

IMPACT REPORT 2014

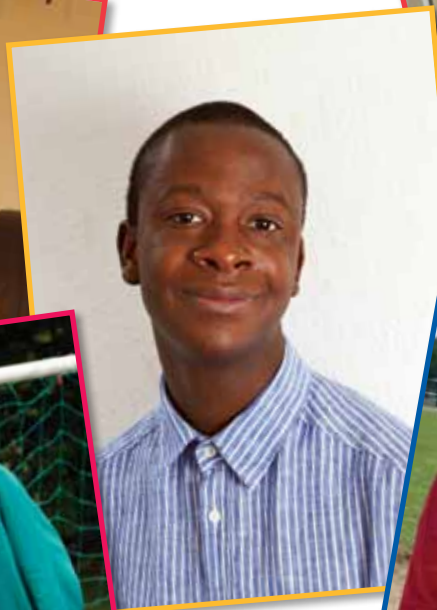


Accept difference. Not indifference.



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Foreword by CEO Mark Lever



The National Autistic Society (NAS) was founded over 50 years ago by a group of friends who were frustrated by the lack of support available for them and their children. They decided to act for themselves, and today, as the UK's leading autism charity, we continue to act on behalf of everyone living with autism.

Our vision is simple and clear – we want a world where everyone affected by autism gets to lead the life they choose. We are lucky to have many committed and enthusiastic supporters who share this vision.

As Chief Executive, I want to be absolutely certain that every single thing we do helps us to get closer to achieving our vision, and that every penny we spend has the greatest possible impact on the lives of the people we support. That's why we have embarked upon an ambitious project to better measure the impact of all the work we do.

There are around 700,000 people with autism in the UK. Together with their families they make up over 2.7 million people who need our support. We are proud of the wide range of services we provide to people living with autism and their families throughout the UK – these have a truly

positive and transformational impact on the lives of hundreds of thousands of people. But we simply don't have the resources to reach everybody. With more support from you, we can do even more.

To gain a deeper understanding of the impact we make, and the areas where we still need to improve, we have created a series of surveys that are specifically designed to capture the impact our services have on people's lives. This report presents the results of those surveys and provides the clearest picture yet of exactly how we are doing.

Our impact is extremely positive in most of our service areas, but the survey results have also highlighted some areas where we are simply 'doing well'. This isn't good enough for The National Autistic Society. The people we support are not statistics – they are people who have the right to lead the life they choose, and it is our duty to do everything we can to make this a reality.

I am proud of the impact The National Autistic Society has made. I am proud of everyone who works tirelessly in our services, and of our supporters who make it possible. But more than anything I am proud of the determination they all have to improve the lives of people affected by autism.

So, while we celebrate our successes, we will also focus relentlessly on improving any service that is not the best it can be. We will also work hard, with the help of our supporters, to raise the funds we desperately need. We are only reaching a fraction of the people who need our essential services and support.

As always, we cannot do this alone. Your support is vital if we are to achieve our vision. I hope that when you read this report, you are impressed. But I also hope that you recognise there is much, much more to do, and that you can help us to widen our impact and transform even more lives.

A handwritten signature in black ink that reads "Mark Lever". The signature is written in a cursive, flowing style.

Mark Lever
CEO, The National Autistic Society

What is autism?

Autism is a lifelong developmental disability affecting how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It's a spectrum condition, meaning that while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.

The three main areas of difficulty that people with autism experience are:

- › difficulty with social interaction – people with autism can find it hard to recognise and understand other people's feelings and to manage their own. Not understanding how to interact with other people can make it hard to form friendships
- › difficulty with social communication – people with autism may struggle to use and understand verbal and non-verbal language, such as gestures, facial expressions and tone of voice
- › difficulty with social imagination – people with autism can find it difficult to understand and predict other people's intentions and behaviour, and to imagine situations outside of their own routine.

People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Throughout this report, unless otherwise specified, where we refer to autism we are referring to the entire autism spectrum, including Asperger syndrome, high-functioning autism and Kanner autism.



We want a world where all people living with autism get to lead the life they choose.

On the following pages, you'll find out how we're measuring the impact of what we do, in order to make these ambitions a reality.

How we measure our impact

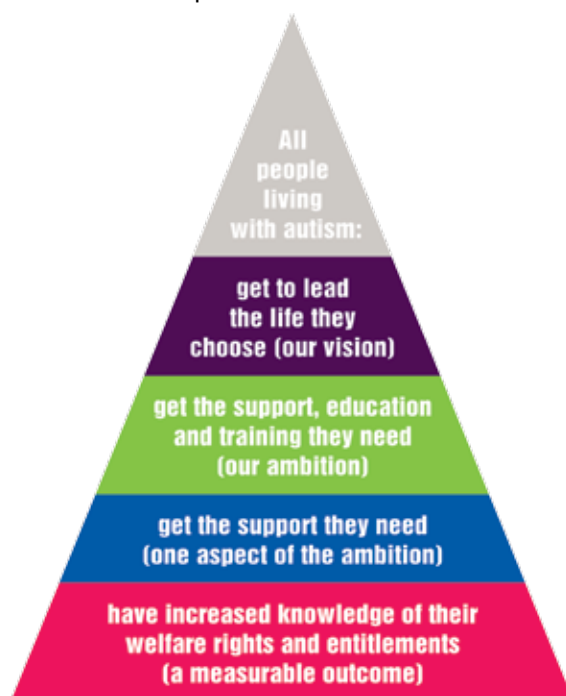
Creating the framework

This impact report represents a starting point: the start of The National Autistic Society's journey to better demonstrate the impact of our services on the lives of people with autism and their families. Throughout this journey, our constant reference point is our vision to create a world where everyone living with autism gets to lead the life they choose.

To establish our impact reporting framework, we first asked the people we support what needs to change in their world in order for us to achieve our vision. Their responses inspired our five ambitions. These are that everyone living with autism will:

1. **Get the support, education and training they need**
2. **Live with dignity and as independently as possible**
3. **Be a part of their community and wider society**
4. **Be understood by all professionals who support them**
5. **Be respected for who they are by a knowledgeable public**

We then split each of these ambitions into single identifiable aims (eg 'to get the support they need') and identified a clear framework of measurable outcomes, all of which led directly back to our core vision. Through these, we can measure how successfully our ambitions – and ultimately our vision – are being met. Here's an example:



Piloting the impact reporting framework
To explore whether our framework could be applied across the full and considerable

breadth of our services, we selected a representative sample to take part in a pilot phase between July 2011 and May 2012. The services chosen were:

- > EarlyBird programmes and Autism Seminars for Families
- > information and advice services (including our national Autism Helpline and specialist telephone helplines)
- > the Robert Ogden School and the Sybil Elgar School (two of our seven specialist schools)
- > a selection of social groups for adults with autism
- > two supported living services for adults with autism
- > our Prospects employment service.

We worked closely with each service to identify those outcomes which were most critical to measuring the impact of that particular service. We then selected a limited and manageable number of outcomes to measure – typically six to ten per service.

We developed outcome statements that were appropriate to the service and the people being surveyed, so that responses to these statements could be measured using a consistent five-point scale (see below).

Level 3 statements	Summary Total number	Strongly agree		Agree		Neither agree nor disagree		Disagree		Strongly disagree	
		Number	%	Number	%	Number	%	Number	%	Number	%
Experience of the Befriending service has increased communication within the family	41	12	29%	16	39%	13	32%	1	2%	1	2%
Involvement with the Befriending service has resulted in our child/teen...											

We then decided who was most appropriate to survey, by what method and via which channel.

We used a combination of face-to-face surveys (for example, when measuring the impact of our supported living service) and post or email surveys (for example, when measuring the impact of our telephone services) but we were also mindful to develop tools that enable all those who use our services to respond, including young people at our schools who are non-verbal.

While we recognise that the views of those who use our services are by far the most important in discerning outcomes, they are unavoidably subjective. Where possible, we have augmented these views with other data which the charity collates as a matter of course. For example, we have added data on the frequency and reach of our media coverage, which contributes enormously to our campaigning work and raises awareness of autism across the UK (see page 31).



Transparency

Within each section of this report, we have chosen to highlight the data that we believe represents the most powerful and important outcomes achieved by our services in 2012-13, regardless of the positivity of the response. Where we state that a percentage of respondents agreed with a statement, this has been calculated by aggregating the ‘strongly agree’ and ‘agree’ responses.

Volumes

The number of individuals we reach varies from service to service. Our Autism Helpline supported more than 19,000 people in 2012-13. Callers overwhelmingly rated the advice they received as appropriate, timely and empowering. Our schools, by comparison, work intensively with relatively fewer individuals. This table shows the number of responses to our outcome statements from each service.

Service	Respondents (to outcome statements)
EarlyBird (post programme)	994
EarlyBird (follow-up)	563
Autism Seminars for Families - Understanding autism	714
Autism Seminars for Families - Managing anger	944
Autism Seminars for Families - Sensory needs	563
Autism Seminars for Families - Teen life	238
Autism Seminars for Families - Common toileting difficulties	82
Autism Seminars for Families - Understanding behaviour	83
Befriending – befriender	34
Befriending – parents and carers	43
Radlett Lodge School	32 students and 17 families
The Robert Ogden School	42 students and 15 parents/carers
Sybil Elgar School	51 students and 10 parents/carers
Supported living – people we support	50
Supported living – families	18
Residential – people we support	82
Residential – families	34
Outreach – people we support	60
Day services – people we support	93
Social groups (people we support)	48
Autism helpline	985
Parent to parent service	50
Education rights service	148
Welfare rights service	126
Community care service	76

Future developments

We know that there are important aspects of our work still to be measured. In particular:

- › the impact of our 100 or so local branches, which provide so much support and information, and undertake effective campaigning work
- › we have not at this stage sought to establish a model for analysing the Social Return on Investment (SROI) for some of our services
- › we have not actively sought the views of further audiences, such as service commissioners.

We expect to develop each of these further by the time our next impact report is published. In the meantime, we have carefully tried not to make

sweeping or unsubstantiated claims about the impact of our work and the outcomes we are effecting. We believe that we have made important strides towards robustly reporting on the impact of our work by developing an impact reporting framework that enables us to gather responses to measurable outcomes. The results show how our work directly feeds into the achievement of our vision – and it is clear from the overwhelmingly positive responses to our outcome statements that we are making a real difference to the lives of the people we support.

The National Autistic Society was founded over 50 years ago by a small group of friends who were frustrated at the lack of education and support available for them and for their children with autism. Since then, we have grown into the UK's leading autism charity, with more than 18,000 members and almost 100 branches. We reach hundreds of thousands of people living with autism every year, in many different ways.

