



The way we are: autism in 2012

by Kathrine Bancroft, Amanda Batten, Sarah Lambert and Tom Madders



Making a difference for 50 years

Acknowledgements

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Prime Minister, David Cameron:

“After 50 years of providing support and care for people with autism, The National Autistic Society has a huge amount to reflect on and to be proud of.

“Their fantastic work has raised awareness of the challenges faced by those affected by autism and provided support for them and their families.

“It says so much about this charity that they have chosen to celebrate their birthday by producing such an informative report on the progress made in this area.”

Deputy Prime Minister, Nick Clegg:

“The National Autistic Society has been instrumental in improving the lives of people with autism over the past 50 years, providing incredible support, education and advice.

“That’s why I, and this government, fully support the work of the NAS and are committed to improving the lives and opportunities of people with autism, ensuring they are fully accepted into society and supporting their families.”

Leader of the Labour Party, Ed Miliband:

“I’m a friend to The National Autistic Society because you help people to understand autism better, and stand up for greater opportunity for people on the autism spectrum.

“The fact that you started because 50 years ago parents of children with autism in one local area got together to support each other, is an inspiring story of solidarity. Happy 50th birthday!”



In 1962, a small group of friends met in north London, frustrated at the lack of understanding and help available for them and their children with autism.

By deciding to act for themselves, they began a movement that went on to transform people's understanding of what autism was and change the lives of everyone it affected.

Fifty years on, what began that day has grown into The National Autistic Society (NAS), the UK's leading charity for people affected by autism.

As the NAS celebrates its 50th birthday, the autism community is reflecting on the many changes that have taken place over the years and the progress we've made.

There is much to be proud of and to celebrate, but we are very much aware that life for people affected by autism can still have enormous challenges. This report – sometimes troubling, often hopeful and always fascinating – makes this only too clear.

The NAS is never complacent and we know that there is much more work to be done.

We hope that you will join us in helping more people with autism, and their families, to lead the life they choose.

Jane Asher

President, The National Autistic Society

Introduction

There are currently more than half a million people in the UK with autism – that is about one in every 100. This means you are likely to know, love or care for someone with autism.

But for all the lives that autism touches, there is still a great deal of misconception about the condition and the reality of life with it. And that's where this report comes in.

To mark our 50th birthday, we commissioned the largest ever survey about autism, in order to show what life is like in the UK for people affected by the condition.

Autism doesn't discriminate – it affects people no matter what their social background, ethnicity, sexuality or gender. From diagnosis to employment, school to independent living, thanks to the more than 8,000 people who participated in the survey, this report tells it like it is.

Some of it makes for sobering reading. It shows that whilst we've taken huge strides from the days when people with

autism were considered 'uneducable' or 'psychotic', there is still much work to do to shatter persisting illusions and ensure that everyone with autism gets to live the life they choose.

But behind every sombre statistic there are also stories of hope, compassion and inspiration. People with autism can and do make a valuable contribution to our communities and to our society. We are committed to ensuring that their voices, and those of the people who love and care for them, are heard.

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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 people with autism experience are:

➤ **difficulty with social interaction**

People with autism 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 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 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.

Some people with autism are able to live relatively independent lives but others may need a lifetime of support.

The way we are diagnosed

"I think we'd be listened to more if we had the diagnosis. I wouldn't be fighting the school every two minutes, because he'd have things in place."

Parent of a child with autism

We know that getting a diagnosis can be a critical milestone for people with autism, providing an explanation for years of feeling 'different' or helping a parent understand their child better. Diagnosis can also offer a gateway to identifying appropriate support and without it, people may find it difficult to access the help they need.

34% of people reported that they had waited three years or more for a diagnosis.

So, unsurprisingly, getting a diagnosis really matters to people. 61% of those who responded to our survey said they felt relieved to get a diagnosis and 58% said that a diagnosis led to getting new or more support.

Yet, despite an increased awareness and identification of autism over the

past 50 years, accessing a diagnosis remains a significant challenge for many and can leave families with uncertainty, sometimes for years.

While responses to our survey showed some improvements to waiting times over the past 20 years,¹ 34% of people reported that they had waited three years

or more for a diagnosis after first raising concerns, with a further 30% saying that it had taken between one and two years. As a result, 55% of those who responded to our survey reported that it took too long to get a diagnosis and half said that the process was too stressful.

In our experience, long waiting times result from a combination of factors. There is a lack of awareness of autism among those who make diagnostic referrals, such as GPs and health visitors. There is also a shortfall in the number of professionals who have the expertise to contribute to autism assessment and diagnosis, particularly in adult services.

For those with autism and a learning disability or other co-occurring disabilities, their autism may be overlooked by professionals, and therefore not recognised or diagnosed.

This may help explain why 1 in 10 respondents paid for a private diagnosis, instead of waiting for an NHS diagnosis. And, while paying for a diagnosis is decreasing among those looking after

children, there has been an increase in the number of adults going private – it has almost doubled over the past ten years.²

Once diagnosed, just 28% of respondents said they received good information about where to go for help or support.

