

About The National Autistic Society

The National Autistic Society is the UK’s leading charity for people affected by autism

We were founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. Today we have over 17,000 members, 80 branches and provide a wide range of advice, information, support and specialist services to 100,000 people each year. A local charity with a national presence, we campaign and lobby for lasting, positive change for people affected by autism.

Written by Laura Simons on behalf of The National Autistic Society.

The photographs used in this report are taken by Robin Hammond as part of the exhibition *As I See It: how people with autism view the world*.

Contents

Foreword	3
Executive summary	4
1 About autism	5
2 Public perceptions of autism	7
3 Impact of public attitudes on people affected by autism	15
4 What next?	23

Foreword

Until relatively recently, the objective in talking or writing about autism was to simply make people aware of the condition. The task was very clear - to ensure that people know about autism: doctors, so that they diagnose it correctly; parents, so that they are alert to the early signs of autism in their children; and others, in an effort to create a more hospitable social environment for people affected by autism.

This large-scale report shows that, to some extent, these efforts have been worthwhile. 92% of people now say that they have heard of autism and most seem to understand that it is a disability. However, though awareness of autism is high, challenges still exist in promoting understanding of the condition.

This report demonstrates widespread misconceptions about the exact characteristics of autism, how common it is and who's affected by it. It also exposes many negative reactions to the typical behaviour commonly associated with autism and the impact that these have on those living with the condition, including family and friends.

We don't know if it will ever be possible to completely eliminate all misconceptions about autism but with renewed effort and commitment we can begin to help people think differently. Simply ensuring that people have heard of autism is relatively straightforward; trying to make people understand what it might be like to have autism, and the personal, social and educational

challenges that it raises is a much longer and more difficult journey.

You can join us on this journey by signing up to The National Autistic Society's **Think Differently About Autism** campaign and helping to spread better understanding of this complex condition, as a first step to ensuring people with autism can enjoy the same rights and freedoms as the rest of society.

Kamran Nazeer

Author of *Send in the idiots – or how we learned to understand the world*

Executive summary

Every day The National Autistic Society hears from people affected by autism about the lack of awareness and understanding of the condition and the impact this has on them and their families. We decided to find out how much these everyday stories matched up with public perceptions of autism.

In June 2007 we commissioned a leading market research company, GfK NOP, to look at levels of awareness and understanding of autism¹ amongst the general public. We found:

- awareness of autism is high but awareness that Asperger syndrome is a form of autism is low
- there's a lack of understanding and awareness about some of the key characteristics of autism
- autism is much more common than people realise
- there's a misconception that people with autism have special abilities
- there's a mistaken belief that autism mostly affects children
- people don't realise that there's no cure for autism
- initial reactions to typical behaviour associated with autism are often very negative
- but knowing someone has autism makes a difference to the way people think.

¹ In this report we use the term 'autism' to refer to all autism spectrum disorders, including Asperger syndrome and high-functioning autism (except in those case studies where a specific diagnosis is specified by the person quoted). This was clarified with respondents at an appropriate point in the survey.

Key statistics

- **92% of people claim to have heard of autism.**
- **90% don't know how common it is.**
- **Only two out of five know there is no cure.**
- **39% think most people with autism have special abilities (these are, in fact, extremely rare).**
- **Only 23% realise that Asperger syndrome is a form of autism.**

Our research shows that awareness of autism is high but there's a lack of understanding about what it really means to live with autism. And we know from our experience that this has a negative impact on people with autism and their families. Whether it's in the community, at school, at work, or in social settings, people with autism are often misunderstood. They suffer discrimination, intolerance and isolation. For many that means a lifetime of exclusion from everyday society.

Our research also shows that people think more positively once they know someone has autism. But there's a significant gap between those good intentions and the reality experienced by people living with the condition.

We want the government, the public, schools, employers and the media to **think differently** about autism so that people with autism get a chance to make the most of their lives. And we want them to **act positively** to address the gaps in understanding, opportunity and support.

1 About autism

What is autism?

Autism is a serious, lifelong and disabling condition

Without the right support, it can have a profound - sometimes devastating – effect on individuals and families.

Autism affects each person in a different way

Autism is a spectrum condition, which means 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 and fulfilling lives. Others may have accompanying learning disabilities and need a lifetime of specialist support. All can make a very positive contribution to the lives of those around them.

People with autism can find it hard to make sense of the world

Autism affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Everyday life for people with autism can be confusing, meaningless and even frightening. Understanding and communicating with others is particularly difficult – which can leave people very isolated.

People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sound, touch, taste, smell, lights or colour.

People with autism share three main areas of difficulty

› Social interaction

This includes recognising and understanding people's feelings and managing their own. Not understanding other people's feelings can make it hard to form friendships.

› Social communication

This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.

› Social imagination

This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Autism doesn't just affect children

Children with autism grow up to be adults with autism.

Autism is a hidden condition

You can't always tell whether someone has autism.

Asperger syndrome

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. People with Asperger syndrome do not usually have learning disabilities but may have specific learning difficulties, including dyslexia and dyspraxia.

How common is autism?

There are over half a million people with autism in the UK

There are over half a million people with autism in the UK – that's 1 person in every 100². If you include their families, autism touches the lives of over two million people every day. And autism is more common than Down's syndrome³ and Cerebral Palsy⁴ combined.



² The Lancet, 2006

³ According to the Down's Syndrome Association, for every 1,000 babies born, one will have Down's Syndrome.

⁴ According to Scope, about 1 in 400 children have Cerebral Palsy.

