

Summary of Findings

Better for the Break?

Support for children and teenagers with autistic spectrum disorders and their families

Summary and Key points

Short break/family support services supporting children with autistic spectrum disorders (ASD) include: family based and residential short breaks, domiciliary/outreach services, playschemes, clubs, sitting and befriending services.

Services are often desperately needed by children and their families but families struggle to gain access to services for disabled children. Service providers are often poorly informed regarding the specific needs of children with ASD and are unable to meet the level of demand for services because of a lack of supporters (carers/workers/volunteers) and funding. Services, however, can be provided successfully when staff at all levels are properly informed about ASD and have the time and resources to enable them to meet each child's specific needs.

- Families with a child/teenager with ASD are under a great deal of stress. Large numbers of families are providing constant care. Siblings lose parental attention and are affected by their brother or sisters strict routine and often unusual behaviour.
 - Short breaks are beneficial for children with ASD - if provided appropriately. They enable children to access new environments, activities and relationships while providing their parents and siblings with some time to themselves away from the constant demands of caring for their child for 24 hours a day.
 - A quarter of children using short break services have ASD. Children with ASD make up a third of the waiting lists of relevant services
- The provision of support for children and teenagers with ASD and their families is inhibited by a lack of services and adequate funding.
 - Service providers struggle to understand the specific needs and behaviour of children with ASD and to provide them with consistent, high levels of support.
 - When families are able to gain access to services, their choice of service is limited.
 - Families require a flexible mix of services that provide support and routine in the school holidays and ongoing support throughout the year.
 - Service providers and front line supporters need training in ASD.
 - Services need substantially increased funding in order to ensure the needs of children with ASD are met.
 - Services must recognise that children with Asperger syndrome have both a need for and a right to short breaks. Often children with Asperger syndrome cannot access services because they do not have a recognised "learning disability".

About the study

This exploratory study investigated the provision of short breaks for children and teenagers with ASD. It began from an

understanding that children with ASD were over-represented on the waiting lists for short break services (Prewett 1999). The research aimed to investigate:

- Whether short breaks were appropriate for children/teenagers with ASD?
- Which short breaks services are being used and what services are required?
- How short breaks can be provided appropriately for children with ASD?

The investigation included:

- Discussions about the concept of short breaks with 6 adults with ASD
- 6 focus group interviews with parents of children with ASD
- UK wide questionnaires to parents who use services (135 returned), parents who do not use services (136 returned) and service providers (371 returned)

The research is guided by an advisory group of parents, service providers and researchers.

What are autistic spectrum disorders?

The term autistic spectrum disorders (ASD) is used to acknowledge the fact that autism occurs in varying degrees of severity and in a variety of forms. Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. Their ability to develop friendships is impaired as is their capacity to understand other people's communication and imagination. People with ASD are not physically disabled although around 70% of children with autism do also have additional cognitive impairments (Howlin 1998).

The term Asperger syndrome is used to describe people at the "higher functioning" (more able) end of the autistic spectrum. People with Asperger syndrome have more language but have difficulty with using language appropriately. They often speak fluently though their words can sound formal or stilted. People with Asperger syndrome are often of average or above average intelligence but still have difficulty with social interaction, social communication and imagination.

It has been recognised that increasing numbers of children are being diagnosed with autistic spectrum disorders.

What are short breaks/family support services?

The short break/family support services covered in the research included:

- Family-based short break schemes (often known as shared care or family link services)
- Residential short break services,
- Domiciliary/Outreach services (services provided in or from the family home by a paid worker)
- Playschemes,
- Clubs (afterschool, youth and Saturday)
- Sitting services,
- Befriending schemes.

Why is support needed?

Over 90% of the children and teenagers with ASD require support in coping with new situations. Large numbers of children need high levels of practical support, whether they use services or not, although as shown on the table, families using services have higher support needs.

Support needed by children who are receiving or not receiving services

	Percentage of families	
	Receiving	Not
Securing their safety	96	87
Sense of danger	95	84
Communication	90	78
Personal care	81	64

Of the 136 children using services, 20 had Asperger syndrome in comparison to 61 children not using services. Children using services mainly had a diagnosis of autism and more obvious needs. Children with Asperger syndrome are, however, in great need of social support as they are often very aware of their difficulties with social interaction.

Most informal support, from family and friends, is on an occasional or rare basis. Families had very little informal support whether or not they used services. 38% of families who did not use services and 49% of families who used services reported having informal support less than monthly.

Children with ASD need constant supervision and often have unusual behaviour which leads to high levels of stress in parents and has a profound effect on the lives of siblings.