Our people

We are committed to developing our dedicated workforce, which numbered around **3,500** in the year 2012-13. More than **3,000** of these employees work in our education and adult services teams. In a survey supporting our commitment to employ people with autism and other disabilities, **6.4%** of respondents said that they had autism (compared to an estimated **1%** of the adult population) and a further **20%** said that they had a disability other than autism.

We were delighted to undergo a successful Investors in People review in March 2012 and to retain our accreditation. Working with Investors in People, we've developed a three-year learning and development strategy linked to the achievement of our vision and mission.



Our finance

In 2012-13, our total income was £92.3m and we spent £91.3m, generating a surplus of £1.0m.

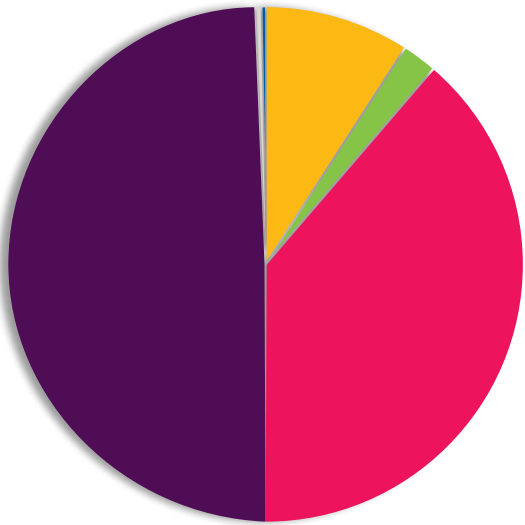
Trustees review reserves as part of the monthly management and annual strategic planning process to ensure that reserves are in line with identified operational and strategic business needs. In 2012-13 our free reserves balance was £5.5m. There are further details in our *Trustees' annual report and accounts* for the year ending 31 March 2013, available online at www.autism.org.uk/about.

Income and expenditure figures were slightly down on the previous year, reflecting the tough economic climate in which we are operating. A decline in school income was partially offset by continuing high demand for our adult residential services.

Combined voluntary income, activities income and investment income rose to £8.8 million. This accounted for 9% of total income.

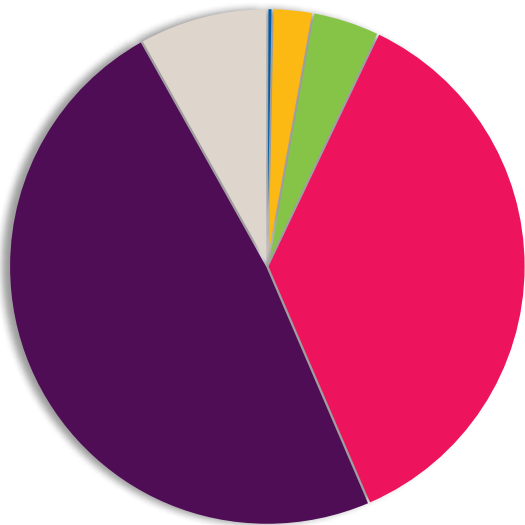


Income



Voluntary Income	8,791	9.53%
Network Autism Community	2,333	2.53%
Education	28,651	31.06%
Social Support	52,091	56.46%
Centre for Autism	389	0.42%
Other	2	0.00%
Total	92,257	100.00%

Resources expended



Activities for Generating Income	2,466	2.70%
Network Autism Community	4,461	4.89%
Education	27,284	29.90%
Social Support	49,718	54.48%
Centre for Autism	7,040	7.71%
Governance	284	0.31%
Total	91,253	100.00%



Quotes from the many people that we support

“Our son is now 18 years old but I’m sure we wouldn’t all still be together today had it not been for your help.”

- Parent

“I called the Parent to Parent line one evening and spoke to Stuart. He listened and listened to my questions and made me feel a sense of relief that I was not alone.”

- Parent

“Thank you for helping people like me when they need you.”

- Person with Asperger syndrome

“You really do change lives and help people cope in difficult situations.”

- Supporter

“The minute I walked in I thought, this is where my daughter fits in. There’s been a huge change in her over two years. I’d love her to stay until she’s 19.”

- Parent of NAS school pupil

“Your support is immeasurable in so many ways to so many families.”

- Family member

“Your Autism Magazine throws a lifeline to families struggling to cope - Your efforts are vital to so many of us.”

- Parent

“Autism seems to be a ‘silent disorder’ in so many ways - it’s great to know you are there to listen.”

- Helpline caller



401 young people attended our autism-specific schools. Even more attended our out-of-school clubs or benefited from our education outreach.



- 271 in day education**
- 81 in 52-week residential provision**
- 49 in 38-week residential provision**

We also support 214 students in Key Stage 5 or further education across our schools, and we are increasing links with local further education colleges to make sure students can access appropriate support wherever possible.

3,959 families benefited from direct support programmes, including:

- 1,201 who accessed our EarlyBird programmes delivered locally through licensed teams.**
- 1,076 families who accessed our EarlyBird Plus programmes.**
- 1,468 families who attended Autism Seminars for Families.**
- 214 professionals also participated in these family support programmes or have been trained in their use.**



1,378 adults with autism were supported by us, including:

232 in residential accommodation

529 through 800,000 hours of supported living and outreach services

256 in day services



Many other adults with autism enjoyed attending one of our social groups around the UK.



19,300 enquiries were supported through our Autism Helpline.

4,629 enquiries were supported in more depth through our Welfare Rights, Community Care and Education Rights services.

Our wonderful NAS branches run countless local services, such as:

Support for parents and carers

Information and advice for parents and carers

Social groups

Play schemes

Our Autism Action Network has brought together 100 volunteer Autism Ambassadors across the UK to campaign locally and nationally.

We campaign and lobby in all the nations of the United Kingdom to ensure that government and local authority policies take account of the needs of families living with autism.

Online services

Our website is one of the largest online autism resources in the world, allowing visitors to personalise the information they want and search for autism services throughout the UK.

More than 2 million visits to the NAS website over the course of the year.

200,000 unique visitors every month.

A social media following of more than 62,000 people.



Thousands of professionals were supported by us, including:

132 clinicians trained in use of our diagnostic tool DISCO at the NAS Lorna Wing Centre

More than 2,000 professionals trained in how to better support people with autism in employment

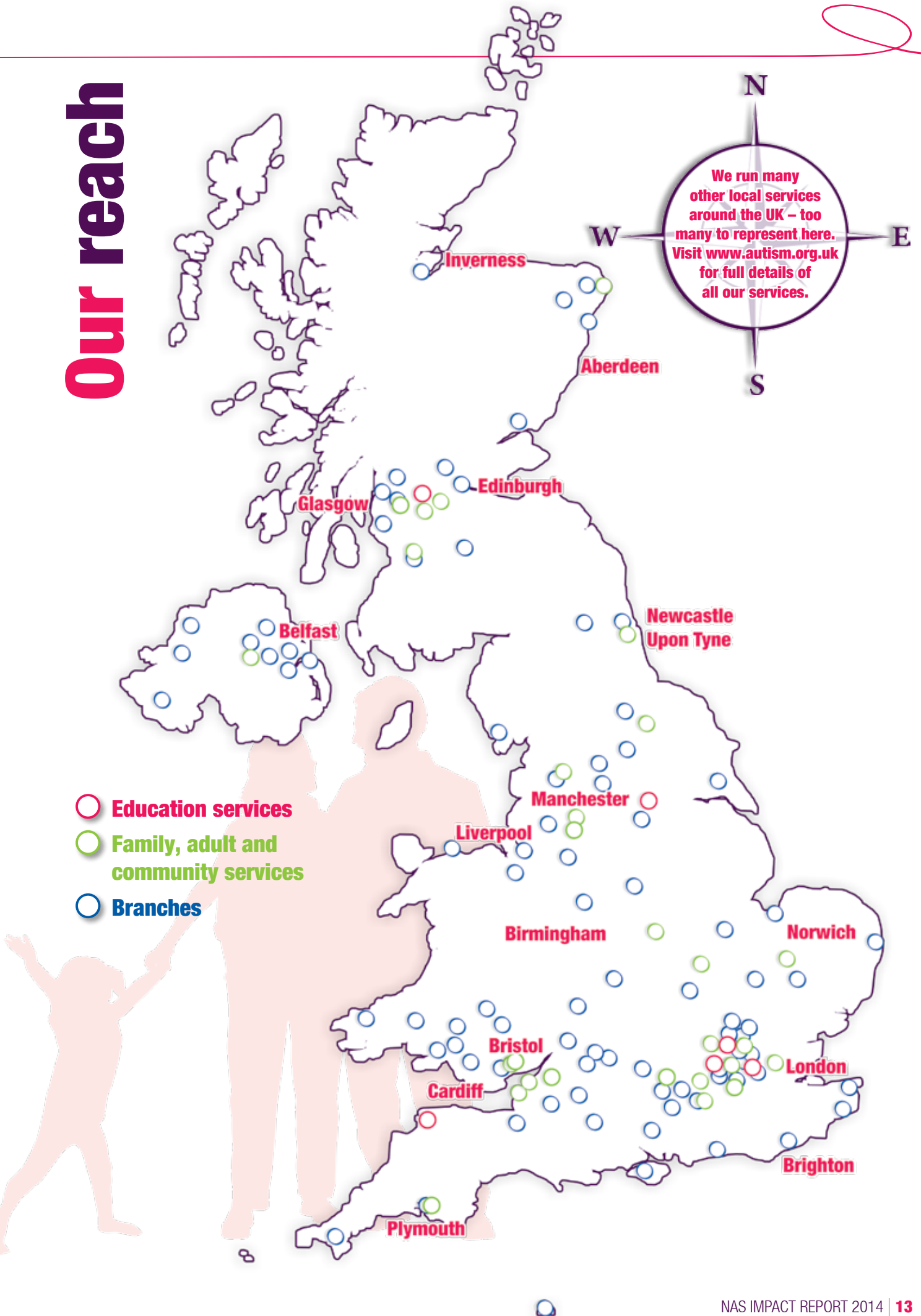
470 members of our Autism Accreditation scheme

3,200 registrants to Network Autism, our online community for professionals



And around 2,000 professionals attended our full and diverse programme of conferences.

Our reach



Supporting families

Whenever a child is diagnosed with autism, it is a deeply uncertain time for their parents and carers. Far too many parents say they are given no guidance about what to do next. Not surprisingly, some end up feeling confused, frightened and isolated.

Our report *The way we are: autism in 2012* revealed that just 28% of families feel they received good information about where to go for help once their child obtained an autism diagnosis. For many, it took three or more years of struggle with their local health or education services before they even got the diagnosis.

The impact of being told your child has autism can be overwhelming and heartbreaking – but with the right support, it is a challenge that families can and do overcome.