Leading the way for 50 years

We have been working tirelessly over the past 50 years around diagnosis and assessment, and our research does illustrate some improvements in experiences. But there is still more to do and we are far from complacent.

In 1991, we established the UK's first ever centre to provide a complete diagnostic, assessment and advice service for people with autism. The NAS Lorna Wing Centre was set up to support parents who were experiencing major difficulties in getting a diagnosis and an explanation for their child's behaviour. Today, the centre works to increase capacity in diagnosis by training professionals across the UK in diagnostic techniques. It also diagnoses

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and assesses some of the most complex cases.

We have also developed information seminars for parents to help them understand autism and what a diagnosis means for them and their child. And we know this works: three months after attending our EarlyBird programme for parents of newly diagnosed children, 96% of parents agreed that their daily life had improved as a result.³

Improving capacity in the NHS in diagnosis and assessment of autism is a pressing priority. After extensive campaigning by the NAS, there are now official guidelines for diagnosis either in place or in development in all nations in the UK.⁴ And national autism strategies in each of the nations have all put in place clear actions on diagnosis.

We will be supporting our campaigners locally and will be campaigning nationally to make sure this action translates into improved experiences.

Our birthday wish

That the UK and devolved governments ensure that the NHS follows national guidelines on diagnosis and assessment, so that people with autism can access the right support as early as possible.

Gender differences

Getting a diagnosis is difficult and stressful for everyone. But responses to our survey indicate that it may be harder still for women and girls, particularly those who have Asperger syndrome or high functioning autism.

Just one-fifth of females were diagnosed with Asperger syndrome or high-functioning autism by the age of 11, as compared to half of the males. They were also more likely to be misdiagnosed, with 42% of them being diagnosed with another condition as compared to 30% of males. This may be because autism is predominantly seen as a male condition and can present differently in women.

Once diagnosed, half (49%) of females with Asperger syndrome or high functioning autism said that the diagnosis made no difference to the support they received. This compares to 39% of males.

Our survey suggests some quite clear challenges for women and girls with autism, particularly around getting their needs identified.

We are currently a partner in a European research project looking at the needs of young women with autism, which is likely to identify areas for further research and policy.

Our survey suggests some quite clear challenges for women and girls with autism.

Our birthday wish

That more research be carried out into how autism affects both genders differently, and how we can ensure gender does not act as an additional barrier to getting the right support.

Karen and Callum's story



Karen's son Callum is nine years old and has autism. She describes him as "a caring boy who wants to make others happy". He lives with his parents and younger sister, Niamh, in Macclesfield in Cheshire.

Callum is prone to anxiety and problems crop up for him on most days. Often these problems occur during unstructured time, or when there are

changes to plans. When his anxieties become too much for him and he can no longer cope, it may lead to disruptive behaviour.

During the school day, Callum tends to bottle up his anxieties and frustrations, but then he comes home and explodes. He is keen to please his teachers and demonstrate that he is coping, even when he is feeling anxious.

He received an informal diagnosis after starting primary school. He had trouble settling in and his teachers viewed him as disruptive. The school nurse intervened and, at the end of Callum's first year at the school, he was referred to child and adolescent mental health services (CAMHS). At first it was thought that Callum had attention deficit hyperactivity disorder (ADHD), but a specialist noted the elements of autism in his behaviour. Yet, despite this informal diagnosis, which itself had taken a long time to get, his parents were still having to fill out questionnaires at the end of his second year at the school.

He was eventually referred on for a full diagnostic assessment in 2010. At the time of the family's interview for this report in the winter of 2012, they were still waiting for a diagnosis and had been told to expect a four-year wait.

The family believe that an official diagnosis would help them to access services and support, and that without it, it's very difficult to convince staff and services of Callum's very real needs.

"It's a shame that some of these children have to get to a point where they're at risk before anybody will do anything. Whereas if all the things were in place first, these children wouldn't get to that point. They would be achieving. They would hopefully be in a happy, comfortable environment."

Karen has recently been in touch to say that Callum has now had a formal diagnosis of autism spectrum disorder and emotional disorder. She hopes this will lead to the support Callum needs.

"It's a shame that some of these children have to get to a point where they're at risk before anybody will do anything."

The way we grow up

"I would like to be like any other child: make friends, be able to enjoy life and laugh at what others laugh at, not to have fears and phobias; to be able to understand what teachers say and ask me, and to become a writer and a musician." Young person with autism

Most children and young people with autism share the same hopes, aspirations and worries as other children: they want to make friends, do well at school and grow up happy and fulfilled.

They talked about their aspirations to be happy, get married, have friends and get the jobs they wanted.

In our survey, young people with autism told us their hopes for the future. Among them were aspiring actors, musicians, chefs, racing car drivers, doctors, pilots, Manchester United footballers and police officers. Others wanted to be LEGO builders, window washers, scrap yard owners, writers for Dr Who and computer games inventors. As with any young people, they talked about their aspirations to be happy, get married, have friends and get the jobs they wanted.