Photo by Robin Hammond, of Sarah, 27, diagnosed with Asperger syndrome aged 23

2 Public perceptions of autism

Public perceptions of autism

Every day The National Autistic Society hears from people affected by autism about the lack of awareness and understanding of the condition and the impact this has on them and their families. We hear about intolerance, discrimination and isolation; we hear about rudeness, impatience and lack of compassion; we hear about problems at school, at work and at home; we hear about assumptions and misconceptions both amongst the general public and within statutory agencies.

For people affected by autism these attitudes lead to a lifetime of exclusion – exclusion from life in the community; exclusion from employment; exclusion from education. And denial of the help they need to live their lives.

"One thing I'd like is for people to learn more about Asperger's."

My so-called-friends don't want to know me now I've had my diagnosis. I did belong to the local darts team, but they threw me out because someone had told them I was a threat and a danger. To lose that was very upsetting as it was getting me out and about and building my confidence.

My mum found it very upsetting and tried to go round the village explaining that I'm not a danger. I just stay in my house now though. Apart from my mum and my sister nobody really understands. You can try and talk to them and they just don't want to know."

Young woman with Asperger syndrome

We decided to find out how much these everyday stories matched up with public perceptions of autism. We wanted to know how much people understand about the condition, what misconceptions they have and what their attitudes are towards people with autism.

Our survey of the general public

In June 2007 we commissioned a leading market research company, GfK NOP, to look at levels of awareness and understanding of autism⁵ amongst the general public.

A representative sample of over 2,000 adults aged 16 and over was surveyed across 175 sites in England, Wales, Scotland and Northern Ireland. Interviews were conducted face-to-face in people's homes. (See www.think-differently.org.uk for a copy of the questionnaire.)

Key survey findings

There are certain misconceptions about people with autism and many people don't realise that there's no cure.

FICTION

- Autism only affects children.
- Most people with autism have special abilities, for example in maths or art.
- Autism can be cured

There was considerable confusion in our survey about who is affected by autism and whether it can be cured. 27% of those who had heard of autism mistakenly thought that it mostly affects children, and only 39% – that's less than half, were aware that there is no cure. 10% said they thought autism was not a disability.

⁵ In this report we use the term 'autism' to refer to all autism spectrum disorders, including Asperger syndrome and high-functioning autism (except in those case studies where a specific diagnosis is specified by the person quoted). This was clarified with respondents at an appropriate point in the survey.

What's more, the 'Rainman myth' clearly lives on. Over a third of our respondents (39%) said they thought most people with autism have special abilities, for example in maths or art. In fact, it's estimated that only 1 in 200 people with autism have special abilities⁶.

Beliefs such as this make it all the more difficult for people with autism to get the right kind of support or, indeed, to get any support at all. Apparent ability in some areas may lead people to underestimate the challenges an individual faces in other parts of their life. For example, a person with autism may have a degree but still be unable to live independently without the right support.

"People with Asperger's appear very articulate but so often they can't make themselves understood or say what they want. For example, I can't ask for a loaf of bread or say 'pass the salt'."

Middle-aged woman with Asperger syndrome

⁶ Hermelin B. (2001). *Bright splinters of the mind*. London: Jessica Kingsley

2 Public perceptions of autism

There's a lack of awareness and understanding about some of the key characteristics of autism

We asked people to identify the key characteristics of autism from a list of typical behaviours and perceptions, some of which were unrelated to the condition.

FACT

Typical behaviours associated with autism are:

- > Difficulty communicating with others
- > Difficulty making friends
- > Difficulty making sense of the world
- > Resistance to change in routine
- > Obsessive behaviours.

Many people correctly identified some of the key characteristics of autism: 68% of those who had heard of autism were aware that people with autism have difficulty communicating with others; 60% were aware they have difficulty making friends; 58% were aware that people with autism have difficulty making sense of the world; 53% were aware of resistance to change in routine; and 52% were aware of obsessive behaviours.

However, some other common characteristics such as the need for clear unambiguous instructions (identified by 41%), being disturbed by noise and by touch (identified by 36%), and

having difficulty sleeping (identified by only 17%), were less well known.

This lack of awareness and understanding about some of the key characteristics of autism has a direct impact on people with autism and their families. Whether it's at school, at work, or in social settings, people with autism are often misunderstood because of it.

"You have to constantly explain what's wrong with him. People don't understand, they don't live with it 24 hours a day and get the constraints that come with him - I can't take him to Asda, can't take him on holiday because he can't stand the cabin pressure. It governs absolutely everything, where you go, what you eat, it's your whole life, even down to whether the patterns on the wallpaper are going to upset him. I can't do the simplest things that other people take for granted."

Parent of seven-year-old boy with autism

FICTION

- > People with autism are intentionally rude.
- > Children with autism are just badly behaved.

"There's no such thing as Asperger syndrome. It's just an excuse for bad behaviour."

Said to parent by a Special Education Needs Co-ordinator

A small but significant proportion of respondents mistakenly thought that people with autism swear inappropriately (16%), were intentionally rude (10%), and unable to walk (4%). And 13% thought that some children with autism are not disabled they're just badly behaved.

"He didn't used to like going into supermarkets, I suppose because of the bright lights, the noise, all the people around him. He would scream as soon as he went in. People would come up and say to me, 'If that was my child I'd smack him' or 'He needs a good slap'. People pass so many comments you've got to grow a thick skin otherwise you'd stay in all the time."

Parent of six-year-old boy with autism

FACT

- > 1 person in every 100 is affected by autism.
- > Autism is a lifelong and incurable condition.

Autism is much more common than people realise.

We asked our respondents how many people they thought were affected by autism. The vast majority - 90% - didn't know how common it is.

Awareness of autism amongst the general public is high but awareness that Asperger syndrome is a form of autism is low.

