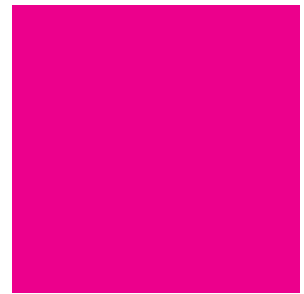


Breaking Down the Barriers



How short
breaks are
helping families
of children
with autism
to be "more like
other families"



Shared Care Network

2008

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Introduction

Shared Care Network’s “Breaking Down the Barriers” report is based on a survey of families of children with autism getting short breaks. We carried out this survey in response to a report called “A Life Less Ordinary”- People with autism; A guide for donors and funders (1) by charity New Philanthropy Capital. This highlighted the barriers faced by people with autism and their families in living ordinary lives and highlighted areas in need of further investment. Short break services was one of the key areas highlighted in this report. We wanted to see if short break services help to break down some of the barriers the report identified; and if short breaks are helping families of children with autism to be “more like other families”.

About Short Breaks

Shared Care Network is the national charity representing short break services for disabled children and young people. Short break services link disabled children with carers who provide them with short-term care on a regular basis. Short break carers spend time with disabled children. They help them enjoy opportunities and take part in many of the activities that non-disabled children take for granted. At the same time short breaks give their parents and siblings a break from the demands of caring.

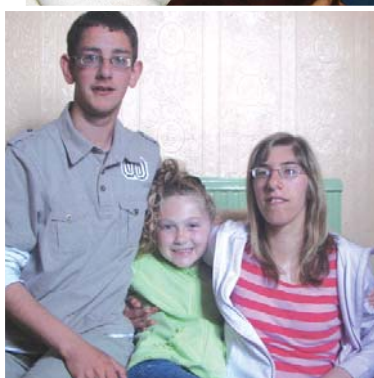
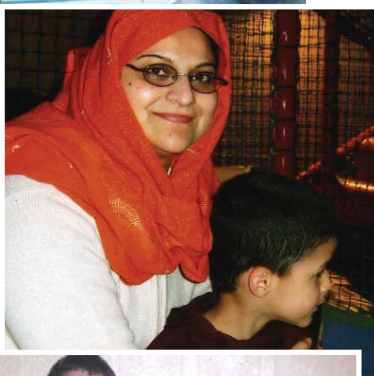
Children with autism and short breaks

Shared Care Network’s latest UK survey (2006) (2) showed that children with autism are amongst those disabled children who wait longest for short break services. A previous survey by Shared Care Network showed a third of disabled children on waiting lists have autism.

Autism is a lifelong developmental disability – children with autism go on to be adults with autism. The three main areas of difficulty for people with autism are sometimes known as the 'triad of impairments'. They are difficulties with social communication, social interaction and social imagination. Children with autism can struggle to cope in a world they find confusing and find many social environments stressful.

Shared Care Network’s survey of families

We surveyed families of children with autism nationwide to see whether short breaks are helping to break down the barriers identified in the “A Life Less Ordinary” report. Our report, “Breaking Down the Barriers” (3) highlights the findings of this survey and illustrates the ways in which short breaks are helping children with autism learn new skills and enabling families of children with autism to be “more like other families”.



How short breaks are helping to break down the barriers experienced by families of children with autism

"He enjoys his "fun" weekends, He is happy at home too because his parents have had a chance to "recharge" their batteries!" Parent of child with autism

Do short breaks help children with autism to make friends?

Making friends can be difficult for children and adults with autism. The "A Life Less Ordinary" report highlighted the fact that four out of ten children with autism have no friends at all.

Over half of the parents in Shared Care Network's survey said short breaks did give their child opportunities to make friends. Over a third said they were not sure if it did. The vast majority however, said getting short breaks had helped their child develop their social skills.