Many simply said they want to be able to be around people who understand and accept them, to be less anxious, to fit into society, and not be thought of as 'silly' or 'weird'. 78% of young people with autism who responded to our survey think that people outside their family don't know enough about autism. Lots of children with autism struggle to make friends. Young people with autism may be picked on because they stand out as different, or other pupils may take

advantage of them and lead them into inappropriate behaviour. 22% of young people with autism told us they have no friends at all, and one in ten said their friends are mainly adults. Yet, half of children said they would like more friends than they have now.

Unfortunately, 63% of young people with autism have been bullied at school. This rises to 75% when we look at secondary school age, and 82% of young people with high functioning autism or Asperger syndrome. Schools' responses to bullying vary greatly. While some schools have excellent strategies, others do not always recognise the seriousness of the issue. For example, in Wales, 50% of parents whose child has been bullied said they were not happy with the school's response.⁵

With the right support, children with autism can make good progress and gain skills that will allow them to thrive, and schools play a critical role in this. But children with autism often struggle to get the support they need, and parents have to go to great lengths to make sure it is put in place.

Over a quarter of parents in England said they waited more than two years for their child to get the right support.⁶ In Scotland, 37% of Additional Support Needs Tribunal appeals concern children with autism, even though this group make up only 12% of those with identified additional support needs.⁷

Many miss significant chunks of school because they are excluded, either formally or informally, something which is generally avoidable with the right support. 27% of children with autism have been excluded from school, compared with 4% of children without autism.⁸

Furthermore, in our recent survey in Northern Ireland, 18% of parents reported having to pick up their child early from school, often on a regular basis, even though their child was not ill.⁹ This pattern of illegal informal exclusions is also reflected elsewhere in the UK.¹⁰

Leading the way for 50 years

While our research shows that there are still huge challenges facing some families in getting the support they need

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for their children with autism, the picture is unrecognisable compared to where we were 50 years ago. At that time, many children with autism weren't even considered able to learn and weren't even sent to school. Recognising the potential in their children, our founders felt compelled to set up their own school.

Fifty years on, we now run six schools across the UK and have plans for more. We are also developing new models of support, including the recent opening of a 'satellite' school in Scotland. This new initiative, connected to our Daldorch School, helps us to educate more children and allows them to attend a school that is closer to their homes.

We also work to increase capacity and expertise in autism in mainstream schools. For example, our Helen Allison School acts as a hub that delivers training to school staff across the south east as part of the Autism Education Trust.

A recent survey of children who attend our Robert Ogden School found that 83% of children got the help they need at school and 81% are happy at school.

All the parents said they had confidence in the school.¹¹

Our Education Rights Service provides information, support and advice to help guide parents through the education system. Following contact with the service, 93% felt better able to make informed decisions about their child's education.¹²

In addition, with planned reforms to the special educational needs (SEN) systems in England, Wales and Northern Ireland, and as Additional Support for Learning is implemented in Scotland, there are new opportunities for us to campaign and lobby to ensure that children with autism are better supported in every school.

Our birthday wish

That reforms to the education system ensure that children with autism can access the right support to thrive at school.

Dion's story



Dion is 17 years old and has been a student at our Broomhayes School for three years.

He is making plans for his future. He would love to learn to drive and is planning to save money to buy his own car. He is also looking forward to the world of work. He loves watching others work and wants to be a lorry driver when he's older.

Dion would also like to live in a flat on his own, somewhere nearer his family. He currently lives at Broomhayes and loves it there, but he misses his family, who are over 200 miles away in Leicester. "The only thing I don't like here is that it's so far away from my mum," he says. He talks to his mum on the phone every night and speaks to his brothers using Facebook.

He found previous schools very difficult to cope with and has been excluded multiple times. He ran away on several occasions and could behave violently towards other people. At one point, he needed to be put in a secure unit. He also had many negative thoughts about himself: "When I was younger I used to say to myself 'I wish I was dead' and stuff like that."

These days, Dion is much more positive. Broomhayes provides Dion with a calm, structured environment, where he has clear rules and boundaries, and he is making good progress with his studies and independence skills.

"I do good activities. I'm all good and healthy. They're doing really well to help me get my independence. It's better than any of the other schools that I've been to. They were horrible. I used to get bullied."

Dion has recently joined our Young Campaigners Group. He has been campaigning so that other children and young people have a better time in the education system than he initially had. In this role, he has even had the opportunity to tell his story to the Education Minister, Sarah Teather.

Dion is also learning to become more independent. He now makes his own way to lessons during the school day. He enjoys cooking and on certain evenings, with help from the staff, he cooks for the other students in his house. One day, he says, he would like to cook a meal for his mother, so that she can see the progress he has made.



"When I was younger I used to say to myself 'I wish I was dead' and stuff like that."

The way we live: independence

"For the last two years she's been in her own house, about a mile away. She has 24/7 one-to-one support from the NAS, and that's working very well. We see her reasonably regularly - I've been to the house today to take her something. But she's sufficiently far that there's good independence for her." Parent of an adult with autism

Autism is a condition which affects people in different ways. Some are able to live relatively 'everyday' lives; others need a lifetime of specialist support. Yet, the right support at the right time can make an enormous difference to people's lives and help them to lead the life they choose.