Most people have certainly heard of autism - 92% of all respondents in our survey said they had heard of autism, and four out of five of those who had heard of it thought it was a very serious or serious condition.

Far fewer people have heard of Asperger syndrome - only 48% in our survey. Those who have heard of it don't realise it's a form of autism - only 41% of respondents who had heard of Asperger syndrome were aware that it's a form of autism.

This combination of myths and misconceptions has an impact on the way the public think about people with autism and on the way they behave towards people with autism. This in turn has an impact on the everyday experiences of people living with autism.

2 Public perceptions of autism

Attitudes to people with autism

"I usually get **stares and tuts from people** who just think I'm a bad mother. I even once had a woman in a supermarket tell me that I shouldn't take my son out in public **even after I explained that he is autistic**. People have even made complaints to store managers about my son's behaviour because his screaming has bothered them."

Mother of an eight-year-old boy with autism

One of the key aims of the survey was to find out more about public attitudes to people with autism and to look at how that matches what people with autism tell us. We know from our experience that members of the public are often intolerant of people with autism and their families and we wanted to try and find out why. Is it because they simply don't recognise or understand the characteristics of autism, or are there other reasons? So, we tested out initial reactions to people with autism using some typical scenarios.

Scenario 1

Imagine that you're in the supermarket and you see a parent struggling to control their young child who is screaming and kicking violently. What would be your first thought?

Initial reactions to typical behaviour associated with autism are often very negative

By asking people what their first thought would be if faced with a screaming child in a supermarket we uncovered some very negative attitudes.

Nearly half of all respondents were critical: 25% were critical of the parents and 21% were critical of the child.

- 21% of respondents said their first thought would be 'they should be able to control their child' and 4% said 'they are not a good parent'.
- 21% said 'the child is being naughty'.
- Only 3% said 'the child may have a disability'.
- Sadly, 50 people (2.5%) said they would smack the child.
- Another 50 people (2.5%) said they would walk away or ignore what was happening.
- And only four people (0.2%) thought the child could have autism.

A small but significant number of people were more understanding: 10% said they felt sorry for the parent; another 4% generally empathised in some way; and a small number (2%) said they would offer to help.

But knowing someone has autism makes a difference to the way people think

Attitudes changed when autism was mentioned. Just under two thirds (65%) said they would definitely or probably **think differently** if they knew the child had autism.

Scenario 1

Imagine that you're waiting at a bus stop and a young man you've never seen before comes up to you. He gets quite close and speaks to you very loudly in a monotone voice. He keeps asking when the bus is coming and shifting from one foot to another. What would be your first thought about this man?

The results were very similar when we presented a scenario with an adult displaying some typical behaviour associated with autism. Some people reacted negatively, thinking he was either dangerous (8%), on drugs (7%) or drunk (6%). Others felt scared, threatened, anxious or nervous, cautious, wary or suspicious. Some were clear that they would back away and five people said they would hit him.

Others were sympathetic, thinking he needs help (5%), that there was something disturbing him (13%) or that he might have a mental illness (2%). 15% simply thought he was odd.

Only one in seven respondents (16%) thought he might have a disability and even fewer – just 11 people – thought he might have autism.

Again, attitudes changed at the mention of autism – over two thirds of respondents (68%) said they would definitely or probably **think differently** if they knew the man had autism.

Most people with children or grandchildren currently attending nursery or school say they would not be concerned if a child with autism joined their child's/grandchild's class

We asked people with children or grandchildren at school or nursery how concerned they would be if a child with autism joined their child's/grandchild's class. The vast majority (84%) said they would not be concerned; one fifth recognised that having a child in their class with autism would be a positive experience for their child; and the same number felt that diversity in the classroom is important. Only 3% of respondents felt that a child with autism shouldn't be educated in this type of school.

Reasons given specifically by the small number (12%) who said they would be concerned included class disruption, the need for the school to provide extra support for the child, concern that not enough attention would be given to their child/grandchild and concern for the safety of other children in the class.



Photo collage by Penelope Dunbar, a woman with Asperger syndrome. She describes that it "allowed me to gain insight into an important aspect of my disability which I struggle with on a daily basis".

2 Public perceptions of autism

FACT

- > One in five children with autism have been excluded from school and 67% of those have been excluded more than once⁷.
- > Over 40% of children with autism have been bullied at school⁸.

Despite the findings in our survey, we know from our experience that many children with autism suffer discrimination in the education system. Too often they're misunderstood by pupils and teachers; they're bullied; they're excluded; and they're unhappy. And that means children with autism are often denied access to education and the opportunities that education provides.

"He goes to a small village school. The head teacher laughed at me when I told her the diagnosis. *He's being bullied.* He doesn't get any sort of support. We're applying for a statutory assessment at the moment. *The teaching assistant in his class didn't even know what Asperger's was.* That's what you're up against."

Mother of nine-year-old boy with Asperger syndrome

So although the majority of people want to welcome children with autism into mainstream schools, this is undermined by concerns about a lack of resources for schools to support

inclusion effectively. And there's a gap between what people say they would do and the reality for people with autism.

Most people say they would feel comfortable about working with someone with autism

We know that the reaction to people with autism in the workplace is often very negative and that people with autism suffer as a result. So we asked people in our survey how comfortable they would feel about working with someone with autism. The majority of respondents were unconcerned.

- > Over two thirds (67%) of respondents said they would feel very or quite comfortable about working with someone with autism; only 16% said they would feel quite uncomfortable or very uncomfortable.
- > 17% of respondents said they thought it would be a positive experience and 11% said they already work with someone with autism.

Only a small minority expressed concerns about the prospect.

- > 12% of respondents said they would not know how to support them.
- > There appeared to be little concern (2%) about the ability of someone with autism to do their job properly or about unpredictable behaviour (3%).