Our EarlyBird programme for parents and carers of pre-school children with autism provides a vital foundation of knowledge, understanding and support. The programme includes group training sessions, individual home visits and ongoing work with the child at home. We also run an EarlyBird Plus programme for parents and carers of children who receive a later diagnosis. During 2012-13, our EarlyBird programmes helped 2,277 families. Families that attended our EarlyBird Plus programmes were accompanied by 661 education and social care professionals.

We also support families through our Autism Seminars for Families. In 2012-13, 1,468 families benefitted from seminars on subjects such as understanding sensory needs or managing

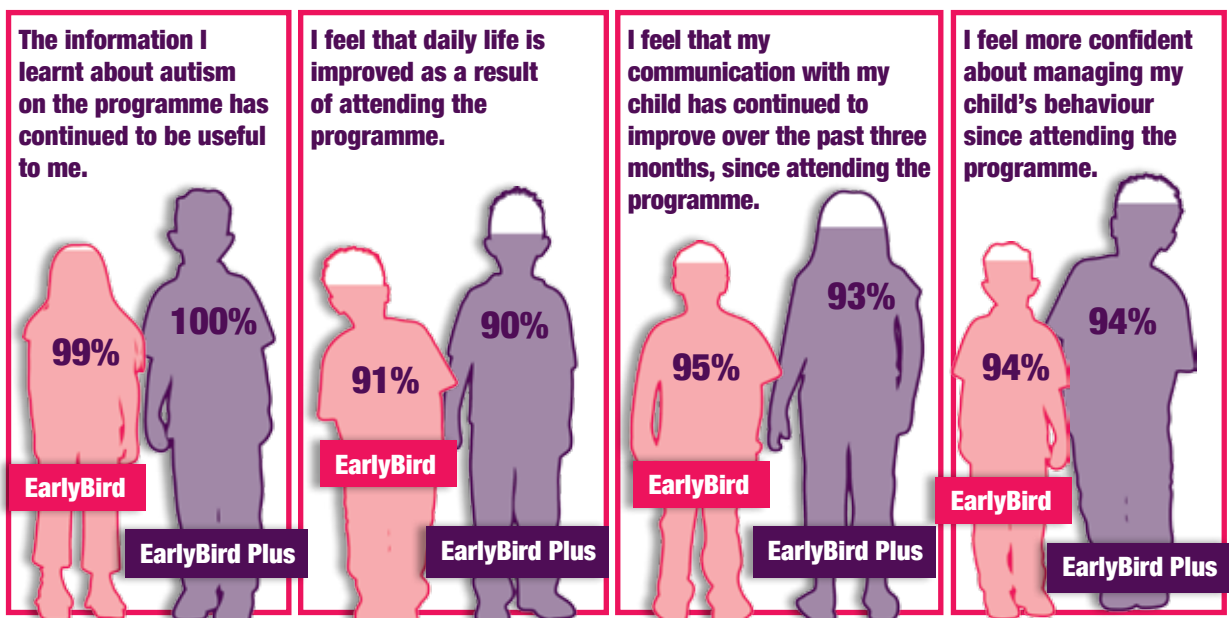
anger. We also trained 14 professionals in the use of Autism Seminars for Families materials.

But for many families, the most valuable help is that which they get in their day-to-day lives. Our befriending volunteers spend a few hours each week with a child or adult with autism, or their family. Some spend time in the family home, others go out and about. All make a huge difference. We also offer e-befriending online.

When we studied the impact of these services, we found overwhelmingly positive results. More than 90% of parents who had attended an EarlyBird programme told us that their daily life had improved as a result. They said they felt more confident about understanding and managing challenging behaviours as a result. Likewise, feedback from our Autism Seminars for Families tells us that, after most seminars, around nine out of ten participants feel more confident in their ability to meet their child's needs.

Over 60% of people with autism who were visited by a befriender (befriendees) said that they felt more confident as a result – and 95% of parents and carers felt that their child had gained greater confidence. More than 50% of befriendees also said that their communication with friends and family had improved.

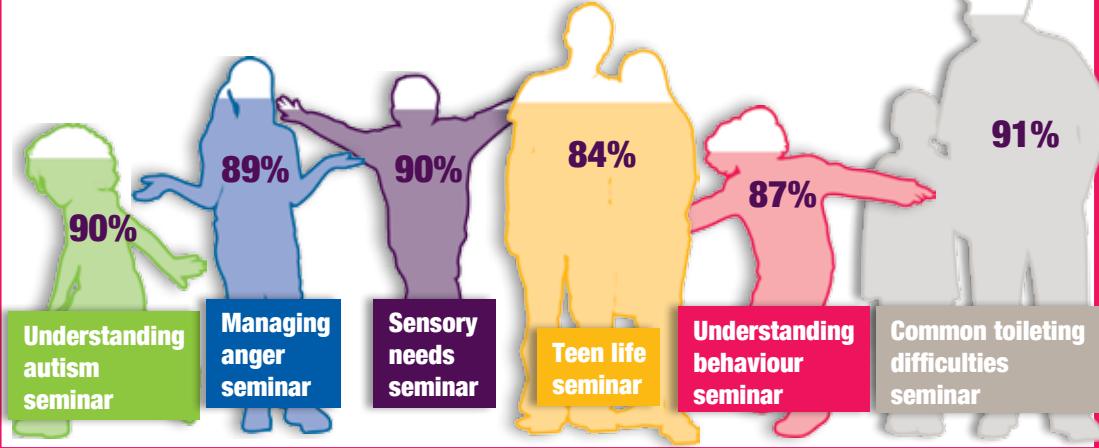
After three months, parents who attended our EarlyBird programmes said:





Parents who attended our Autism Seminars for Families said:

I feel more confident in my ability to meet my child's needs.



I feel more optimistic about the future.



I feel that I have a better understanding of my child's challenges with anger.



I have gained practical ideas to help me and my child learn how to manage their anger.



I have greater knowledge of low-arousal strategies to help my child cope with potentially stressful situations.



I feel that I have a better understanding of sensory processing.



I am more aware of sensory issues that affect my child and how to use relevant strategies to support my child's needs.



Experiences of our befriending service

Experience of the befriending service has increased communication within the family - 63%

Involvement with the befriending service has resulted in our child/family feeling listened to and understood - 81%

The befriending service has resulted in our child gaining improved decision-making skills - 55%

The befriending service has improved our child's/family life - 71%

The befriending service has helped our child to gain greater confidence - 95%



Since having a befriender, I am better at communicating with friends - 56%

I feel listened to - 79%

I feel better about myself - 65%

I feel more confident - 62%

When we asked about our e-befriending service, the results were positive but less impactful than face-to-face befriending. We found that 39% of respondents agreed that their confidence had improved and 31% said that they had become better at communicating with friends and family.

Supporting families case study

Five-year-old Holly is bright and clever, independent and outspoken. But until her mother Amanda attended our unique EarlyBird Plus programme, she found her daughter could be “hell on legs”.

Holly smashed the television, attacked her parents, her teenage brother and the family dog and cat, and threw things around the home. Her public meltdowns provoked cruel comments from strangers, who told Amanda that her daughter needed “a good slap” and “shouldn’t play with normal children”. Shopping was a nightmare for Amanda, as Holly would disappear under shelves or tear displays apart in an effort to find a place to hide.

The turning point for Amanda was when Holly was diagnosed with autism. The news was a massive shock: “I just thought she was very clever, very bright”, says Amanda. “Autism never even crossed my mind.”

Amanda’s quest for answers brought her to our EarlyBird Plus course – a training programme especially designed for parents and carers of young children with a recent autism diagnosis. The programme gave Amanda new insights into why Holly acted the way she does, and what the family could do to support her. “It’s more personal,” explains Amanda, “because you become part of a family group – you get to know the other parents, you are talking about your children, and the EarlyBird trainer does home visits as well. You aren’t just talking about a photograph, you are talking about a child.”

Amanda has now modified the family home to help Holly cope with her sensory issues around sound, touch and balance – issues which could otherwise trigger anxiety and lead to meltdowns. “We’ve got lowered handrails on the stairs and Holly’s bedroom is a sensory den.”

EarlyBird Plus also helped with another of Amanda’s concerns: “Sometimes you feel as a parent that you’re not listened to at school

because the things that you see at home, like the meltdowns, are not seen in school.” Bringing Holly’s school support worker along to the course gave Amanda the reassurance that her daughter will now be better understood in class.

“Holly’s so bright and clever, she’s quite capable of holding it together at school and doing the same as everyone else is doing. And then when she gets home she’s just had enough, she just wants to be alone. She wants to go to her bedroom on her own or she just falls asleep because she’s physically and emotionally shattered. And they don’t see that side in school.”

By going on a programme like EarlyBird Plus with parents, school staff get to hear from other professionals and other parents about what actually happens in the home, says Amanda. “They see that this is not just a mum telling you a whole lot of stuff – it happens across the board and is part of the autistic spectrum. And that actually takes a lot of weight off my shoulders.”

“I also know I’ve got The National Autistic Society around, and they are only a phone call away.”

Amanda knows her daughter will always face challenges in a world that largely fails to understand autism. But she hopes that future employers will recognise Holly’s rare skills. “How many of us would love to just say what we think? She is honest and speaks her mind. She’ll make a brilliant manager because she won’t be scared to ask the questions that need answering.”

“Sometimes you feel as a parent that you’re not listened to at school because the things that you see at home, like the meltdowns, are not seen in school.” - Amanda



Our report, *The way we are: autism in 2012*, revealed the huge range of hopes that people with autism have for the future. They want to be actors, musicians, chefs, racing car drivers, doctors, pilots, and even writers for *Doctor Who*.

Our education services work to make sure that as many young people with autism as possible can fulfill their potential. But the challenge is daunting. Around 25% of children with autism have been excluded from mainstream schools, compared to just 4% of children without autism. Nearly two-thirds of young people with autism in mainstream education have been bullied at school.

We are making a real difference, running a network of autism-specific schools across the UK. Since we opened our first school in 1965, more than 1,500 children have received an education in our safe and supportive environments. In 2012-13 we supported 615 children in our schools and further education units. We also opened up Thames Valley School, a new free school, through the NAS Academies Trust.

Radlett Lodge School

Parents said:

My child's additional needs are met at school.

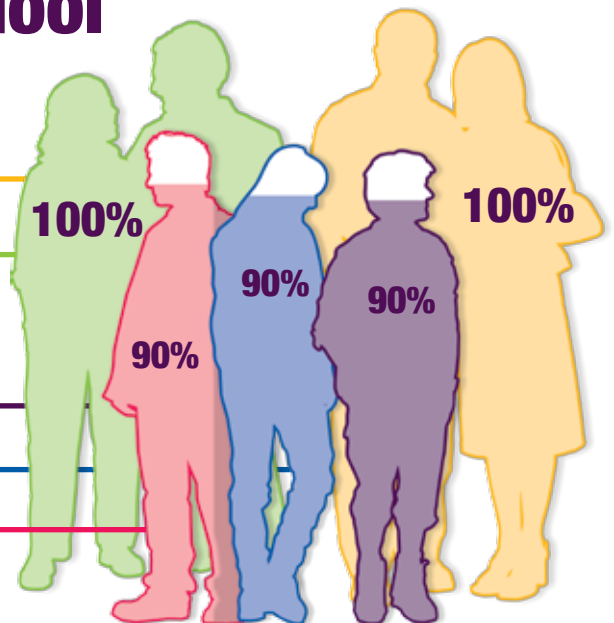
School helps my child develop important life skills.