62% of adults with autism said they do not have enough support.

We asked adults with autism about a series of basic everyday activities. 35% of respondents would need support to do a food shop. We also found that without support:

- 48% could not go to the cinema
- 56% could not go to a pub or restaurant
- 28% could not travel on public transport on a route they know/

have practised

- and 54% could not travel on public transport on an unfamiliar route.

However, 62% of adults with autism said they do not have enough support to meet their needs. This means that many of the ordinary day-to-day activities listed above remain a real challenge for too many people. Worryingly, 61% of adults said their local authority has



never assessed their needs as adults, which means that their needs are not recognised, let alone met.

As a result of this lack of support, our survey indicates that adults with autism have to rely on their families for financial support and don't have the level of independence they'd like. 65% of the adults we surveyed said they rely on their family to some extent. This percentage increases to 75% for those with higher support needs.

Many people with autism share the same aspirations as others and want their own home and independence. 38% of adults still live at home with their parents but 48% of this group said they would like to live in their own home, with or without support.

Leading the way for 50 years

Addressing the lack of support and services available for adults with autism is one of our key priorities. We train professionals to support adults with autism effectively and campaign for change.

Our specialist residential services provide person-centred support for adults with

autism. One of these services, Somerset Court, was the first ever specialist centre for people with autism in the UK. Opened in the 1970s, it remains home to some of the original residents.

We also provide innovative and specialist supported living and outreach services. Our Ty Nant scheme, for example, is a six flat development in south Wales. Each of the six flats incorporates assistive technology to facilitate the specific needs of the individual tenants, enabling them to live as independently as possible. We recently asked tenants about their experiences of Ty Nant. All of them said that they liked their flat and that they are able to do more things now than they were before.

We believe it is vital that more action is taken at national and local levels to ensure that adults with autism can get the help they need. As a direct result of our campaigning, national strategies and related policies in England, Scotland, Wales and Northern Ireland now set out clear actions to improve services and support for adults with autism. This includes successfully campaigning for the UK's first ever disability-specific legislation, the Autism Act 2009.¹³

**It is vital that
more action
is taken.**

Our birthday wish

That national government strategies and policies be implemented in full at a local level across the UK to ensure that adults with autism can live the lives they choose.

James' story



James is 26 and lives on the Aberdeenshire coast with his wife Jenny and their dog Molly.

James was diagnosed with autism at the age of 13, but from an early age his parents had suspected that he had autism, and he attended a specialist nursery. James began his secondary school career in mainstream school but found the transition extremely difficult and was unable to cope. He spent time in a psychiatric ward, finding it increasingly difficult to deal with the world around him. He was obsessive about football, playing

in every break at school and training eight times a week. However, as he got older, he found it increasingly difficult to handle the social aspects of the game: he couldn't understand people's comments or read their intentions. Other areas of life were also challenging – getting on a bus was fraught and he began to feel very negatively about life and about being a burden to people. A pivotal moment came when James moved schools and started receiving support to help him to integrate into daily life at school. Over time, James was taught a range of techniques to

cope with daily life and found that he was increasingly able to take part in normal lessons, do things independently and – as he moved into his later teenage years – socialise and go to parties.

James studied for his first degree at the University of Aberdeen, where he chose to live in halls rather than stay at home. He wanted to challenge himself and put himself in an environment where had to cope.

James' autism still affects him on a daily basis, but he has learnt coping strategies which enable him to get on with daily life. He recognises that he can sometimes be obsessive in his approach to work. He can become fixated on a topic and lose track of time. He can struggle with organising his time, finding it difficult to think of actions in sequence.

He also has trouble with his sleep, finding it difficult to switch off and relax at nights, and this can mean that he is tired in the mornings. He can become anxious and feels that in some ways he will need to work harder to meet his goals in life.

James recently completed his PhD at the University of Aberdeen and told us: "Whilst my autism is an issue, thanks to good support through my teenage years, it's not a crippling one."



"Whilst my autism is an issue, thanks to good support through my teenage years, it's not a crippling one."

The way we live: friendship and isolation

"I would like to have friends but I don't know how."

Person with autism

People with autism can find making sense of the world extremely hard.

Everyday life can be confusing, meaningless or even frightening. Understanding and communicating with other people is particularly difficult and can leave people very lonely.

Our survey found that the support that people with autism most want is helping them to socialise and become less isolated.

Lack of support can affect adults with autism in all areas of their life. For those that feel they don't have enough support:

- 70% said with more support they would be less isolated
- 62% said they would be able to socialise
- 62% said their general health would improve
- 61% said they would be more independent.

The social and communication difficulties that people with autism experience can make it hard for them to form close friendships and relationships. 59% of adults with autism told us they find it hard to make friends and only 3% said they find it easy.

24% of adults with autism said that they have no friends and just 42% have between one and three friends. In addition, 66% of adults also said that their main friends are their family or carer. Friendship is more of a struggle for those who also have a learning disability, with one third of this group saying that they have no friends at all.