FACT

- > Only 15% of adults with autism are in full-time employment⁹.

Again, we know from our experience that many people with autism are able to work. And we also know that they want to work. But recent research shows that only 15% of adults with autism are in full-time employment. And we know that people with autism often move in and out of jobs because of lack of support in the workplace.

Whilst not everyone with autism will be able to work, it is vital that those who are able should be given the opportunity and support to do so.

Our survey suggests that there is considerable scope for the inclusion of people with autism in the workplace and that many employees would be supportive of such initiatives. But there's a gap between what people say they would do and the reality for people with autism. Appropriate training and support would be needed for employers and employees to ensure that people with autism are actually welcomed into the workplace and supported day-to-day.



Artwork by a child with autism, who entered our 'make school make sense' art competition.

⁷ Batten, A. et al (2006). *Make school make sense - Autism and education: the reality for families today*. London: NAS

⁸ Batten, A. et al (2006). Op cit.

⁹ Reid, B. (2006). *Moving on up? Negotiating the transition to adulthood for young people with autism*. London: NAS

3 Impact of public attitudes

Impact of public attitudes on people affected by autism

We know from our day-to-day work with people affected by autism that public attitudes have a direct impact on them and on their families. Sadly, all too often that impact is negative. Forthcoming research amongst adults affected by autism bears this out.¹⁰

FACT

- > 83% of individuals with Asperger syndrome felt strongly or very strongly that many of the problems they faced were as a direct result of others not understanding them¹¹.

Lack of understanding and awareness of autism causes problems both for children and for adults in all areas of their lives:

- > in the community
- > at school
- > in social settings
- > at work.

Impact on the family

"People don't understand her behaviour - why she's so anti-social on some occasions and why on others she is so effusive. *She tries to mimic social behaviour, but it's exaggerated.* She can go from being quite nasty with some people to being obsequious with others, almost fawning. People don't know how to cope with that sort of behaviour."

Parent of a young woman with Asperger syndrome

Lack of understanding and awareness of autism has an impact not only on people with autism and but also on their families. Our survey showed that people can be hostile when faced with a child behaving badly. This is borne out both by what parents tell us and by other research¹² which shows that people often stare and make rude comments. In shops, in restaurants, on public transport - every day and in all sorts of places, parents face lack of understanding and intolerance and this in turn causes considerable stress and anxiety.

"The unfamiliar surroundings were making Davis anxious and he was whining. *'Give him a slap'*, growled the young workman. There was an awkward silence from the other people in the cafe. *'He has a disability'* I said. The workman retreated into his paper. The others relaxed and returned to what they were doing. *It had worked.*"

Parent of young child with autism

Parents also find that having a child with autism can impact on how they are perceived socially: people don't invite them to their homes for social occasions, or if they do they don't invite them back. Many are literally shunned by their neighbours, avoided on the streets, and effectively ostracised. For some families, lack of tolerance amongst their neighbours is also a major issue, as this case amply demonstrates:

"My family have been threatened to be evicted from our house as our neighbours have complained about my child head-banging on the walls. The Authority won't help us to make adaptations to the house to have soft-padded walls."

Parent of a child with autism

As children with autism get older, their parents get older too, but there's no let up in the demands on their time and energy. And they're often required to continue to provide constant support because of a lack of appropriate services.

"I have to take him out myself because there isn't anything else there. *He asks me whether it's normal for a 21-year-old man to go out socially with his mum,* which I obviously say yes to, but it's not really is it?"

Parent of a young man with Asperger syndrome

Other children in the family are also affected, not only in the short-term, but often for the rest of their lives:

"My 23-year-old daughter feels that x is her responsibility as well, and as much as I think she's to be applauded for feeling that, I do think it's sad. But I do want her to be his guardian once we've gone."

Parent of a young man with Asperger syndrome

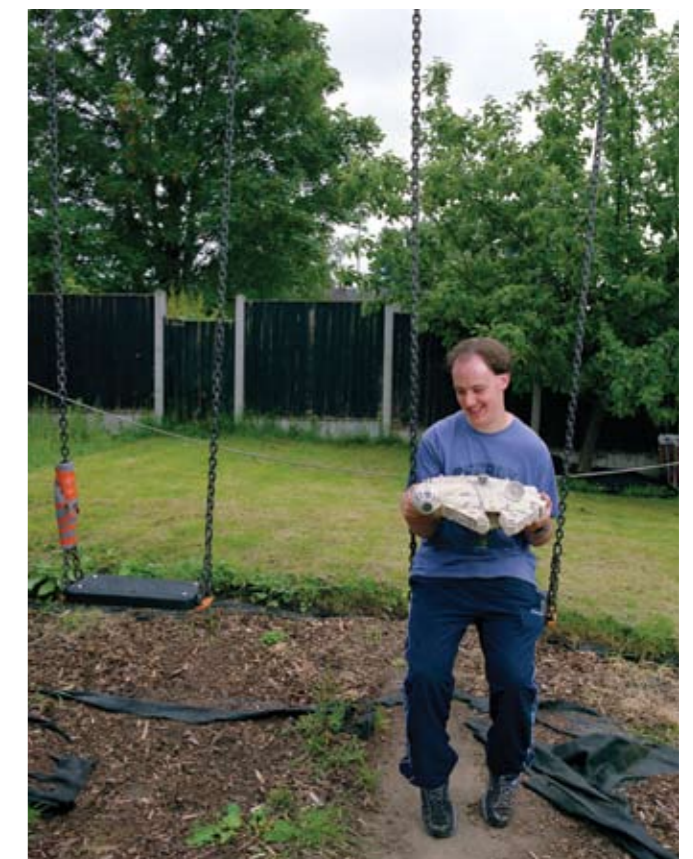


Photo by Robin Hammond, of Max, 26, with Asperger syndrome

¹⁰ NAS research into adult services due to be published in Spring 2008.