4 out of ten children with autism have no friends – A Life Less Ordinary report

Over half of parents in our survey said getting short breaks meant their child had opportunities to make friends - Shared Care Network's (SCN) Survey

"Short breaks means he has contact with another child of the same age." Parent

"Daniel often has the opportunity to go out with the family and some of their children's friends too. He has built up a really good relationship with his carers and their (four) children." Parent

"Sam has autism and he often prefers his own company however, with age he does relate to people a little better but is still predominantly isolated with regard to friendship." Parent

"Sebastian is "not into friends" but as he gets older he makes more social contact." Parent

Over 92% of parents in our survey said that getting short breaks had helped their child develop social skills - SCN Survey

"Although Ben has understanding and communicates well verbally and has a good sense of humour, he is vulnerable and finds it difficult understanding situations and emotions and can be inappropriate too. It has helped him with his social skills and working towards learning what is acceptable and what isn't." Parent

"It is giving him the opportunity to socially interact independently outside of the family setting. His shared carer is able to guide him in what is appropriate and what isn't." Parent

"He is learning to wait – for example for his turn in games, learning to share and learning to "ask nicely", saying please and thank you." Parent





Do short breaks help children with autism take part in social activities?

Taking part in social activities can be difficult for children with autism and their families. The “A Life Less Ordinary” report highlighted the fact that many adults with autism do not take part in any social activities.

Most of the parents in Shared Care Network’s survey said short breaks did give their child opportunities to take part in social activities.

A third of adults with autism do not take part in any social activities -A Life Less Ordinary report

Over four fifths of parents in our survey said getting short breaks helped their child take part in social activities - SCN Survey

“He enjoys the activities he does with his short break carer” Parent

“I like to watch television and use Andrew's computer and laptop. They’re a great, fun couple. Ben (5) who has autism

“Parents sometimes are too exhausted to want to take their child swimming or to the cinema. You can’t always be sure of their behaviour. The carers on short breaks take my son out enabling him to take part in activities on a regular basis.” Parent

“Dan is able to try different things and cope with a variety of situations. He can try new activities whilst gaining independence in a supportive environment.” Parent

“The carers take our daughter out for walks along the beach and out shopping, share music and dance.” Parent

Do short breaks help children with autism to be independent?

The “A Life Less Ordinary” report highlighted the fact that only a tiny percentage of children go on to live independently as adults with over half still living with their family. It also showed many adults with autism are not happy with where they live.

Most parents in our survey said short breaks were helping their child learn independence skills though over a third of parents were not sure.

Only 3% of adults with autism live independently and over half live with their family – A Life Less Ordinary Report

Nearly two thirds of parents in our survey said getting short breaks had helped their child learn independence skills – SCN Survey

“They do ordinary things like cooking together and shopping together.” Parent

“Joe spends time at Cathy’s cooking his own lunch and snacks.” Parent

“Our carers encourage her to feed herself and to experience new foods.” Parent

“He would help his carer in her house; put things away, decorate the Christmas tree, and help her set the table. He is not totally able to have independence on his own yet but in time hopefully he will.” Parent

“He has learned to go into public toilets (although they must still have a white light), go bowling through the carer’s persistence – in constantly trying and trying and has become more outgoing. He is happier to interact with other people now.” Parent

Do short breaks make children with autism happier?

Having autism can make the world seem a confusing and stressful place. The “A Life Less Ordinary” report highlighted the fact that the majority of people with autism have a mental illness.

In our survey we asked parents if they thought that getting short breaks made their child happier. Most parents in our survey said yes (though nearly a quarter said they did not know). Responses to the rest of the questions in the survey seem to show that parents do feel short breaks help their children cope better with their condition.

Three-fifths of people with autism have a mental illness - A Life Less Ordinary report

Over three quarters of parents in our survey said getting short breaks made their child happier – SCN Survey

“He really enjoys going. He refers to the date on the calendar when he is going. He gets 1:1 attention which is what he likes.” Parent

“He enjoys the activities he does with his short break carer. He enjoys having a relationship which is personal to him and independence from the family.” Parent

“I don’t know (if short breaks make him happier). He is out of the family, and on his own (which is what he loves anyway!)” Parent



Do short breaks help parents of children with autism cope with the demands of caring?

Looking after a child with autism can be very demanding and stressful. The “A Life Less Ordinary” report highlighted the fact that just under half of parents of children with autism experience mental distress.

All the parents in our survey said getting short breaks helped their families cope with the demands of caring. Many stressed the importance of knowing that their child was safe and that their condition was understood by their carers.