59% of adults with autism told us they find it hard to make friends and only 3% said they find it easy.

A misconception is that all adults with autism prefer their own company and don't want any friends. 65% of adults in our survey said they would like to have more friends.

Teaching life skills and providing services like befriending and social groups can help adults with autism to live more independently and to be less isolated. They also prevent adults with autism from developing more complex needs in the long run. Despite the strong economic case for local areas to fund services like these, not nearly enough are providing them.

Leading the way for 50 years

Tackling isolation is a core part of our work. For a number of years, we have run befriending schemes, where people with autism are paired with volunteers who meet with them regularly to do activities that the person with autism enjoys, helping them to develop their self-confidence, understanding of relationships and their interactions with others.

We run this alongside an innovative e-befriending service, which provides

people with autism and their families with regular online support and social contact. Our e-befrienders exchange emails with the people they are supporting on a wide variety of subjects, from chatting about TV to issues affecting people's lives – whatever people are interested in or concerned about.

We also run a free online community for people with autism, parents, carers, relatives and professionals. People registering on the community find a welcoming place to share their questions, thoughts and experiences, as well as a forum for making friends and finding support.

In addition, across the country our staff and volunteers run social groups, where people with autism can get together and socialise with their peers. 82% of those attending Scottish social groups said that they had learnt new skills as a result of attending, with 72% saying that thanks to attending the group they now had sufficient confidence to socialise outside of it.¹⁴

**Tackling isolation
is a core part of
our work.**

Our birthday wish
That every local
authority across the
UK provides a range of
services that meet the
diverse needs of the
adults with autism who
live in the area.

Gabriel's story



Gabriel is 26 and lives with his stepmother, Mary, in east London. As well as being on the autism spectrum, he has cerebral palsy and epilepsy. Gabriel is intelligent but is non-verbal and communicates via yes/no answers using a simple electronic device.

In the past, it was common for Gabriel to be marginalised by those who were meant to be supporting him. Because

he is non-verbal, some carers have talked over his head, rather than addressing him directly, and people from social services have treated him as though he doesn't exist. Gabriel gets uncomfortable when people don't talk to him directly.

When he finished school, Gabriel's choice was either to attend a day service or to apply for direct payments.

He wasn't happy with the day projects that he visited, so he chose to apply for direct payments. Access to direct payments meant Gabriel could get a personal assistant (PA) and choose who to recruit.

Gabriel wanted someone from his age group who shared his passions for music and art. One of his first recruits was Ben, an artist, who although no longer Gabriel's full-time PA, has become a friend and mentor to him.

Gabriel's stepmother says that PA support – and in particular the arrival of Ben – was incredibly positive, enabling him to share interests with people of his own age and take part in culture. "It helped him to be a young person," says Mary.

Among other activities, Ben worked with Gabriel to set up 'PigPen', a regular night of music and culture, which they still collaborate successfully on together, with Gabriel choosing the acts on the internet using his yes/no device.

Mary understood that parents aren't the right people to help someone like

Gabriel to be a young person, to mix with people his own age and to pursue his real passions. "PA support helped Gabriel to accomplish more than anyone had previously thought possible," she says.



An illustration of Ben and Gabriel, by Ben Connors

"PA support helped Gabriel to accomplish more than anyone had previously thought possible."

The way we work

"I don't want to spend the rest of my life either unemployed or in work that is unsuitable. I would love a job that took my skills and harnessed them, because of who I am and what I am, rather than in spite of it." Person with autism

Given the opportunity, people with autism can and do make a valuable and positive contribution to society.

They can be a real asset to the workplace and many thrive on the routine a job provides. Not only that, but research from the National Audit Office found that an initial investment in supporting adults with autism into employment would result in huge long-term savings to the public purse.¹⁵ And yet, only 15% of adults with autism are in full-time paid employment.¹⁶

15% of adults with autism are in full time employment.

Our survey revealed that a high proportion of adults with autism are 'not in education, employment or training' (NEET) at a young age and sadly go on to be 'NEET for life'. Of those surveyed, a third of those aged 16-24 with autism

are NEET. This is more than double the number among the general population.¹⁷ In addition, 37% of adults have never been in paid employment after the age of 16, with 41% of people over 55 spending more than ten years without



a paid job. Among those who aren't currently employed, 59% don't believe or don't know if they will ever get a job.

Among those who have ever worked, around a third have experienced bullying and said they have been at the end of unfair treatment or discrimination at work because of their autism. 43% told us that they have left or lost a job because of their condition.

Only 10% of adults with autism currently receive employment support but 53% want it.

Paid work isn't going to be right for everyone, but with the proper support, many people with autism can overcome the barriers to work that they face. Simple adjustments like making job interviews more accessible and assistance to understand the 'unwritten rules' of the workplace, can unlock the potential of a whole army of people ready and willing to work.

Leading the way for 50 years

Ensuring that people with autism can make the most of their skills and find

suitable, sustainable employment is a crucial part of our work.