Students said:

I like my lessons.

School helps me learn how to be kind.

I do activities at school.



Sybil Elgar School

Parents said:

I would recommend my child's school to other parents.

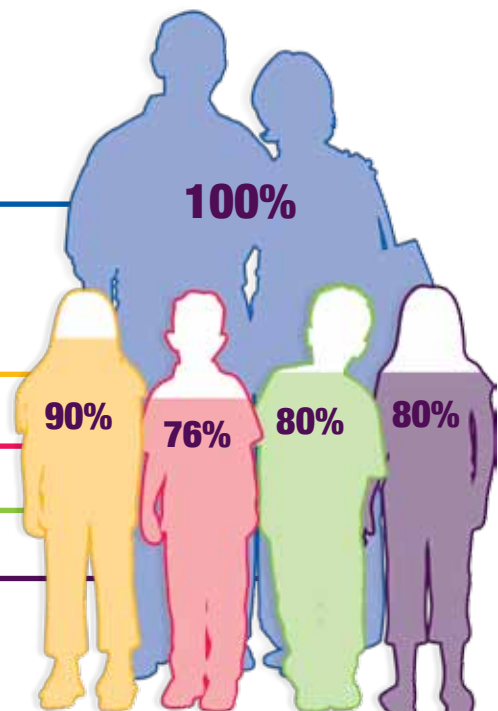
Students said:

I learn how to stay calm and to be kind to others at school.

I can make things better at school.

I can let others know what I want.

I enjoy the activities I do at school.





Robert Ogden School

Parents said:

I have confidence in my child's school.

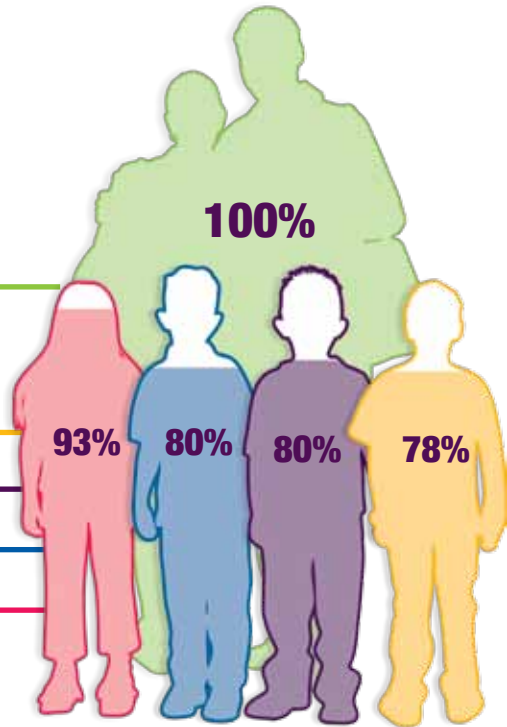
Students said:

I try to keep the rules.

I ask for things I want.

I am happy at school.

I like doing things at school.

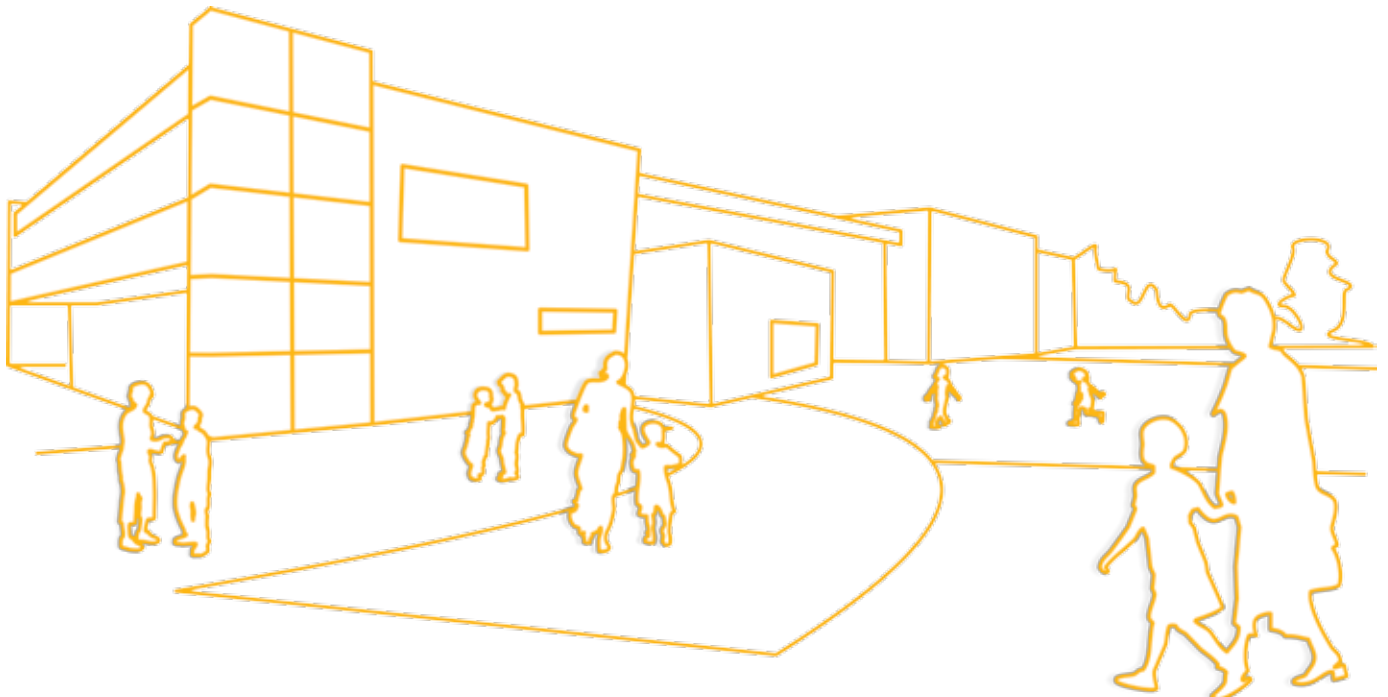


Radlett Lodge School in Hertfordshire has opened a post-16 service and residential provision, while continuing to offer short breaks. In Ayrshire, Daldorch House School also provides short breaks, residential placements and emergency respite.

Sybil Elgar School in London and Robert Ogden School in Yorkshire have extended their age ranges to include primary-aged children. Meanwhile, Helen Allison School in Kent has opened an inclusion base for students who need support to maintain school placements.

Important as they are, our schools can only support a fraction of the young people with autism in the UK. That's why we also promote best practice in mainstream schools, run out-of-school clubs and outreach services, and support young people in further and higher education. We are developing new models of support, including a 'satellite' school in South Lanarkshire and a number of free schools.

As our schools data demonstrates, children, young people and their parents told us that the outcomes that matter in terms of safety, happiness and improved behaviour are being delivered consistently.



Improving education case study

David is 17 and has Asperger syndrome. He attends both a mainstream school and our own autism-specialist school, the Helen Allison School in Kent, which he's been going to since he was four.

David's placement at Helen Allison School was offered to him on the specific condition that he was also given support to integrate into the local mainstream primary school.

Before starting school, David went to a mainstream nursery, where he had full-time support but still never managed to complete a full afternoon session. Alongside his nursery placement, David's local authority arranged sessions at the family home to help prepare him for learning at school. David's mother Emma says: "Our other local choices at the time were schools for children with learning difficulties, one of which had an autism unit. Everyone felt these were unsuitable for David, as he clearly didn't have learning difficulties."

Helen Allison School provides an individually-tailored education, with small classes and high levels of teaching support. All staff have specialist training in autism, and speech and language therapists and an educational psychologist are always on hand to help and suggest strategies. Most importantly, they will intervene quite early on, which means that problems don't escalate and get completely out of control.

The environment at Helen Allison School is designed to be autism-friendly and safe. "We find that staff are 'tuned in' to pupils' needs and moods," says Emma. "They teach as much as they can, when they can, in a clear and meaningful way – and they understand when not to expect too much." The timetable includes social communication classes alongside academic learning. Some lessons take place off-site to allow pupils to pick up practical skills and prepare for 'real-life' challenges.

Once David had settled into Helen Allison School, integration into mainstream education began with maths and English classes. David always had full-time, one-to-one support

provided by a familiar staff member from Helen Allison School. Over the past few years this has been very gradually reduced, so the teaching assistant is not actually in the classroom, just nearby and offering support between lessons. Recently the teaching assistant has been totally withdrawn at some times.

David is now going to mainstream sixth form to study maths and physics A-levels. He has also just finished an AS-level in computing. While integration into mainstream is very important to David, he has never considered it to be a suitable, full-time placement. Instead, going for shorter, controlled periods means he has the opportunity to experience a mainstream environment, academically and socially, in a positive way. If things get overwhelming or he cannot cope with a situation, he can leave and join his class at Helen Allison School.

Everyone – including the schools, the local authority, David's family and, of course, David himself – has worked together, which has been key to the success of the arrangement. "I can only guess what would have happened if David had been forced into mainstream full-time," says Emma. "It wouldn't have lasted very long and he would be stuck out of school. Instead, he's planning to apply to university next year, and he hopes to have a fulfilling life with a good job and a family."

"I can only guess what would have happened if David had been forced into mainstream full-time." - David's mother





Transforming adulthood

Autism is a lifelong condition, so children with autism grow up to be adults with autism.