¹¹ Beardon, L. and Edmonds, G. (2007). *ASPECT consultancy report: a national report on the needs of adults with Asperger syndrome*. Sheffield: Sheffield Hallam University

¹² Gray, D. E. (2002). Everybody just freezes. Everybody is just embarrassed: felt and enacted stigma among parents of children with high functioning autism. *Sociology of health and illness*, 24(6), pp734-749

3 Impact of public attitudes

School experiences

With the right support many children with autism can flourish at school. For some that may be in a mainstream environment, while others need specialist support. But for many children with autism school can be a difficult and even scary place.

Lack of awareness and understanding among staff and other pupils of the needs of children with autism at school is a major concern, not only for parents of children with autism but for schools and the general public too. Without awareness and understanding children don't get appropriate support, which can leave them struggling to learn, isolated, bullied and even excluded. Surveys we've carried out show:

- 72% of schools are dissatisfied with their teachers' training in autism¹³
- only 30% of parents of children with autism are satisfied with the level of understanding of autism across the school¹⁴
- 98% of the general public think that teachers in mainstream schools should be trained in autism.¹⁵

Previous research by us¹⁶ also shows that bullying at school is a major problem. Over 40% of children with autism have been bullied at school. Children with Asperger syndrome

are particularly vulnerable, with 59% of parents reporting that their children have been bullied.

The impact of bullying can be devastating. It not only damages a child's self-esteem, but can lead to self-harm and suicidal feelings. And it can also severely disrupt the child's education, causing them to miss or change schools, or even refuse to go school at all. The following cases are typical:

"The other children laugh at me sometimes. I don't know why they tease me... I hide under the desk, because there are lots of boxes and that is a good place to hide."

11-year-old boy with Asperger syndrome

"I just got to a point where school had become a phobia and I couldn't get out of the car. As soon as I got in the car to go to school, I'd start having a panic attack."

16-year-old boy with Asperger syndrome

This shows how important it is for everyone right across the system to have an understanding of autism. Teachers need to understand so that they can make their lessons accessible, and pupils need to understand so that children with autism can play a full role in school life. Without training and awareness-raising children with autism will continue to lose out on their education.

Difficulty with social situations

"I have never been able to cope with relationships and have lived on my own for 20 years. I am often lonely, depressed and very anxious."

Man with Asperger syndrome

People with autism often have difficulty in social situations and can find them very stressful. As a result, they become anxious and often either exclude themselves or find themselves excluded. Many lead solitary lives with little contact with the outside world.

Below, people with autism describe a typical day:

"I spent a lot of the day on my PC, talking to 'friends' on instant messenger. I don't know these people in real life, and I find it difficult to communicate with other people. When no-one was online I would play a game or write my story."

Young man with autism

"Have walked dogs twice today; housework and washing. Talked to a farmer briefly. No other social contact. Smoked too many cigarettes and worried a lot."

Man with autism

People with autism also have difficulty making friends and maintaining relationships. A survey by the Office of National Statistics found that over 70% of children with autism found it harder than average to make and keep friends.¹⁷ Our survey about school bore this out. And our own

forthcoming research amongst adults tells the same story. Children, adults and their families all tell us they want support to cope in social situations and learn social skills. Unfortunately, there is currently a huge shortfall in the kinds of low-cost services that can help individuals to overcome the isolation they face.

"There's something so intimidating when you're sitting on your own at a table and everyone else is in groups... they've got lots of friends but you haven't."

16-year-old girl with autism

"My son was arrested by the police as he wanted to talk to a girl in the club and approached her like people do on TV. I tried to explain to the police that he has Asperger syndrome and has difficulty with communication and interaction so may need help when being questioned."

Mother of a young man with Asperger syndrome

¹³ Barnard, J. et al (2002). *Autism in schools: crisis or challenge?* London: NAS

¹⁴ Batten, A. et al (2006). Op cit

¹⁵ *Autism Counts* survey. NAS 2005

¹⁶ Batten, A. et al (2006). Op cit

¹⁷ Office for National Statistics (2005). *Mental health of children and young people in Great Britain, 2004*. London: Office for National Statistics

3 Impact of public attitudes

Difficulty finding and keeping work

People with autism have difficulty finding and keeping work

We know from our experience that many people with autism have valuable skills to offer prospective employers and that employment is a gateway to the outside world. Honesty, diligence, punctuality, reliability, attention to detail and technical skills are just some of the valuable employability skills many can offer.

Yet many adults cite employment as the single biggest issue or barrier facing them.¹⁸ And we also know that the number of people with autism in employment is disappointingly low. Recent research shows that only 15% of people with autism are in full-time employment and for many of those who are employed, lack of understanding about autism can make life at work a misery.

Some employers are ill-informed and unsupportive

For many people with autism, their experiences at work are marred by misunderstanding and inadequate support. Employers don't realise how challenging the workplace can be for people with autism: they're intolerant of what can look like anti-social behaviour; they get impatient when required to repeat instructions; and they don't understand how to make the most of the skills on offer.

"She's had one good employer, who did not know of her diagnosis. *They were very good, lots of patience and understanding. Another employer discriminated against her because of her diagnosis.* They made no attempt to adapt the working environment even when the community liaison officer offered advice and support. The HR department in this very large public company had no understanding at all of Asperger's and *actually told us they don't touch Asperger's with a barge pole.*"

Parent/carer of a young woman with Asperger syndrome

Some people with autism are bullied at work

For some people with autism, lack of understanding amongst employers and employees can cause bullying and discrimination.