Our specialist employment support service, Prospects, as well as our wider adult and transition services, successfully support many adults with autism into employment. Over a three year period, 70% of adults with autism supported by Prospects found employment.¹⁸ We also work with a diverse range of willing employers to help with the recruitment, training and retention of staff with autism.

We have been working with the Government to improve employer awareness of how to support people with autism in the workplace. As part of our campaign, *The undiscovered workforce*, we are working with MPs to take a lead on these issues in their own constituencies.

Our birthday wish

That all Government initiatives to help people into work recognise the specific and varied needs of people with autism, so that they can achieve sustainable employment.

**70% of adults
with autism
supported by
Prospects found
employment.**

Kay's story



Kay is 26 and has Asperger syndrome, and lives with her partner in north east Wales. She has had a varied career so far, having started studying to be a teacher and then a nurse, before working for a couple of years in a bank.

She has struggled in the workplace because of her difficulties in negotiating social situations, which has led to some bullying. The daily commute, which is stressful for most people, can often be debilitating for Kay, due to the uncertainties involved and her hyper-sensitivity, which means that even a strong perfume scent on a fellow passenger can mean she may get to work feeling stressed.

But despite the difficulties and challenges Kay faces, she is very keen to work and is a passionate advocate for the rights of people with autism to do so:

"It's never been about the quality of my work. I've always been a top performer in every job... But I've not been able to deal with the social chit chat. I always seem to get it wrong and get people's backs up.

"It's not that I'm incapable of working. It's about finding the right environment. I want to be independent.

"What annoys me about society is that people frown upon people on benefits, people who sit at home and do nothing, but there is no support and there's no one to enable you to get into work.

"What I think is sad is that most people with Asperger syndrome really, really want to work. They want to contribute... I feel stuck. It's not a nice life, really."

"What I think is sad is that most people with Asperger syndrome really, really want to work."

For decades,
we have
provided a
wide range
of support
for families
and carers.

"Once my child outlives us, what will happen to him? Who will look out for him, as he will always be vulnerable? Who will have him at Christmas, and check he isn't being ripped off or hurt or intimidated or worse? This is my biggest fear and worry and keeps me awake at night - and he's only ten."

Parent of a child with autism

Caring for someone with autism is not always an easy task.

Support for carers is vital in helping the carer not only meet the needs of the person with autism but their own needs too.

Yet our survey found that 80% of the carers have never had their needs assessed and 74% don't get any support for being a carer.

For many, lack of support has led to anxiety (81%), depression (64%) and isolation (70%), with 61% feeling a strain on their marriage. Over half reported a negative impact on household finances

and a third of carers under 40 told us that they'd like to work but can't because of their role as a carer. Many more have had to give up work, reduce hours, work part time or take a lower paid job in order to care for someone with autism.

Adults with autism told us that they want to live as independently as

74% don't get any support for being a carer.

Our birthday wish

That all carers can access a carer's assessment and the financial and practical support to ensure that both they and those they care for can live fulfilling and rewarding lives.

possible but this survey has shown that many of them rely on their parents and families for support. Those parents find themselves supporting their children with autism well into adulthood and an overwhelming 96% of carers said they are worried about their son or daughter's future when they are no longer able to support them.

For all its difficulties, half of those surveyed (52%) said loving and caring for someone with autism can be rewarding and life enriching.

Carers legislation and national policies have given clear rights and entitlements to those who care. And there has been progress in recognising the importance of providing short breaks to carers.

However, at a local level, many are still unable to get the support they need. Carers told us they would like a single point of contact for information and support (63%), help in applying for benefits (40%) and more opportunities to learn about autism (48%), meet other families and carers (46%), and access respite care or short breaks (45%).

Leading the way for 50 years

For decades, we have provided a wide range of services and support for families and carers.

Our Autism Helpline provides information and advice on a range of issues, helping people to understand their rights and entitlements, including welfare benefits and community care. And we know this is making a difference: 98% of people who used our helpline said the information that they were given was helpful.¹⁹

Our Parent to Parent Service offers confidential support and a listening ear to parents and carers of people with autism. It is manned by trained parent volunteers from across the UK who have first hand experience of bringing up a child with autism. 87% of those who used the service agreed that they felt less isolated as a result of having spoken to someone who could relate to their experience.²⁰

We also have a network of over 100 branches across the UK, run by dedicated volunteers who provide invaluable support and services locally. While our useful Autism Services Directory tells people about the services available in their area.

The Griffins' story



Ann and Laurence Griffin have four sons: Stephen (21), Christopher (28), Michael (30) and Peter (31). Peter and Stephen both have Asperger syndrome and attention deficit hyperactivity disorder (ADHD), and live with their parents in Hertfordshire.

Peter is highly intelligent and has an MSc. He struggled to get a job following his degree and “spent three years in his bedroom”. But Ann eventually helped him to find work as a teaching assistant. With this opportunity, Peter is making big steps forward in independent living.

Stephen was less able academically and is less able to function independently in the wider world. In recent years, he has been receiving a few hours of help per week from a support worker. Since then, his confidence has grown enormously and his horizons have broadened. But despite this progress, it is unlikely that he will ever be able to live without support.

