make school make sense

Autism and education: the reality for families today

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The National Autistic Society

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To join the *make school make sense* campaign go to www.autism.org.uk/campaign or email campaign@nas.org.uk or call 020 7923 5799 (answer phone).

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Contents

Note: the photographs in this report feature young people who attend National Autistic Society schools, not the interviewees whose responses are included throughout the text.

Key findings and recommendations

In this report we reveal what families of children with autism want, and what they actually get, from the education system today. We highlight solutions to the problems they outline, which if delivered will help *make school make sense* for all children with autism.

The right school for every child with autism

- Parents want a range of provision including mainstream schools, special schools, resource bases in mainstream schools and dual placements.
- Autism expertise is of paramount importance to parents, regardless of whether the school is mainstream or special.
- Over 50% of children are not in the kind of school their parents believe would best support them.
- 66% of parents said their choice of school was limited by a lack of appropriate placements for children with autism in their local area.

Recommendations

- The Government and the Welsh Assembly Government should enshrine in law a duty upon local authorities to ensure that every child with autism has local access to a diverse range of mainstream and specialist educational provision, including autism-specific resource bases attached to mainstream schools, special schools and specialist outreach support.
- Local authorities should ensure that every child with autism has local access to this diverse range of mainstream and specialist educational provision, and report publicly on the range of provision that is provided.

The right training for every teacher

- Only 30% of parents of children in mainstream education are satisfied with the level of understanding of autism across the school.
- In mainstream schools only 27% of parents say that all their child's teachers could adjust their approach and teaching materials – and therefore meet their legal duties under the *SEN and Disability Act (2001)*.
- Special Educational Needs Co-ordinators (SENCOs) are responsible for co-ordinating provision for children with autism in schools, yet 23% of parents are dissatisfied with SENCOs' level of understanding of autism.
- Over 40% of children with autism have been bullied at school.

Recommendations

- The Government and Welsh Assembly Government should fund, develop and distribute resource packs on autism for teachers and support staff, which provide practical information, ideas and support on how best to support the differing needs of children with autism.
- The Government, Welsh Assembly Government and local authorities must ensure that all Special Education Needs Co-ordinators (SENCOs) receive training in autism. This training must be sufficiently in depth that they are able to meet the needs of children with autism, and can disseminate best practice to other staff in the school.

The right approach in every school

- 45% of parents say it took over a year for their child to receive any support.
- There are more appeals to the Special Educational Needs (SEN) and Disability Tribunal in England about autism than any other type of SEN. 79% of parents who appealed to the Tribunal in this survey won their case.
- Parents say the biggest gap in provision is social skills programmes.
- 1 in 5 children with autism has been excluded from school, and 67% of these have been excluded more than once.
- The support and adjustments children with autism need can be straightforward and can enable a child with autism to play a full role in their school.
- Only 53% of young people aged 14 to 19 years have transition plans, falling to just 34% of students in mainstream schools.

Recommendations

- Local authorities must ensure schools' disability accessibility plans refer to the specific needs of children with autism and are implemented effectively.
- Local authorities should embrace the opportunity presented by the new Disability Equality Duty to ensure that schools in their area promote and provide a positive environment for children with autism now and in the future.
- Local authorities in England must review implementation and promote the use of the *Autistic spectrum disorders: good practice guidance.*
- The Welsh Assembly Government should adopt the *Good practice guidance* or develop an equivalent for use in Wales.

Autism is complex. Our demands are simple. *make school make sense.*

Introduction

The inclusion of children[1] with special educational needs in mainstream schools has become the focus of an increasingly polarised public debate. In this report we reveal what parents and children with autism really want, and what they actually get, from the education system today.

A survey was sent to all National Autistic Society members in October 2005. With a response rate of 13.5%[2], this report is based on the views and experiences of 1,271 parents[3] of school age children with autism in England and Wales.[4] We also asked children with autism to tell us what they think, carrying out in-depth interviews with 25 children across England and Wales.

This report is therefore based on the biggest survey on autism education ever carried out in the UK. The characteristics of our sample coincide with what we know about the broader population of families of children with autism nationwide.

In this report we look at what needs to take place in schools so that children with autism can learn, play a full part in school life and achieve their potential. We break down the concept of inclusion to find out what it means for children with autism, and what needs to happen to make it a reality.