"He went to work in a restaurant but was *bullied by the other team members,* I guess because he was different. He then got a job in a horticulture firm. *He was bullied here as well.* His particular work ethos made it so he didn't take tea-breaks and tried to get the work done as quickly as possible. I tried to explain that the others wouldn't appreciate that as he would be making them look bad but he didn't understand."

Parent of a young man with Asperger syndrome

Increased awareness and understanding in the workplace is key

Most people in our survey said they would feel comfortable about working with someone with autism, and there appeared to be little concern about the ability of someone with autism to do their job properly or about unpredictable behaviour.

But there's a gap between what the research suggests and what people with autism tell us. This may indicate that people need information and advice to put their good intentions into practice. Without increased awareness and understanding of autism amongst employers and employees, people with autism will continue to be discriminated against and employers will continue to lose out on a potentially valuable resource.

"It would be helpful to take the burden off me to have to explain to my colleagues what Asperger's is. I'd like it if Asperger's was more well-known, and if I was able to say to my employer *I want everyone to know what Asperger's is.* I want people to know why I don't remember their name, why I don't always say hello. I'd like them to know or be told - *I would like for everyone in my building to know.*"

Middle-aged man with Asperger syndrome

Positive experiences

Whilst lack of awareness and understanding causes problems for people affected by autism, we know that with the right support and in the right environment, people with autism can live rich and fulfilling lives. Awareness and understanding of what it's like to live with autism can really make a difference. Here are just a few examples of the positive experiences we hear about:

Getting the most from education

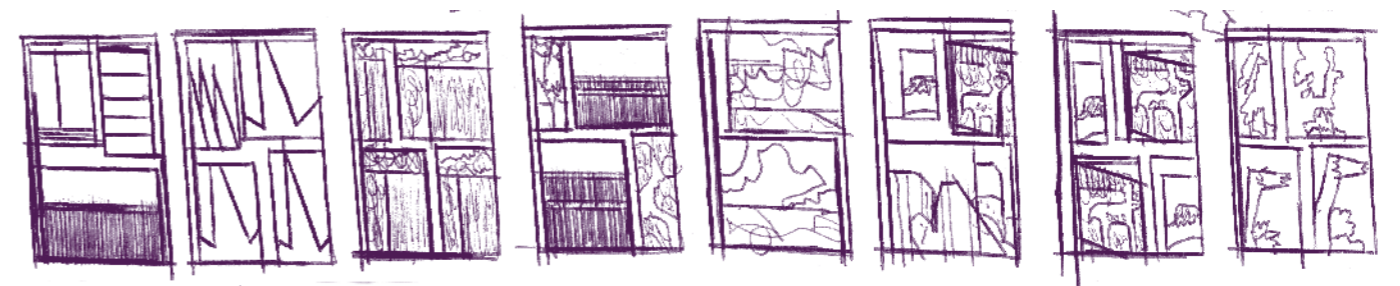
With the right support and in the right environment people with autism can get the most from their education:

"I have multiple helpers. They sit with me in class. Sometimes I ask, sometimes I do it without help."

11-year-old boy with autism

"I started college in February 2006. The teaching methods are much better for me and they also help me by giving me time to take in the information. *I'm doing things now which I didn't think I could do* and, with the help of the college, I challenge myself too."

Young man with Asperger syndrome



Artwork by Mike, a man with autism. Mike is non-verbal and his drawings record the things he has seen or done during the day.

¹⁸ Barnard, J. et al (2001). *Ignored and ineligible? The reality for families with autistic spectrum disorders.* London: NAS

3 Impact of public attitudes

Enjoying a good social life

Whether it's one-to-one or in a group, people with autism can have a good social life too.

"I'm part of a social group that meets every Thursday afternoon. We meet in a particularly nice pub which we chose because it has no music, no football, no noisy crowds. I find the social contact very useful. Although we might have difficulty in understanding other people we can get on with each other. We're very straightforward with each other. I like knowing where I stand."

Middle-aged man with Asperger syndrome

Being happy at work

Working with people who understand autism makes a real difference.

"My work is my passion. I'm a self-employed trainer. I'm the one in charge of the work I do. I have told one or two customers about my Asperger's, and I'm lucky that the passions and skills I've got are what my customers want from me and they support me."

Middle-aged man with Asperger syndrome

For this man with Asperger syndrome, the diagnosis turned his life around, helping him and his employer:

"The minute we knew about my husband's condition, I downloaded the employer's guide from the NAS website, and I asked him to take it in to his line manager. He read it from cover to cover and informed all the people who needed to know. Since that day they have focused on my husband's skills and strengths and they have given him work which he can do superbly well. Before the diagnosis people had focused on what he couldn't do rather than what he could do. His life has turned around."