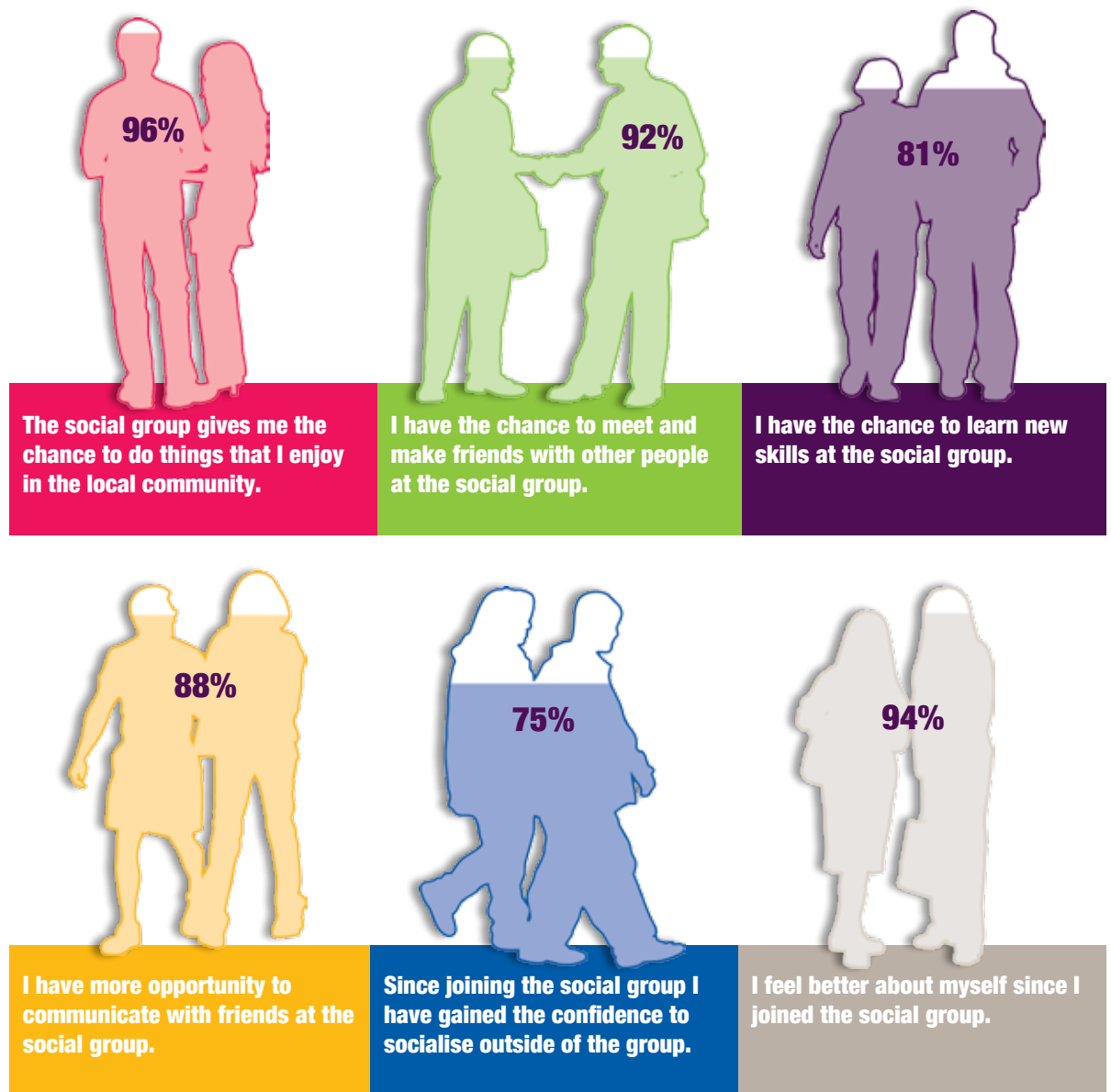
We work tirelessly to make sure that people with autism can live with independence and dignity as they move into adulthood. For some, that means living independently while getting help to do certain things that they find difficult. For others, it means a lifetime of continuous specialist support. Everyone on the autism spectrum is different, so we offer the right support for each person's individual needs.

People with autism find it difficult to communicate and make sense of the world around them. Many experience severe over- or under-sensitivity to noise, light, taste, smell or

touch – this makes it extremely stressful to do everyday things that other people take for granted. Our report, *The way we are: autism in 2012*, found that one-third of adults with autism need support to do a food shop, half are not able to go to the cinema, and more than half cannot go to a pub or restaurant or use an unfamiliar public transport route.

Shockingly, 62% of adults with autism told us that they do not have enough support to meet their needs. A similar number told us that their local authority had never assessed their needs as adults.

Adults who attend our social groups said:





As a result, nearly two-thirds of adults with autism depend on their families for financial support, and 38% still live at home with their parents – even though half of those adults with autism living at home would prefer to have places of their own. Our supported living and outreach services provide support for those who want to live by themselves.

We estimate that only 15% of adults with autism are in full-time employment. Many people with autism can flourish in their careers, but they often need professional support and guidance to make the first steps into the world of work.

Our employment service provides training to organisations and employability professionals so that they can recruit, train and retain staff with autism. Training is also available for further and higher education staff. Our activity extends to campaigning for better services, and making sure that people with autism are not written off by employers or the state. In Cardiff and Glasgow we provide job-finding support to people with autism.

We also train professionals to support people with autism – in the last year alone, 4,365 professionals have benefitted from our training courses, including 84 clinicians.

A brother of a person with autism told us about the impact our services had had on his sibling’s life:

“My brother has for the first time in his life some semblance of a ‘normal’ life after so long being locked in a secure facility, and for that I am eternally grateful.”

One of the biggest challenges facing adults with autism is social isolation. We work to overcome this through social groups, social skills training courses and our befriending and e-befriending services. We also run a free online community for people with autism, parents, carers, relatives and professionals. The evidence shows that this support has a positive effect on people’s health, helping them to become more independent and make friends.

The results of our surveys suggest that our programmes are succeeding in helping adults with autism to live with greater independence, dignity and social inclusion. But these services are currently facing huge financial pressures.

Despite all the good work, our services for adults with autism are only able to reach a small proportion of the people who need them. Our residential services are at full capacity for most of the year and we are unable to meet the additional demand for places, which is why we have started planning a significant increase in capacity, subject to funding.

Adults in supported living said:

- I am able to choose for myself - 82%**
- I like my flat - 80%**
- I can do more things now - 88%**
- I now talk to people more - 74%**
- I have made new friends - 64%**
- I can ask for things I want - 94%**

Families of adults in supported living said:

- We are involved in relevant decision-making - 72%**
- People listen and respect our opinion - 78%**
- Our family member is supported to live as independently as possible - 94%**
- The physical environment is appropriately developed to support my family member to live independently - 89%**
- Our family member has more confidence now - 100%**
- Our family member enjoys activities and participating in life - 94%**
- Our family member is encouraged to develop increased social skills - 89%**
- Our family member is supported to communicate - 94%**

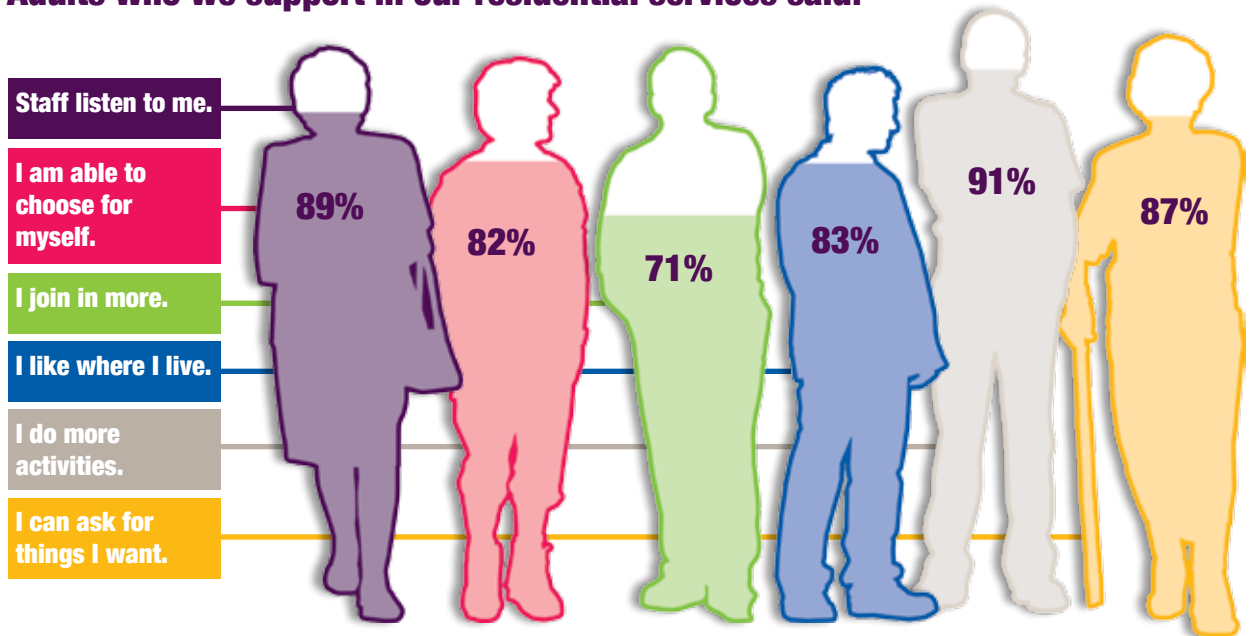


Some of the adults we support choose to live in our properties, which contain a mix of assistive technologies.

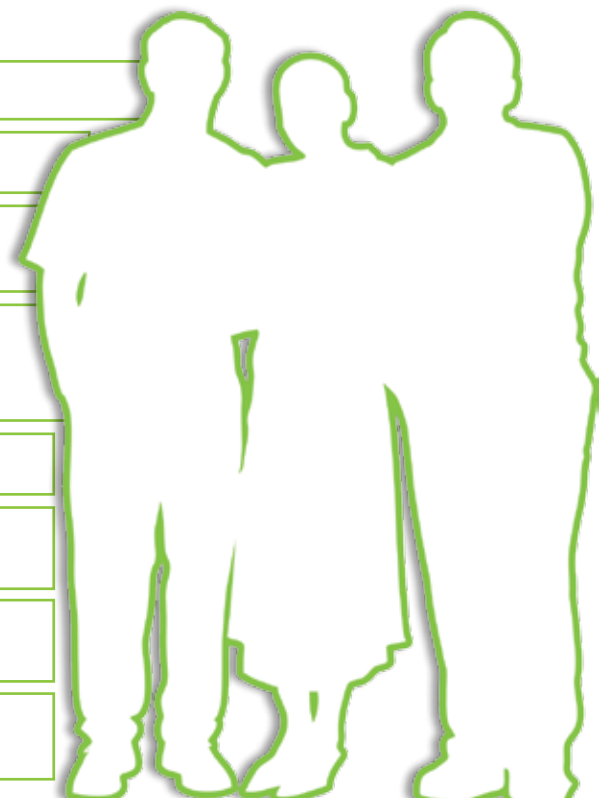
In total 232 adults with autism lived in our accommodation in 2012-13, and we are working to expand the number of places we can offer. We provide residential services for adults across the autism spectrum, offering specialised, person-centred support. Each residential service provides accommodation 52 weeks per year, 24 hours per day, offering security and continuity.

In addition, 256 adults with autism used our day services, which provide a place for people to come for support, social interaction and to develop new skills. We offer a wide range of groups, classes and activities outside the home that allow adults to pursue their interests and develop their life skills in a meaningful way.