Ann told us about the challenges of being the parent of adult children who are not fully independent: “When you have your children, you think: ‘OK, I’m going to nurture them. I’m going to teach them. I’m going to skill them so

that they can become independent, like my parents did with me. I will then get a life – the next phase of my life, which will be just the two of us together.’ But that’s not the case.

“There’s something about that transition from a parent to a carer that takes place – and you don’t always know it’s taken place. You stop and look at things and think: ‘Oh, I’m surprised that I’m still doing this.’ I’m a carer, and the difference is clear to me. Yes I’m a parent, but as a parent I wouldn’t expect to be doing the things for my adult children that I’m doing, and that’s a carer’s role.

“I didn’t sign up to be a carer. I’m happy to do it – most of the time. But sometimes it’s hard work... My fear is that one of us will get ill and we’ll have to care for that person plus the two boys, and that will be difficult.

“They’re lovely people to be around, and I do think it’s a privilege to have them in our house. I wouldn’t change them because that’s who they are. They’re our children, and they wouldn’t be who they are if they didn’t have autism.”



"My fear is that one of us will get ill and we'll have to care for that person plus the two boys, and that will be difficult."

Mark's story



Mark and Cathy Mulholland are the parents of six-year-old Malachy, who was diagnosed with classic autism at the age of two-and-a-half. The couple have two other children under the age of five and live in Northern Ireland. Malachy is non-verbal but communicates through some sign language, having created his own signs.

Mark says he is a very active, happy boy with high energy levels. He especially

enjoys swimming and trampolining. He is introverted in his behaviour and he doesn't need wide social interaction. Since the age of three-and-a-half, Malachy has been attending a special school for children with learning disabilities, which his parents describe as "the best option in Northern Ireland". However, Mark is concerned that there is not much development or progress. "Malachy is being cared for, but not being educated," he says. However, he recognises that the school operates under budgetary constraints and deals with a wide range of abilities.

Caring for Malachy is exhausting and relentless, as he will often be up half the night for several nights a week. Mark often finds himself having to go to work on only three or four hours sleep. As far as Mark's social life is concerned, he and Cathy rarely have the time or ability to do things that normal couples can do. They've had three evenings out in the last six months and it has been about a year since he and Cathy last went out as a couple.

"There's a very fine line between being generous in spirit and approaching

burn-out. We're at a point where you're so tense and run down that everything becomes an issue – all the small things.

“Previously, I think we might have been a bit more romantic in our idea of autism and what it meant. We just thought: we'll deal with it and cope with it, and it will all be fine.

“But three or four years down the line, you look at Malachy's autism and difficulties, and it's like a timebomb within your family. He completely dominates everyday life. It permeates my employment. Cathy had to give up work. It permeates the situation with the two younger children. In a sense, Malachy is the dominant child.

“He's dominant in the house, and the other two lose out. There are times when we're going to the park or somewhere and then, because of Malachy's challenging behaviour, we all don't go. He gets a lot of one-to-one attention from me, which means I'm not doing things with the other two. My wife is at home with them, and she needs to do things like clean the house. So, within

the same household, you have these two parallel existences – two different realities.”

But Mark hopes that Malachy's condition will also have a positive impact on his siblings' characters, encouraging qualities such as understanding, patience and generosity: “He forces everyone within the house to be a bit less selfish.”



“He forces everyone within the house to be a bit less selfish.”

Hopes for the future

We asked children and adults with autism, and their parents and carers, about their hopes and aspirations for the future. This is what they told us.

"To be the best scientist ever!"

"To be happy and understood and not made to feel like a freak."

"I hope people will start to understand what autism is about and not to be frightened by it or worried about being around someone with autism."

"For my mum to always be alive."

"Sweets."

"That people stop asking me if he has a special skill!"

"I hope that my beautiful daughter will have the necessary support to enable her to have the safe, happy, healthy future she deserves in society."

"I hope society accept me for who I am, love me, respect me and let me live my life happily."

"That I could stop checking stuff and worrying and having to do my 'sorry' so much."

"Getting a good job working at LEGO and having a wife."

"The world should accept my son, not the other way round."

"To be able to have friends and know how to play with them correctly."

"To become the British Ambassador for Japan."

"To have a pet goose or parrot."

Conclusion

"As a parent it helps that you can now say the word 'autism' and people have some kind of understanding." Parent of a person with autism

There have been real and significant changes in the lives of people with autism and their families over the past 50 years. We are proud of the difference that we and the wider autism community have made to the lives of people affected by autism.

Through our huge range of cutting-edge services, we provide direct and indirect support to thousands of people with autism and their families each year. And through campaigning, lobbying and awareness raising, today autism is more widely understood and accepted than it was in 1962 when we started. As one of our founding parents told us: "As a parent, it helps that you can now say the word 'autism' and people have some kind of understanding."

But as this survey all too clearly shows, people with autism still face significant

and diverse barriers, whether they be to independent living, employment or education. Many struggle with isolation and continue to fight for the recognition, support and services they deserve. The pressures on many families are immense and all too often the huge potential of people with autism goes to waste. Battles have been won but there are many more still left to fight. And yet for all the stark realities of life with autism in 2012 highlighted in this report, our resounding message is one of hope and commitment.