Just under half of parents of children with autism experience mental distress – A Life Less Ordinary report

100% of parents in our survey said getting short breaks helped their families cope - SCN Survey

“With Sebastian, there is no compromise. If he wants something he wants it now or has tantrums. He slams doors. He bounces on beds and chairs. He will scream the place down if something happens he is unhappy with. Having a break from this provides a relief and having time with my other two children is a help. And, I know that he is safe. That is a real comfort - in that I know Jane - I know she can deal with any problems that arise (probably better than me!)” Parent



Do short breaks help families of children with autism live more ordinary lives?

New Philanthropy Capital's report highlighted that families of children with autism live "A Life Less Ordinary". In Shared Care Network's survey we asked families if short breaks were helping them to live "more ordinary lives". Whilst all the parents said short breaks helped the rest of their family to live "a more ordinary life" not all felt short breaks helped their child to live a more ordinary life. Many parents pointed out that the very fact their child has autism meant it was difficult for them to live more ordinary lives.

100% of parents in our survey said getting short breaks helped them and the rest of their family live "a more ordinary life" - SCN Survey

Nearly three-quarters of parents said getting short breaks helped their child with autism live "a more ordinary life" – SCN Survey

"Yes, instead of going to a friend for a sleepover she goes to respite." Parent

"Sam's befriender takes him to different activities which help him a lot ...such as ball parks and climbing frames which my other son is too old for. He loves these activities which help him socially being with other children. Often sadly children will speak to Sam but soon realise he's not answering them appropriately and often walk off." Parent

"Does it help my child live a more ordinary life? Yes and no. He still isn't able to do things that a normal child would do at his age. I feel that children with autism are naturally segregated from their normal (peer) community but that is the very essence of the problem/condition. On the plus side it has given the opportunity to form a "normal" friendship he would otherwise not have made." Parent



Do short breaks help families of children with autism to be “more like other families”?

In our survey we asked parents, siblings of children with autism and children with autism what family activities they are able to do that would be difficult if they did not get short break services.

The main activities highlighted by the survey were that siblings benefit from one-to-one time with their parents, as well as opportunities to do activities which are difficult to do with a child with autism.

Parents get a chance to spend time with each-other, with their (non-disabled) children and other adults.

Both parents and siblings get a break from the stress and demands of caring for a child with autism. At the same time children with autism get a chance to have fun, take part in activities and gain social and independence skills away from the family environment.

Short breaks give siblings one-to-one attention from their parents and opportunities to do things which are difficult or impossible to do with a child with autism

“Short breaks are good for the family because me and my little brother can do things that we like but Daniel doesn’t - so we do them!”
Zoë (11) Sister of child with autism

“Having short breaks has enabled me to take my (other) son to swimming lessons and have relaxed homework time.” Parent

“We can do something spontaneous!” Parent

“I can spend time with mummy on my own without Adam being around. I can have a friend to tea.” Hannah (9) Sister of child with autism

“It also gives my daughter the opportunity to have a friend round without her brother making such a visit difficult for her as it means he is out of his routine when someone else is in the house.” Parent

Short breaks give parents and sibilngs a break from the demands of caring e.g. from stress, being “on watch” and following routines

“The demands are still the same at all other times but the respite time gives us all a valuable break from living with autism.” Parent

“We feel more relaxed. I like being able to leave my personal belongings out without them being messed up.” Stephen (14) Brother of child with autism

“It is nice for my mum to have some time alone to relax and do what she wants. It is also a good thing for me because it gives me time and space which has greatly benefited us when things are difficult.” Ben (15) who has autism

“We don’t have to double lock all the doors and windows.” Parent

The ‘triad of impairments’ - difficulties with social communication, social interaction and social imagination.

Short breaks give parents and siblings “time out” for themselves

“Short breaks are like a ray of light at the end of a tunnel. When things are tough they are something you can reliably look forward to. You can plan a social life. You can do things that people in a “normal” family take for granted.” Parent

“It gives me and my husband quality time as I can get some help for my youngest son but not my son with autism.” Parent

“I can catch up on chores like mowing the lawn. I can use the washing machine at any time of day – our son hates “noise” so these sorts of things are difficult to do normally.” Parent

“It enables me to breathe, to think about myself, catch up on sleep, recharge my batteries.” Parent

“It means we are able to do “normal” things like go out to dinner, go to the cinema, and have a stress-free house for a while.” Parent

Short breaks give children with autism a chance to have fun, take part in activities and gain social and independence skills outside the family environment

“He gets used to being with other people other than his family.” Parent

“I like to go to football matches.