Adults who we support in our residential services said:



Families of adults who we support in our residential services said:





People who use our day services said:

I feel safe - 87%
Staff listen to me - 89%
I get support to help me with any concerns that I have - 83%
I am able to choose for myself - 86%
I have learned new skills - 68%
I have made new friends - 71%
I am better at communicating with other people - 76%

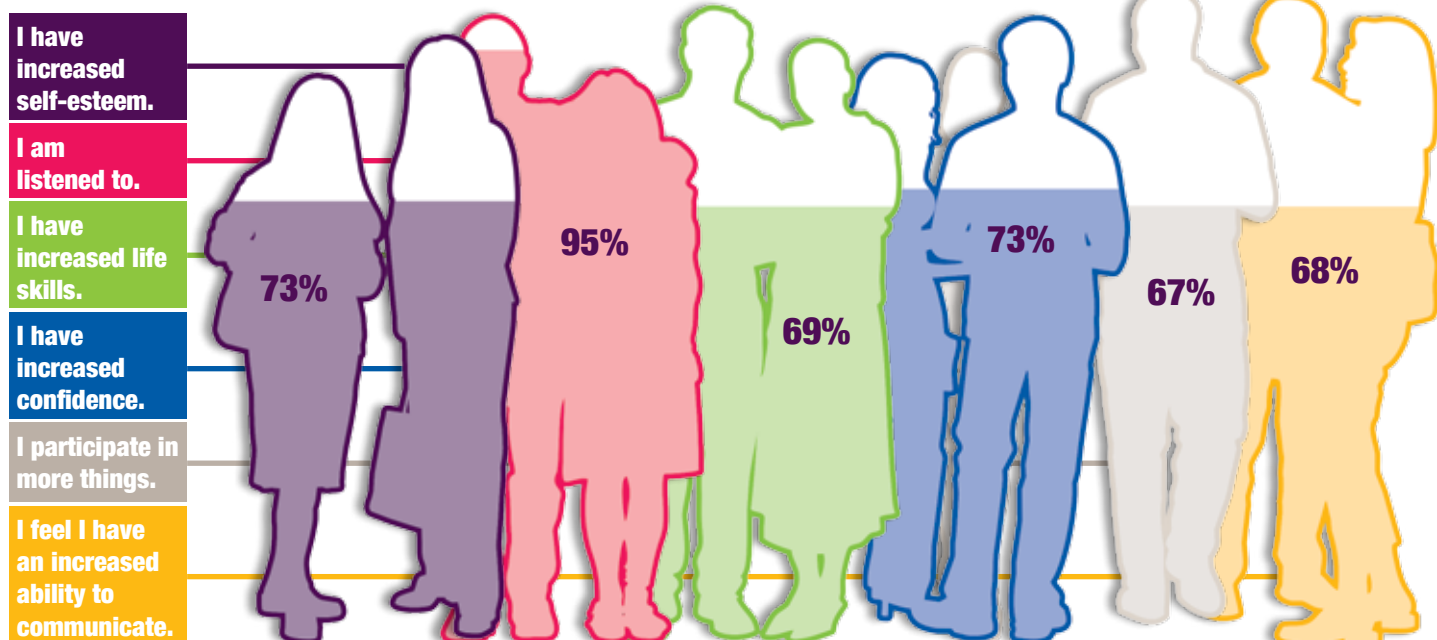


Our flexible outreach service helps people with autism to access opportunities and activities outside their home - and through this, to achieve their aspirations, and become more confident and independent. We might assist people to take part in their favourite sport or attend a college course. We also provide support in the home.

In 2012-13, our outreach workers spent more than 800,000 hours working with 529 adults who live in their own flats and houses. This is fewer people but more hours than in the previous year (when 563 people received 714,000 hours of support), reflecting the increasingly specialised nature of our work and the severe impact that autism can have on people's lives.

Our trained staff can provide anything from a few hours of support a week to help with everyday tasks, to comprehensive 24-hour care packages for people with more complex needs.

People who we support through our outreach services said:



Transforming adulthood case study

Jonathan is a business analyst at Goldman Sachs, the world-famous investment bank. His story illustrates how people with autism can excel in their chosen careers – and how our support services can be life-changing for people making the transition into adulthood and independent living.

Jonathan was diagnosed with Asperger syndrome at the age of 18. Up to that point he'd been told he had dyspraxia, and the various specialists he saw struggled to understand how somehow so clearly intelligent could be having difficulties at school. "From the age of five until the age of 18 my life was basically a minefield of various tests. Nothing really seemed to add up." Finally, getting a diagnosis of Asperger syndrome completed the picture.

Jonathan went on to university, where he had an impressive academic record. His problems only really started when he finished his studies and began applying for jobs. "I didn't know really where to go after that. You look everywhere for jobs, and there's nothing really which you think appeals to you." Although Jonathan did apply for jobs, he found it difficult to get past the first interview – while his classmates were all beginning their careers, he was unable to make that crucial first step. He feels his Asperger syndrome played a significant role in this failure to get on to the career ladder.

The change came when he was introduced to our Prospects employment service, which helps people with autism to find and stay in work. The Prospects team put Jonathan through a rigorous series of tests to determine what types of work he'd be suited to, and appointed a counsellor to help him with his applications. "He knew me very well, he knew exactly what sort of person I was," says Jonathan.

"Another thing Prospects does well is that they manage to fine tune everything. For example, an interview or an application form for a job is very different to one for university – even though they both need exactly the same sort of strengths and skill sets. I think Prospects is

really able to put you in the right direction and turn what was already a strength into a greater strength."

At the time when Jonathan was completing his assessment process, Prospects had recently formed a work placement partnership with investment bank, Goldman Sachs. Jonathan was one of the very first people Prospects placed there.

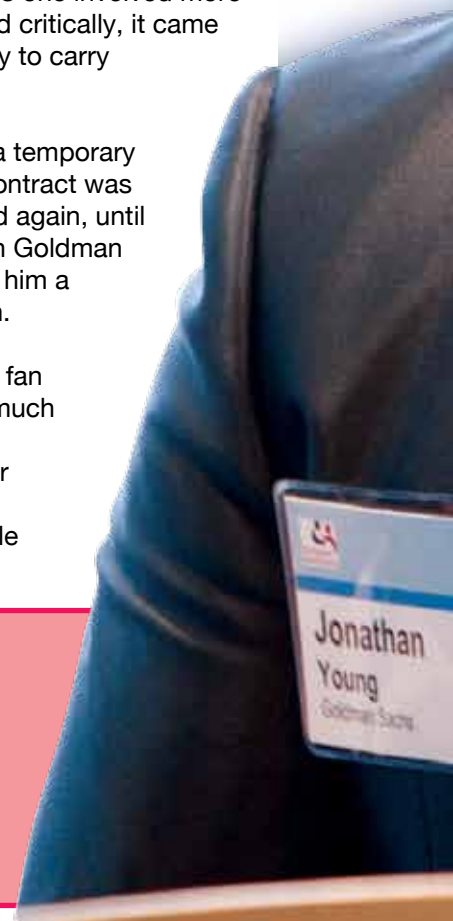
Jonathan's first placement ran for two months, and was basically a form of work experience, shadowing a manager and having real-life experiences of working in an office environment. "At the time there weren't any full-time positions available, but just having that two months placement with Goldman Sachs on my CV opened up a lot more doors going forward for me. I could get a lot more paid placements very easily. Before, there wasn't really anything."

About a year later, Goldman Sachs called again and said they had another temporary placement – but this one involved more hands-on work, and critically, it came with the opportunity to carry on afterwards.

Although this was a temporary role, Jonathan's contract was extended again and again, until after two years with Goldman Sachs they offered him a permanent position.

Jonathan is a huge fan of Prospects – so much so that he's now become a volunteer mentor to the next generation of people on placements.

"The Prospects team are very dedicated, very professional and very knowledgeable"
- Jonathan





Sharing knowledge

If you, or your child, are diagnosed with autism, the first thing you look for is answers. Autism is a complex and little understood disability, but most people who receive a diagnosis are left to cope in isolation, without the vital information they really need.

Our information and advice services are a vital lifeline for thousands of people affected by autism. We help them to fully understand their rights and get information they can trust about living with, working with or caring for a person with autism.

Our website is one of the world's largest online resources about autism, and is visited by more than two million people every year. Our Autism Helpline supported 19,300 enquiries in 2012-13.

This is a really important part of our work. People living with autism need information they can trust to help them make important decisions. Many often face discrimination in the workplace, at school and in society generally, and they need help and advice to stand up for their rights.

We know that people living with autism, and their families, can be desperately isolated. When we conducted our survey for our report, *The way we are: autism in 2012* we were told by 59% of adults with autism that they find it hard to make friends. A staggering 24% of adults with autism said that they have no friends at all, and just 42% have between one and three friends. Overall, 66% of adults said that their

main friends are their family or carer.

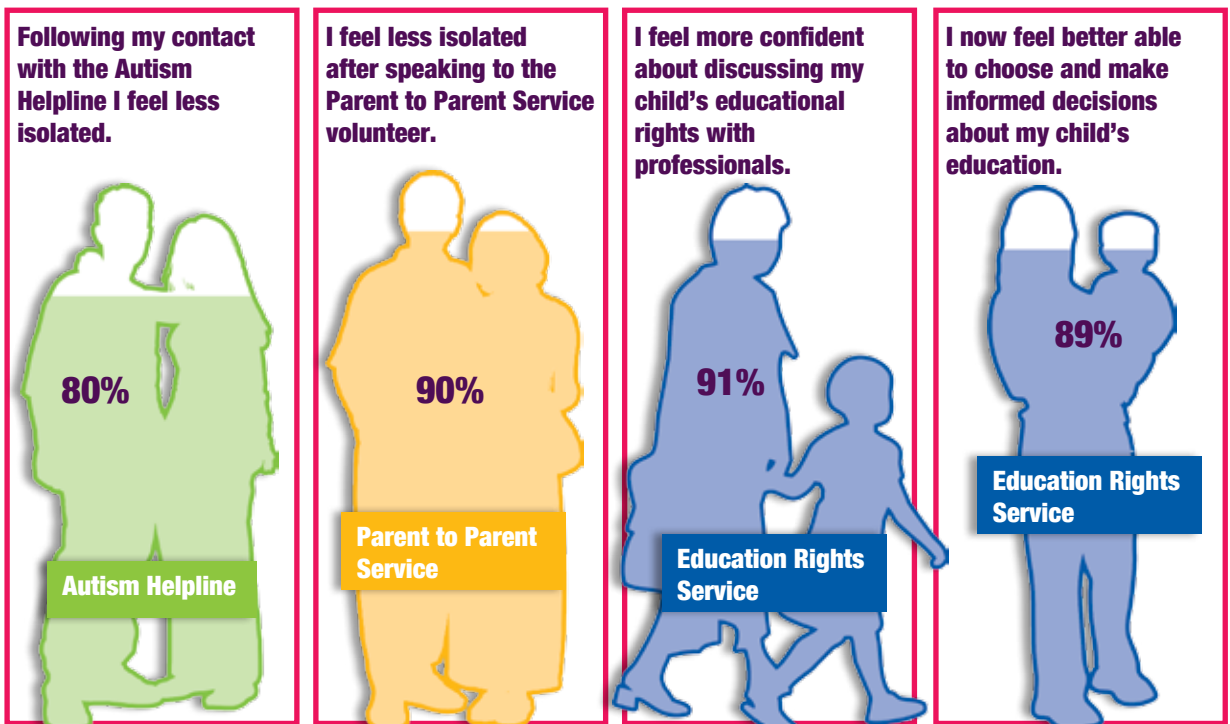
The situation is little better for children and young people with autism – 63% of them have been bullied at school and 27% have been excluded from school. Facing situations like this, adults with autism and parents of children alike turn to us for reliable, specialist information and advice.