Other studies (Preece 2000) have shown that the stress experienced by parents is often higher than that of parents whose children are disabled in other ways. ASD is an "invisible disability" in that it is not initially obvious and is often not understood by family and friends as well as general society. Consequently, parents are often criticised for their child's unusual or inappropriate behaviour in public, and offered less support.

Appropriateness of short breaks for children with ASD

The adults with ASD who were interviewed believed that short breaks were beneficial for children if they were provided appropriately and with high expectations. They felt that services need to recognise children's vulnerability, confusion and need for consistency. Children with ASD enjoy the safety of routine and dislike change. However, they highlighted that if handled appropriately then change can be beneficial for children and enable them to learn and experience new activities and environments.

Benefits for families

Parents confirmed the adults' view that short breaks can provide children with new activities, experience and relationships as well as provide themselves and their child's sibling/s with a break. Nearly half of all the families who used services highlighted that short break services provided their only form of support. Parents stressed the importance of new experiences for their child. Many highlighted the benefits of activities in the community.

Issues regarding short breaks

Access to services was inhibited by factors common to disability services as well as some specific to ASD.

General factors included a *lack of*:

- local services
- funding for services,
- appropriate supporters/workers
- information about the services

Parents also highlighted difficulties with allocation and booking systems, transport and the lack of inclusion of siblings and a specific difficulty in family based short break schemes in placing older children with ASD.

Specific issues relating to ASD indicate the need for:

- adequate understanding of ASD and each child's specific needs. Over 80% of services required factual information regarding ASD while 62% required a specific training package for supporters.
- the need for consistent support by service providers with an appropriately high level of staffing - preferably 1:1.
- The need for funding and appropriately trained staff to enable service providers to offer adequate support.

Social services departments often refuse provision for children with Asperger syndrome because they do not consider them to have a recognised "learning disability" although they have a right to services under the White Paper "Valuing People".

Services used

Families usually used one or two short break services. Most families used playschemes, family based and residential short breaks. Less than a quarter had access to sitting and domiciliary support and small percentages clubs and befrienders. These families used the only services available to them.

Services required

86% of families who did not use services knew which services they would like to use. All families wanted flexible packages of support that focus on child and parents' needs. Parents need on-going support throughout the year as well as specific support in the holidays, ie playscheme or one to one support. Services should be at times that suit family life ie afterschool and at weekends.

Most families wanted a combination of various types of service. For example, families combined playschemes with sitting services and one or more of the other

services such as youth clubs, family based short breaks, afterschool clubs, befrienders or domiciliary/outreach/one to one support.

A substantial minority requesting flexible use of residential establishments (15%). Most families wanted 3 services.

Services currently available

24% (5146) of the 21, 277 children using the 371 services involved in the survey had ASD. The services were mainly for disabled children, although 30 services were specifically for children with ASD. A small number of services were inclusive of disabled and non-disabled children.

All of the services that recorded unmet needs had children with ASD waiting for services. Nearly a third (32%) of all the children (36% of the disabled children) waiting for services had ASD.

Providing services appropriately

Understanding ASD is the key to providing services appropriately. When services have a detailed understanding of ASD they recognise the importance of:

- Acceptance of the child/teenager
- Matching with appropriate supporters who have similar interests
- Preparing children for their short break
- Appropriate introductions which take as long as necessary
- Thorough planning, which reduces anxiety but allows for carefully introduced new experiences
- Suitably sized environments in which children are safe and secure
- Consistency in provision by ensuring the same supporter is available and services are provided at consistent times
- Partnerships with parents and other agencies to ensure the child's individual needs are met and their behaviour managed consistently
- High staffing levels so that children can have 1:1 support
- High levels of training and support for staff

Supporters working with children with ASD should receive training in ASD as well as gain a detailed understanding of the child through

working in partnership with their parents, school and any other agencies.

Funding

Short break services are already struggling to meet the demand for services for disabled children. A considerable on-going financial commitment is required to enable services to provide consistent, high quality services with appropriate staffing levels for the growing number of children with ASD.

Further information

For further information regarding autistic spectrum disorders contact the National Autistic Society telephone: 020 7833 2299 www.nas.org.uk

Further information regarding the research is available from Beth Tarleton, Norah Fry Research Centre, 3 Priory Road, Clifton, Bristol, BS8 1TX.

A report about the research, called Better for the Break, will be available in October 2002 from: Barnardo's Despatch Services, Paycocke Road, Basildon, Essex, SS14 3DR. Tel: 01268 522 872 (direct line) Fax: 01268 284 804. Email: despatch.services@barnardos.org.uk

Shared Care Network, the Umbrella charity for family based short breaks in England, Wales and Northern Ireland can be contacted on 0117 941 5361. Shared Care Scotland can be contacted on 01383 622462.