Wife of a middle-aged man with Asperger syndrome

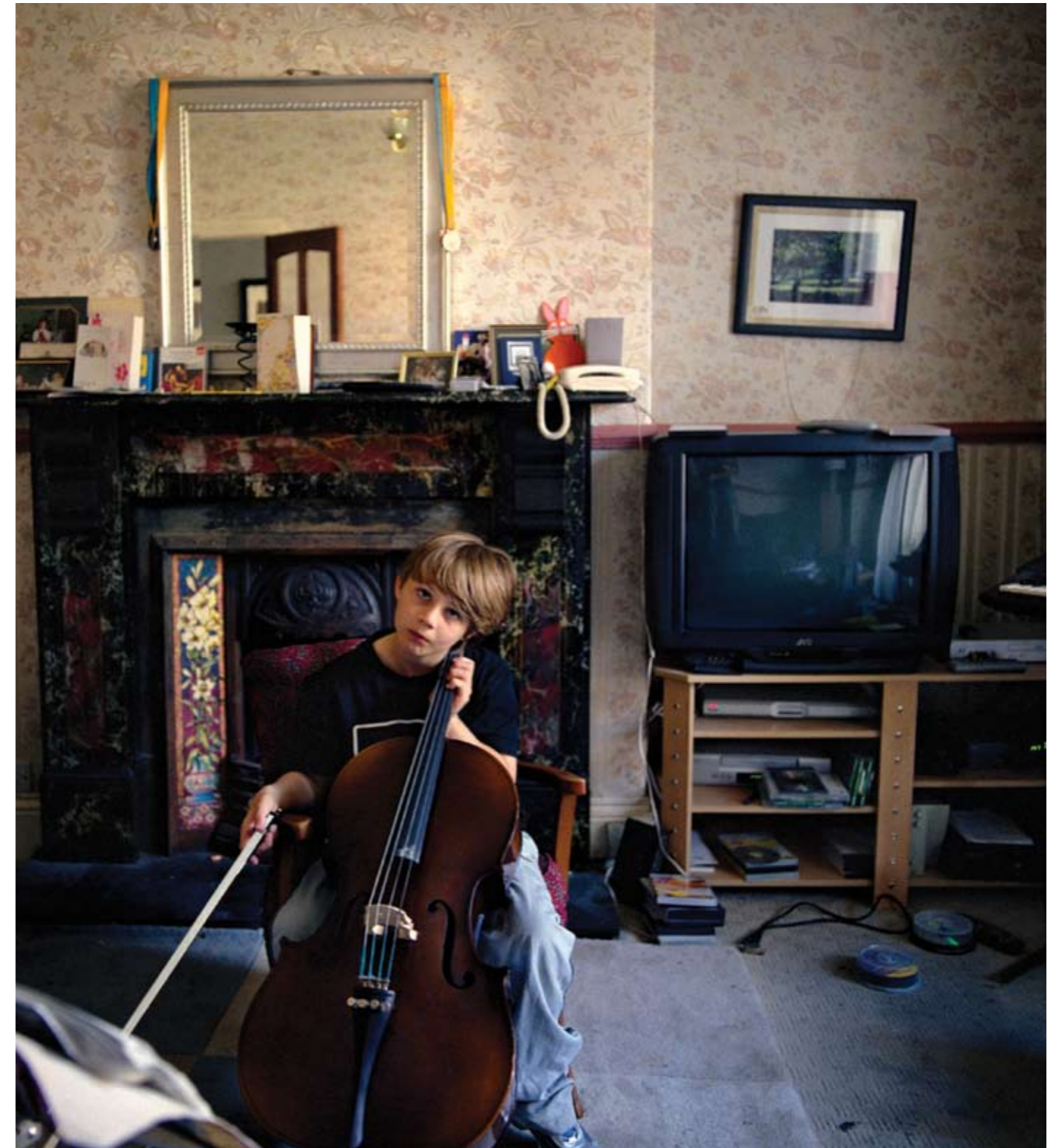


Photo by Robin Hammond, of Robert, 10, with autism

What next?

Our survey clearly highlights the gaps between what people know about autism and what daily life is like for those living with the condition. It also shows that many people have good intentions but all too often those good intentions are not translated into action.

We all need to think differently about autism so that people with autism get a chance to make the most of their lives. And we need to act positively to address the gaps in awareness, understanding, opportunity and support.

Think differently - act positively

"If people had a little more training or education then you wouldn't need to change anything. People in councils, job centres, etc need to have some sort of training about autism. People who work with the public should be able to ask themselves whether the people they're working with have got autism."

Middle-aged man with Asperger syndrome

The general public

The general public needs to have a better understanding of what it's really like to live with autism. Increased awareness and understanding is vital to ensure that people with autism are able to participate in society and get the support and services they need. Everyone needs to **think differently** about people with autism and **act positively** to create environments where they and their families feel welcome.

Employers

Employers need to think differently about people with autism. They should recognise the skills that people with autism can bring to the job and actively welcome them as prospective employees.

Employers must recognise that autism is considered a disability under the Disability Discrimination Act. That means they need to take reasonable steps to make employment accessible for people with autism, for example by:

- ensuring the application process is fair for people with autism
- creating an autism-friendly environment

- providing training for all staff about autism.

Schools

Schools need to think differently about people with autism. They have a vital role to play both in supporting children with autism and promoting awareness and understanding amongst staff and pupils.

- All school staff should have training in autism so that they can provide the right support for every child.
- All schools should promote disability equality for children with autism and take action to eliminate bullying and harassment.
- Autism awareness should be included in citizenship or PSHE lessons to improve understanding amongst pupils and overcome prejudice and discrimination.

Although teachers are legally required to meet the needs of children with autism, there is no legal requirement for them to be trained to do so. Teachers and school staff need training to help them support children with autism, and schools need to be able to promote disability equality. Investment is needed to enable them to do it.

The media

"Some 'autistic' children aren't ill, they're just badly behaved."

Headline in Sunday Times (Ecosse edition), 14 May 2006

The media play an important role in shaping public perceptions and influencing public opinion and could be a powerful ally in raising awareness of autism and countering stereotypes. Families

affected by autism find relentless negative portrayals of autism extremely distressing. More positive news reports about autism and features about people living with autism are needed to increase awareness and understanding amongst the general public. And people living with autism need positive portrayals to demonstrate what's possible.

Local authorities and local services

All public authorities have a duty under the Disability Discrimination Act (2005) to involve disabled people in decisions about planning and delivery of services. The best way to make services and environments accessible to people with autism is to ask them for their views and experiences. The National Autistic Society has produced a guide with practical tips on involving people with autism to help public bodies to do just this.¹⁹

- Services should find out what people with autism think so that they can act positively to create more autism-friendly ways of working.