The largest single reason people call our Autism Helpline is to get advice on diagnosis. Topics such as benefits, education, community care and challenging behaviour also generate huge numbers of calls. The feedback we've received from callers has been overwhelmingly positive: they tell us that calling our Autism Helpline made them feel less isolated and gave them practical information they could act upon.

Our specialist welfare rights, community care and education rights helplines also supported 4,629 enquiries in 2012-13. Again, the feedback from callers has been extremely positive; they told us that speaking to our expert advisers made them realise they are not alone, and they are not powerless.

One Autism Helpline caller told us: "The Autism

People who called our helplines said:



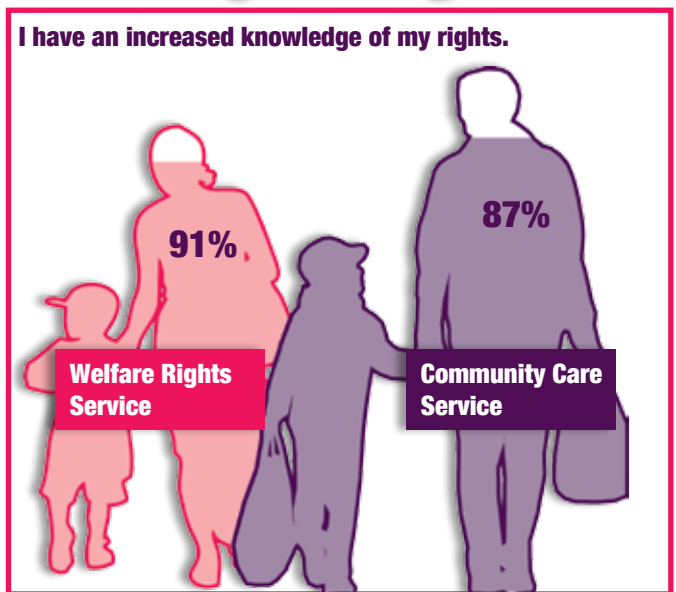
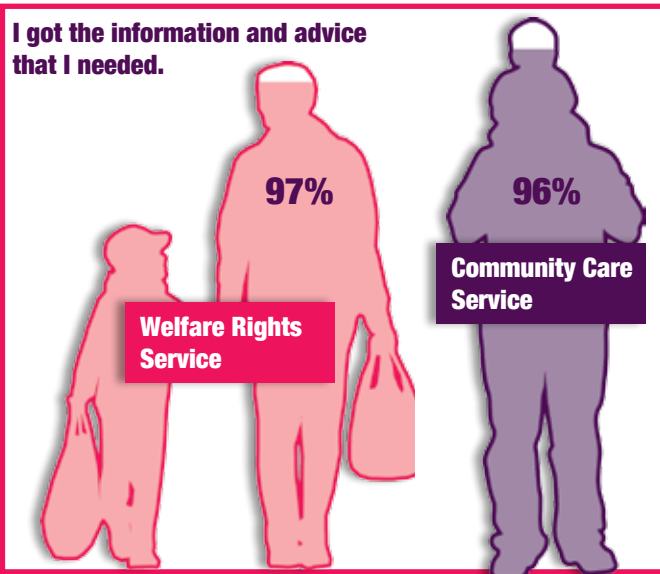


Helpline was my lifeline. Afterwards I felt less isolated and more ready to accept and deal with the situation that my son's autism presents.”

The impact of these services is very clear – but with more resources we could help even more people. In the year to March 2013, over 82,000 calls were made to our Autism Helpline, but we were only able to support

about half of them. Some were missed because the calls were made at weekends or at other times when our helpline isn't staffed; others because the caller couldn't hold on and wait for an adviser to answer. Responding to the needs of everyone who looks to us for information and advice is a huge challenge, but it can be done with the right funding and resources.

People who spoke to our welfare rights and community care advisers said:



When we asked almost 9,000 callers to our telephone helplines whether they felt they would be able to use the information and advice we provided, 98% answered 'yes'.

Our Autism Helpline received more than 82,000 calls in total during the year from around 27,000 different callers. Around 13,600 of these were answered by frontline staff, which means a large volume of calls did not succeed in getting through because lines were busy or the call was made out of hours.

Our expert helpline advisers also responded to voicemail requests for information, text requests, email and letters, bringing the total number of people supported to around 19,300.



Sharing knowledge case study

Hannah's son Oliver has autism. When his school refused to cooperate in getting him a statement of special educational needs, Hannah contacted our Education Rights Service for help.

We provided Hannah with information about school support and statementing, which meant she could approach the school knowing much more about her son's rights and requirements and secure the support that Oliver desperately needed.

"When our paediatrician gave us Oliver's diagnosis, she suggested we join The National Autistic Society," says Hannah. "The NAS replied to our email and introduced themselves to us, explaining the best places to start to look for information. I remember receiving a pack in the post full of information leaflets and posters; it was a huge relief. There was no pressure to become a member, no rush to get money from you; it really felt that they just genuinely wanted to help. Later, we did become members."

Hannah describes our website as "fantastic, with loads of really useful information". She was particularly impressed by the fact that our online information was written simply and in a variety of ways, to suit people of all ages and abilities. Although we aren't the only source of online information, Hannah was overwhelmed by all the conflicting advice, false cures and money-making scams she found elsewhere.

She also appreciated the fact that our website is backed up by real people through our Autism Helpline. "I have called the NAS and burst into tears, not really knowing what to say to the poor person on the phone... they were great and just helped by being there."

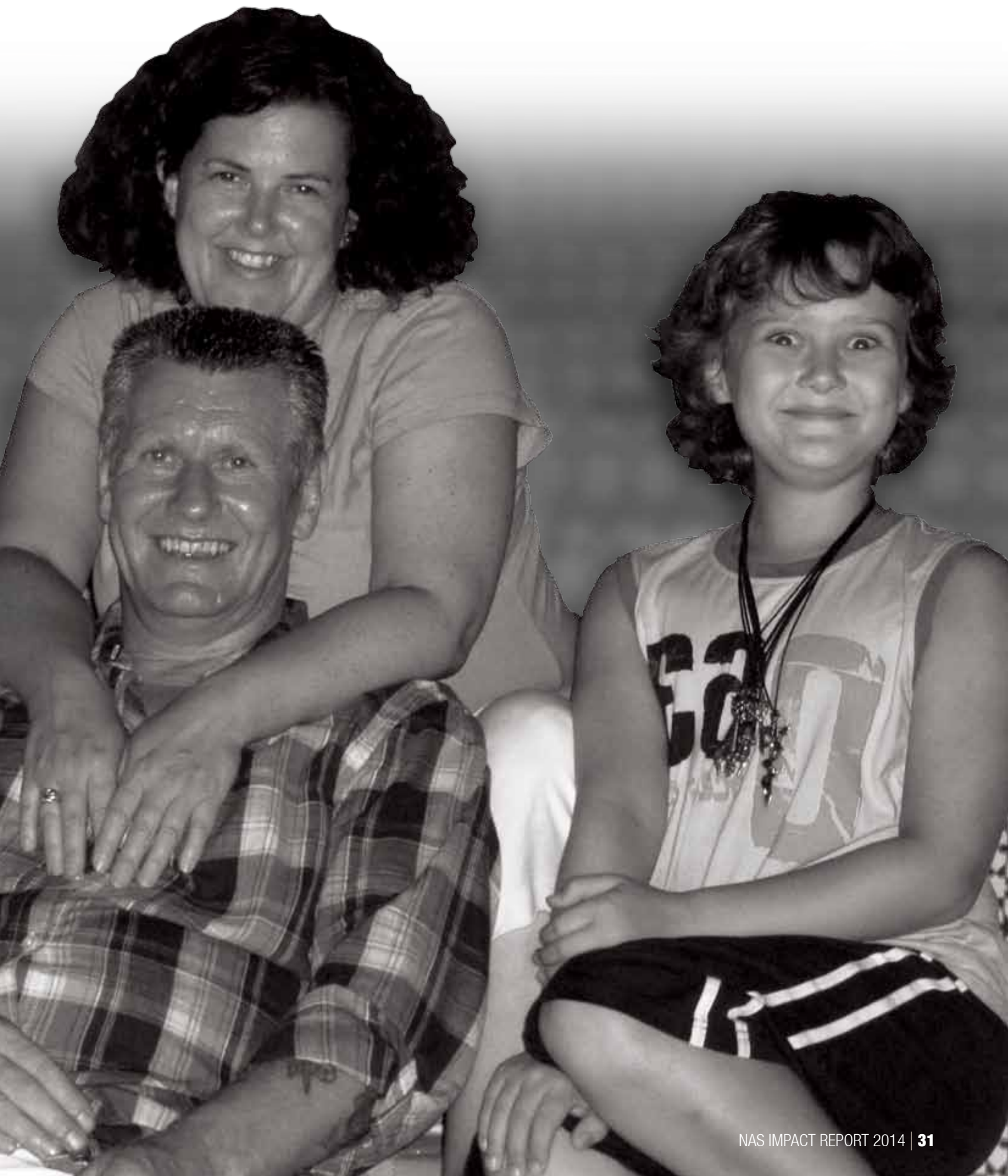
Emily, one of our education rights experts, wrote a letter supporting Oliver's claim to be statemented, and Hannah is convinced that "this wonderful, informative and emotive letter" helped them win their case.

All the staff at Oliver's old school have now been trained in understanding autism. Hannah believes her fight for Oliver's rights – backed up by the support she received from us – has made a real difference to that school. "Hopefully the staff will now be able to confidently identify and support another child and their family in the future, and not be so quick to accuse the parents or label the child," she says. "We wouldn't want another family to go through the long journey and battle that we had."