Research for this report was carried out across the UK from January to March 2012 by independent researcher, Nick Rand. There were two stages of work: a quantitative survey, which provided many of the statistics quoted in this report; and a series of interviews with people affected by autism.

**A total of 2,938
people with
autism completed
the survey.**

Quantitative survey

We designed an online survey featuring questions for people with autism and also some questions for carers of people with autism. The survey mainly elicited quantitative responses but also included a few questions allowing for lengthier responses.

The survey was open for three weeks during February 2012. An email was sent inviting all our supporters to complete it online. A link to the survey was also advertised on the front page of our website. Paper copies were posted out on request.

A total of 2,938 people with autism completed the survey. This comprised: 1,412 adults aged 18 and over; and 1,380 young people aged 17 and under.

There were an additional 146 people who chose not to provide their age. 1,134 people with autism (39%) filled in the survey by themselves and 1,804 people (61%) were assisted or had the survey filled in on their behalf.

The survey also included a section of questions for carers of people with autism. This section was completed by 5,535 carers.

The survey was conducted using SurveyMonkey software. The responses were then analysed using SPSS software.

Qualitative interviews

We conducted 11 interviews with people with autism and their carers. We spoke to a range of people from across the autism spectrum and of different ages,

genders and geographical locations across the UK.

Interviews were conducted in late January, February and early March 2012. Nine of the interviews were conducted face-to-face, mostly at people's homes; while two interviews were conducted over the telephone. Some interviews were conducted on a one-to-one basis, while other interviews involved more than one person from the same household. The length of the interviews varied from 45 minutes to two hours.

References



- 1 55% of those who were diagnosed before 1992 accessed a diagnosis within two years of first raising concerns, but between 2003-2012 this figure has risen to 61%.
- 2 Of those adults diagnosed prior to 2002, 12% paid for a diagnosis. Since 2003, 22% of those adults who were diagnosed who responded to our survey paid for a diagnosis.
- 3 The National Autistic Society (NAS) (forthcoming). *Impact report 2011-12*. London: NAS
- 4 In 2011, the National Institute of Health and Clinical Excellence (NICE) published a clinical guideline on diagnosing and assessing autism in children and young people. Guidelines on diagnosing, assessing and managing autism in adults and on managing autism in children are under development. These guidelines apply in England and Wales. These guidelines will also be disseminated to the NHS in Northern Ireland. In Scotland, a clinical guideline on assessment, diagnosis and interventions for children and young people with autism was produced by the Scottish Intercollegiate Guidelines Network (SIGN) in 2007.
- 5 Evans, R. (2011). *The Life We Choose: Shaping autism services in Wales*. London: NAS
- 6 Reid, B. (2011). *Great Expectations*. London: NAS
- 7 Additional Support Needs Tribunals for Scotland (2011). *Sixth annual report of the President of the Additional Support Needs Tribunals for Scotland 2010/11*. Glasgow: ASNTS
- 8 Green, H. et al (2005). *Mental health of children and young people in Great Britain, 2004*. Basingstoke: Palgrave Macmillan
- 9 Stewart, S. (2012). *A* for autism*. London: NAS
- 10 See also Reid, B. (2011). Op cit; Reid, B., MacBean, R. and Charles, R. (2010). *We Exist: A Bill for Autism, A Bill for Scotland*. London: NAS
- 11 NAS (forthcoming). Op cit
- 12 Ibid
- 13 The Autism Act requires for a strategy for adults with autism in England, to be published alongside statutory guidance which puts duties on local authorities and the NHS.
- 14 NAS (forthcoming). Op cit
- 15 National Audit Office (2009). *Supporting people with autism through adulthood*. London: The Stationery Office
- 16 Rosenblatt, M. (2008). *I Exist: The message from adults with autism in England*. London: NAS
- 17 In the absence of a UK statistic, we have used the current percentage of the population who are NEET in England as a comparator. See: Department for Education (DfE) (2012). *Statistical release: NEET statistics - quarterly brief, February 2012*. London: DfE
- 18 Gomez, G. (2008). *Factors in maintaining employment for adults with autism and Asperger syndrome*. London: Research Autism
- 19 NAS (forthcoming). Op cit
- 20 Ibid

50 years ago, we started as a small group of friends, frustrated at the lack of understanding and help available for us and our children.

That day, we decided to act for ourselves, to help transform the lives of everyone affected by autism, and now, 50 years later, our small group has grown into a national society of friends and the UK's leading autism charity.

From good times to challenging times, we're there at every stage, for parents who need advice and support for their children or adults on the spectrum who want help to lead the life they choose.

We're proud of our achievements but that doesn't mean our mission is complete. Because as long as indifference to autism exists, we will be here to support, campaign for and empower people living with autism.

Friendships can be difficult for people with autism but if you, or someone you love, are living with autism you'll find a lifelong friend in The National Autistic Society.

We're proud to have been making a difference for 50 years.

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