorities, in partnerships with PCTs, have been designated as pathfinders and have been allocated significant funding from April 2008 to improve services. These pathfinder authorities will be focusing on specific areas of learning, including how to make short breaks more effective for children on the Autism Spectrum. A complete list of pathfinder authorities can be found in Annex C of AHDC Short Breaks Implementation Guidance below.

Other English local authorities will receive significant new funding for short breaks from April 2009, provided they can show their readiness to undertake short break service transformation.

- **The Full Service Offer (FSO)**

The Full Service Offer, laid out in AHDC short breaks implementation guidance, sets out Government's current expectation of short break service development. Among other things, it specifies that a short breaks service must ensure that children and young people on the autism spectrum are not disadvantaged in accessing short breaks. All local authorities and PCTs must meet the standards set out in this by April 2011; those with short break pathfinder status by 2010.

- **Together for Disabled Children**

The Department for Children, Schools and Families (DCSF) has appointed the Together for Disabled Children (TDC) partnership to support the Aiming High for Disabled Children short breaks programme and the development of parent participation forums.

Short Breaks Duty

In March 2008, the Government announced a new duty on local authorities to provide short breaks for disabled children. New legislation places short break services on a statutory footing, and will come into force in April 2011.

This legal provision will make it clear that "Short breaks should therefore not just be used as a crisis intervention, but should also be used routinely to help parents and carers to maintain and improve the quality of care they naturally wish to provide."

The AHDC guidance highlights the fact that the criteria used by local authorities to determine who is eligible for short breaks vary significantly. Many eligibility models are based on a crisis model, i.e. on possibility of family breakdown, rather than a prevention model, or one that enhances the quality of life of the family. Services should be seen as preventative and supportive rather than being based on crisis intervention, and in light of the new funding available, the Government is expecting local authorities to review their eligibility criteria.

Direct payments

The introduction of direct payments has affected the commissioning of short break provision in that families in receipt of such payments are able to make individual purchasing decisions, instead of the local authority arranging that service on their behalf.

Get
help
from...

Beresford, B. (1994). Resources and strategies: how parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*. 35. Pp. 171-209.

Carlin J (2008) *A Job Worth Doing; Contract carer services for disabled children in England*. Shared Care Network

Carlin J, Morrison J, Bullock J and Nawaz S (2004) *All Kinds of Short Breaks. A guide to providing a range of quality services to disabled children and young people*. Shared Care Network and Department for Education and Skills Publication. York: York Publishing Services.

Chan, J and Sigafoos, J (2001). Does respite care reduce parental stress in families with developmentally disabled children? *Children and Youth Care Forum*. 30. Pp. 253-263.

Jones V, Murphy N and Aspinall V (1997) *New Horizons: Family based short breaks for people with autism*. Shared Care Network Publication.

Simmons P (2003) *Essential Guide to recruiting short break carers for disabled children*. A Shared Care Network and Joseph Rowntree Foundation Publication. York: York Publishing Services

Tarleton B and Macaulay F (2002) *Better for the Break? Short break services for children and teenagers with autistic spectrum disorders and their families*. Shared Care Network Publication. York: York Publishing Services

Tarleton B, Kelly N and Macaulay F (2004). *Thinking it through. Providing support services for children and teenagers with autistic spectrum disorders*. Shared Care Network and Norah Fry Research Centre Publication. York: York Publishing Services

[Direct Payments Guidance: Community Care, Services for Carers and Children's Services](#)
(Direct Payment Guidance England 2003)

[TDC's Definition of Short Breaks](#) gives a useful summary of the different types of short breaks available.

[Breaking Down the Barriers: How short breaks are helping families of children with autism to be "more like other families"](#). Shared Care Network

[Aiming High For Disabled Children: Short Breaks Implementation Guidance](#)

Links

[Every Disabled Child Matters](#) (EDCM) is the campaign to get rights and justice for every disabled child.

[Together for Disabled Children](#) The Department for Children, Schools and Families has appointed the Together for Disabled Children partnership to support the Aiming High for Disabled Children short breaks programme and development of parent participation forums.

[Aiming High for Disabled Children](#) launched in May 2007, the Government's transformation programme for disabled children's services, part of the Every Child Matters Reforms.

[Shared Care Network](#). Training, resources and information to promote family-based short breaks for disabled children and young people

[SCIE Resource Guide: Good practice in short breaks for families with children who have complex health needs and disabilities](#)

Case Studies

Good practice example

The model for providing short breaks was traditionally residential care solely for the disabled child. This could be disruptive to family life, so new approaches involve the whole family. The time spent using these services can range from a couple of hours to several days. The flexibility of the model allows the family to stay with the child, take the break at home or in the wider community. Examples include:

- Under-fives schemes.
- Saturday play schemes.
- Summer holiday play schemes (including children with complex health needs).
- Youth clubs.
- Transitions holiday clubs (for young people entering adulthood).
- Home-based care.
- Whole-family residential units. (Ref: SCIE: Having a Break: good practice in short breaks for families with children who have complex health needs and disabilities. 2008)

The Government's three-year transformation programme in short break services for disabled children identified in 2008 twenty-one local authorities to launch receive the first wave of a £370m investment, that will extend to all of England from 2009. The 21 pathfinder authorities who will receive are: Bradford, Bolton, Bournemouth-Dorset-Poole (joint pathfinder), Brighton, Dudley, Derbyshire, Enfield, Gloucestershire, Gateshead, Halton, Kent, North Yorkshire, North Tyneside, Nottinghamshire, Norfolk, Suffolk, Sutton, Sunderland, Telford & Wrekin.

All pathfinders have been assessed as having the capacity to deliver immediate improvements to the short breaks services that they offer, while at the same time developing and sharing information and best practice in short break service commissioning and provision.

Author: HA