Hannah's experiences have made her a passionate advocate of our information and advice services. She recommends them to family and friends when they ask questions, and to other parents and education professionals.

**"We wouldn't want another family to go through the long journey and battle that we had."
- Hannah**





Changing perceptions

Our services make a vital difference to the lives of the people we support – but with our current resources we are only able to reach a modest percentage of the 2.7 million people living with autism in the UK today.

Our influencing and awareness work, on the other hand, has the potential to transform the lives of tens of thousands of people at a stroke every time we secure an amendment to a piece of legislation or build awareness and understanding of autism in the community at large.

That's why one of our strategic aims is to ensure that national and local policy will reflect and meet the needs and aspirations of people with autism and their families.

In 2012-13, our campaigners sent around 8,000 letters to the local and national decision-makers or media demanding better rights and services for people with autism. The sheer volume of action is important because it shows that lots of people care about the issue.

The nature of the engagement matters too, and in 2012 we launched our Autism Action Network to empower people up and down the UK to develop the skills, confidence and motivation to raise awareness and campaign in

partnership with us. This scheme provides support for 100 Autism Ambassadors and 402 Autism Champions.

So far, 80% of our Autism Ambassadors have undertaken campaign actions, such as meeting their MP or doing a media interview. An incredible 77% of our Ambassadors said they felt that the action they had taken as part of the network had had a positive outcome.

Meanwhile, our Young Campaigners' Group wants to inspire other children with autism to start campaigning, so they have produced a toolkit for others based on their experiences. Most of the group said they gained in skills and confidence during the time they have been working with us. The young people have all been in touch with their MPs, launched a petition and a social media campaign, and have held meetings with the Countess of Wessex and former Education Minister, Sarah Teather. One of the outcomes of their work is the guidance that they have produced for school councils to help them to be more autism-friendly.

Our work across the UK

Working with partners, we persuaded the Government to drop its proposal to remove the DLA mobility component from disabled people living in residential services.

We designed an alternative assessment for Employment and Support Allowance with MIND and Mencap, because we know that the current one doesn't accurately pick up on the barriers to work that people with autism face. In 2013 the Government agreed to trial the assessment we designed to see if it would work better.

We also got the Government to make a number of commitments to Parliament about how the assessment for DLA will work for people with autism.

We successfully lobbied for the National Institute of Health and Clinical Excellence (NICE) to develop new quality standards on autism for children and adults. The standards will be part of the way the performance of the whole NHS is measured, and puts accountability for autism services at the heart of the new health and social care system.

Working with partner organisations, we safeguarded SEN local authority funding for another year, protected the rights of children with autism (particularly around exclusions) by getting changes made to the Education Bill, ensured that legal aid will still be available for SEN cases and made sure that parents who use direct payments for their child's educational support are protected by law.

We challenged local council spending decisions which risk disadvantaging people with autism in court through our strategic litigation work. Our involvement in a High Court case helped inform the ruling which set a precedent for other councils who might have planned similar cuts.





Raising awareness through the media is also a powerful tool at our disposal, and coverage of The National Autistic Society has continued to grow. In 2012–13 an average of 79 million people each month were exposed to positive stories about us in print, online and through radio and TV broadcasts, up from 56 million the year before.

We are also continuing to grow the amount of work we do on social networking platforms; the number of people following us on Facebook and Twitter grew to more than 62,000 in 2012-13.

Our work in Scotland

We won a prestigious award in 2012 from the Herald newspaper for our campaign, We Exist – A Bill for Autism, A Bill for Scotland. The award recognised the way in which we involved parents, carers and people with autism in the campaigning work we did in the run-up to the publication of the Scottish Government’s national strategy for autism.

That strategy – which was published in November 2011 – drew a great deal on our input and advice. It promises investment of £13.4 million in services for people living with autism over four years.

The Scottish Government invested part of this funding in work that we have started with two other charities to develop ‘one stop shops’ to help local areas deliver joined-up services and set up a network of autism co-ordinators to map autism services.



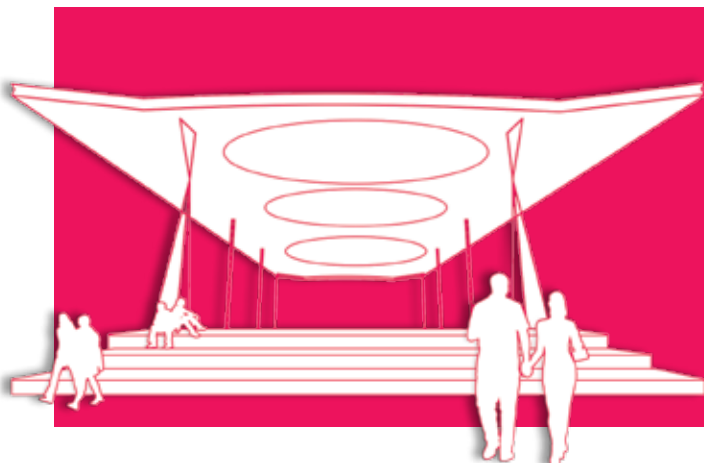
Our work in Northern Ireland

In Northern Ireland we launched our A* for Autism campaign, which calls on MLAs to consider the needs of children with autism as they debate reforms to the special educational needs system.

We worked with the Northern Ireland Assembly Commission to make Parliament Buildings autism-friendly. Around 90 staff received autism awareness training, while improvements to the building included a quiet room and clearer signage. As a result, Parliament Buildings received the first Autism Access Award in the UK.



Our work in Wales



We have been working with Welsh Government on the refresh of the Autistic Spectrum Disorder Strategic Action Plan; this will continue to be a priority for us. With partner organisations we have influenced forthcoming legislation including the Social Services and Well-Being [Wales] Bill and the new framework for special educational needs.

We ensured that the link between Personal Independence Payment (PIP) and blue badges will mean that more adults with autism in Wales will be able to access a blue badge.

Changing perceptions case study

Jennifer became an Autism Ambassador for our Autism Action Network, which campaigns on key issues at a local and national level, in 2011.

Jennifer isn't working currently, and didn't think she'd be accepted when she first applied to be an Ambassador. "Being unable to work causes you to feel useless," she says. "I didn't expect to become an Ambassador. I never really had much in the way of expectations."

But she was welcomed into the network, and the training she received from our campaigns team, and the support she's received since, have made a big difference to her confidence. It's also made a big difference to the impact she has on the lives of people with autism through her campaigning work.

"I've spoken to people who I otherwise wouldn't have had the nerve to approach without the backing of the NAS. I did a radio interview to raise awareness of autism. And I've baked a lot of cake. It's easier to get people to listen when their mouth is stuffed with chocolate cake!"

Jennifer's campaigning work has included going to a parliamentary lobby and meeting her MP to discuss support for adults with autism. "It was nerve-wracking," she says, "but it went okay because the NAS campaigns team supported me and because my MP was easy to talk to. I really felt like he did listen."

The backing she's received since she became an Ambassador has been really important; "Knowing that support and advice is available is a great boost to self-confidence. No matter how small the action is, the NAS campaigns team have had the advice and support I needed, whether it's through in-depth briefings or by confirming that I'm following the right course of action."

And she has no intention of slowing down. "I'm planning a party to raise money and awareness, so it will be fun but there will also be plenty of information and resources – and sneaky ways of educating people while they're having fun, through games and quizzes."

"I've been campaigning on autism training in Birmingham. It's been difficult, but I'm planning to take more action still. I feel that training is an important issue to campaign about because lack of understanding is still a big problem."

Campaigning for us has transformed Jennifer's life. "I'm much more confident. I no longer feel ashamed of telling people I'm on the spectrum. I used to allude to it, or write it down, but now I'm much more used to explaining the ramifications of autism to people. It's easier to say it out right to people."

Jennifer is now an enthusiastic advocate of our Autism Action Network. Asked if she'd advise other people with autism to join, she says: "Yes! Definitely! You can start out thinking you aren't capable of doing anything, but because you've got the training and the backing of the NAS, as well as the impetus to do things, you really can start to change things."

"People often fall into three categories when you tell them you have autism – the ones that flinch away like it's catching, the ones who think they know all about it but haven't got a clue, and the ones who don't know anything about it but figure that the best way to find out is to ask."

"I want everyone to be moved into the third category. The world is set up for neuro-typicals – that's the only thing that makes autism a disability."

"I've spoken to people who I otherwise wouldn't have had the nerve to approach without the backing of the NAS" - Jennifer





Thank you

We would like to thank all of the companies, organisations and individuals who have supported us in 2012-13, through partnerships, donations and fundraising activities.

Geoff Anderson; Filton Golf Club
The Anderson Foundation
Aspinal of London Ltd
The Astor Foundation
AWD Chase de Vere
Axcis Education Recruitment
The Bank Workers Charity
BBC Children in Need
BIC Kids
Cambian Group
The Charity for Civil Servants
The Childwick Trust
Circle of Friends members
Classic FM Foundation
The Clothworkers' Foundation
The Evan Cornish Foundation
Becky Daley and the Spectrum Ball Committee
Colin and Helen David



John Swannell helping to judge our 50th birthday photographic competition in 2012.

Disney Theatrical Group
Rosemary Duke; Lions Clubs International
District 105E
Donald Forrester Trust
Stephen Fry
Goldman Sachs for its financial and in-kind contributions
The Goldman Sachs Partners
The Haberdashers' Company
The David Harding Foundation
HB Cares
Idea is Everything
Imagination Technologies Limited – Pure Radio
Isles of Scilly Steamship Company
Lego

Kathy Lette



A team from the Anderson Group took part in our Paris to London cycle ride.

Cecil and Hilda Lewis Charitable Settlement
The R S Macdonald Charitable Trust
Magimix UK Ltd
The McGregor Charitable Trust
Graham Norton
Jo Perera: Emily's Ball
PF Charitable Trust
Qualcomm
Rachel Vosper Limited
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Red Carnation Hotels (UK) Limited – The Milestone Hotel
The Royal Masonic Trust For Girls And Boys
Russellphilippeek.com
Jo Salmon: Holly's Ball
Dr Scholl Foundation
The N Sethia Foundation
SHEAFFER
Shell UK
Sony DADC
Stella & dot
Timto
The Three Guineas Trust
The Trafigura Foundation for its financial and in-kind contributions
Transforming Lives Project raising over the £100,000 mark, thanks to the work of John and Marianne Swannell and friends
Tresco Estates Limited
VF Europe BFBA – Kipling Division
The IngeWakehurst Trust
The Waterloo Foundation
Garfield Weston Foundation
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Company Secretary

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The National Autistic Society





We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.7 million people whose lives are touched by autism every single day. From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

The National Autistic Society
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Supporter Care: **0808 800 1050**
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Fax: **020 7833 9666**
Email: **nas@nas.org.uk**
Website: **www.autism.org.uk**