I like to go to the top of the house.

I like to go jumping on the trampoline.

I like to play on there playstation (sic).

I like to play with Connor, Jack, Rory and Clare.

I like going to the park.

I like going swimming.

I like going to Brooklands museum.

The thing I like best is playing on the play station and Lego Races 2 computer game.”

Daniel Wolff (13) who has autism



What needs to be done?

Short breaks clearly benefit families of children with autism and children with autism themselves. Families of children with autism desperately need short break services which are appropriate to the needs of children with autism. However these families are amongst those most likely to wait longest for services.

"I had to wait for 4 years before Family Link was able to provide a carer for me." Parent

In addition thousands of families of children with autism are not receiving short breaks at all; people like this family.

"It would be good for us to have some respite, just myself or just my children. My son is autistic, has ADHD and is hyperactive and has no idea of danger. I do everything for my son - showers, changing pads, giving medication three times a day and washing him and ensuring he is safe. It would help us for my son to go on a short break. My daughter and I would have time to ourselves. We could relax and sleep. We could go out for a meal or visit family members." Single parent of two children one of whom (Andrew) has autism

"I would like to have a short break. I enjoy swimming, walking, going on buses, going to the airport, park, play centres and the seaside and playing on the trampoline. It would be good for my sister to have a short break – to take her away from her responsibilities (helping my mum)."

Andrew (11) who has autism

Shared Care Network has welcomed the government's "Aiming High for Disabled Children" initiative which promises significant investment to bring about a step-change in short break provision for disabled children in England. Children with autism are identified as a key priority. The challenge now is to;

- recruit enough carers and professionals nationwide to increase short break provision nationally for children with autism
- raise awareness and deliver training around autism for all carers and professionals involved in short breaks
- develop a wide range of short breaks (including universal and autism-specific services) to meet the needs of children across the spectrum.

Children with autism are amongst those disabled children who wait longest for short break services

What is Shared Care Network doing?

Shared Care Network is currently seeking funding for our Big Breaks campaign which seeks to double the number of children in the UK getting short breaks to 20,000 by the year 2012. As part of this we hope to run a national awareness campaign to recruit carers including carers for children with autism.

Shared Care Network has received funding from the Clothworkers Foundation for our one year "Reaching Out" project to deliver training and promote good practice on providing short breaks for children with autism. We are now seeking funding to deliver further training for carers and professionals. We are now seeking funding to deliver further training. We also wish to produce guides for carers providing breaks to children with autism and resources to help schemes recruit carers.

Over the next three years Shared Care Network will be working closely with local authorities and government to promote good practice in short breaks for children with autism. In particular we will be sharing good practice in setting up contract carers schemes (using paid carers) which are proving an effective way of increasing services to this group of children and sharing good practice amongst residential short break services.

Shared Care Network Cymru is campaigning for investment in short break services for children with autism in Wales in response to the "The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales". Further Government investment in short breaks is still urgently needed in Wales, Scotland and Northern Ireland.

Thank you to all the parents and children who took part in this survey

Thank you to all the families of children receiving short breaks pictured in the report.

Please note that families pictured are not those who took part in the survey and some of the disabled children featured do not have autism.

To find out more about autism go to www.nas.org.uk and go to “What is autism?”

For more information about autism go to www.nas.org.uk

To read the “A Life Less Ordinary” report go to www.philanthropycapital.org

For more information on the “Breaking Down the Barriers” report call Sue Mennear at Shared Care Network on **0117 9415361**.

For more information about the work of Shared Care Network go to www.sharedcarenetwork.org.uk

This document can be made available in alternative formats.

References

(1) **Joy I, Fradd A**, *New Philanthropy Capital*, (2007) *A Life Less Ordinary, People with Autism – A Guide to Donors and Funders* www.philanthropycapital.org

(2) **Carlin J, Cramer H** (2007) *Creative Responses to Changing Needs? Fourth National Survey of Short Break Services for Disabled Children in the UK*
www.sharedcarenetwork.org.uk

(3) The “**Breaking Down the Barriers**” report is based on a survey by **Shared Care Network** ” and is based on the experiences of thirty two members of families of children with autism. This was undertaken as part of a larger survey of parents (and carers) of disabled children including children with autism.



Shared Care Network

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