¹⁹ To order a copy of this guide email thinkdifferently@nas.org.uk

4 What next?

Government

Everyone has a role to play in changing attitudes and making the world a better place for people with autism, and central and local government are key. That's why the UK Government should demonstrate its commitment to raise awareness and promote the rights of people with autism by ratifying the UN Convention on the Rights of Persons with Disabilities. That means:

- taking action to raise awareness and understanding of autism
- taking action to tackle discrimination against people with autism
- ensuring adequate training for all those who come into contact with people living with autism.

People affected by autism

We mustn't forget that people affected by autism also have an important role to play. By sharing their own experiences of living with autism, they can educate those around them and make their own unique contribution to countering the myths and misconceptions that abound.

What we're doing

The NAS has launched the *Think Differently About Autism* campaign to help improve public awareness and understanding of the condition. As part of this campaign, we've produced information for schools and workplaces on steps they can take to become more autism friendly, and tips on how to consult with people with autism.

Over the next year, the *Think Differently* campaign will showcase the reality of living with autism, both positive and negative, through art, new media, photography and personal stories. We are asking anyone affected by autism to share their experiences through the website www.think-differently.org.uk

With the help of this campaign, everyone can learn to **think differently** about autism and **act positively** to eradicate intolerance, misconceptions and discrimination.

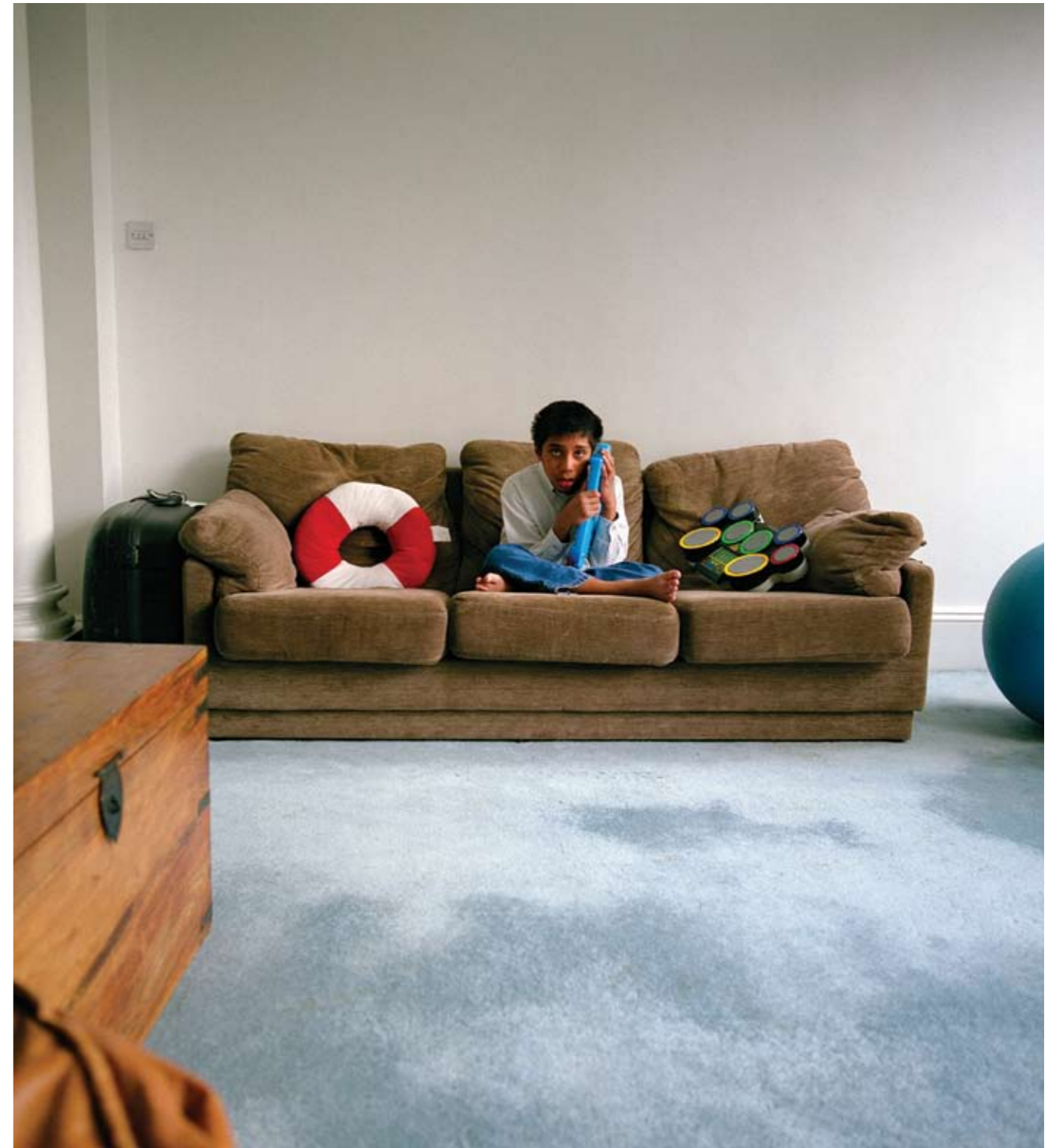


Photo by Robin Hammond, of Ayman, 12, with autism

"I want people to know why I don't remember their name, why I don't always say hello. I'd like them to know or be told - I would like for everyone in my building to know."

The National Autistic Society is the UK's leading charity for people affected by autism.

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.



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think
differently
about
autism



Think differently - act positively

Public perceptions of autism



Your autism charity