Inclusion is not about placing children with autism in mainstream schools and ignoring difference by 'treating all pupils the same'. It is about making appropriate provision to meet each child's needs and reasonable adjustments to enable each child to access the whole life of the school. Every child with autism has different strengths, and a child's individual needs should be the starting point for identifying what type of school they attend and the support they need in that setting.

Inclusion can only happen where:

- adjustments are made to enable the child with autism to access the whole life of the school
- special educational provision is made to meet the needs of the child with autism.

The following chapters outline what needs to change at a national, local and school level in order for inclusion to become a reality for all children on the autistic spectrum. Before this, we look at whether parents would like their child to go to a mainstream or special school, investigate whether families can exercise their preference, and consider the consequences of getting it wrong.

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[1] The term 'child' or 'children' refers to children and young people between 2 and 19 years old, unless otherwise specified.

[2] Of 13,400 NAS members, only parents or carers of children aged 2 – 19 were invited to reply, so the response rate was actually much higher than 13.5% (1,367 responses).

[3] For the sake of brevity, we have used the term 'parent' throughout this report, to include legal guardians, carers and other relatives. Responses also came from grandparents, foster parents and other relatives. Further information on methodology and sampling is available in Appendix 1.

[4] Responses from Scotland and Northern Ireland have been analysed separately.

What is autism?

Autism is a lifelong developmental disorder that affects the way a person relates to the world around them. It affects an estimated 535,000 people in the UK.

As a spectrum disorder, autism manifests itself in many different ways: some people with autism have accompanying learning disabilities, others at the higher end of the spectrum, such as those with Asperger syndrome, have average or above average IQ. But everyone with the condition shares a difficulty in making sense of the world. For the purpose of this report, we use the term 'autism' to describe all autistic spectrum disorders, including Asperger syndrome and other diagnoses noted in responses. Due to the inconsistent and imprecise nature of diagnosis, respondents were asked to describe their child as able (average IQ, verbal), medium-functioning, or less able (limited speech and self-care skills).

People with autism all experience the following three main areas of difficulty, known as the 'triad of impairments':

Social interaction: difficulty with social relationships, ranging from being withdrawn, to appearing aloof and indifferent, to simply not fitting in easily. People with autism may also seem insensitive to the feelings of others. This can lead to problems in the playground, with making friends and in turn, bullying.

Social communication: difficulty with verbal and non-verbal communication, ranging from difficulties with developing speech, to repetitive or formal use of language. People with autism may also not fully understand gestures, facial expressions or tone of voice. Understanding teachers and participating in class can be challenging as a result.

Social imagination: difficulty with understanding how others think and feel and in the development of interpersonal play and imagination. A person with autism may pursue a special interest rigidly and repetitively without recourse to others. Difficulty in the area of social imagination may also manifest itself in response to change, so children with autism may find it hard to cope with changes to their timetable, for example. Children with autism may struggle with subjects that use abstract ideas.

The impact of these three areas of difficulty on the life of a person will vary: every person with autism is an individual. A minority of children will excel in certain areas, but all have strengths to be nurtured.

In addition to the triad of impairments, people with autism often have heightened senses and may be extremely distressed at noise or brightness, for example. Other developmental disorders such as Attention Deficit (Hyperactivity) Disorder, Tourette syndrome and dyslexia often occur amongst people with autism, who are also more vulnerable to mental health problems, particularly depression and anxiety.

1 The right school for every child with autism

- **Autism expertise is of paramount importance to parents, regardless of whether the school is mainstream or special.**
- **Parents want a range of provision including mainstream schools, special schools, resource bases in mainstream schools and dual placements.**
- **Over 50% of children are not in the kind of school their parents believe would best support them.**
- **66% of parents said their choice of school was limited by a lack of appropriate placements for children with autism in their local area.**
- **Parents report a particular need for specialist support for children with Asperger syndrome, and a shortfall in specialist education for secondary school age children.**
- **45% of parents said they did not receive adequate support or information to help them choose a school.**

The inclusion debate: what do parents of children with autism think?

Advocates of mainstream and specialist education for children with autism are often pitted against each other, the two positions apparently irreconcilable. When we asked parents what kind of school they would ideally like their child to go to, no clear front-runner emerged.

Taking their views as a whole the answer is not mainstream or special, but both. When given a theoretical choice, parents are fairly evenly split between mainstream schools, special schools and resource bases in mainstream schools as the best option for their child.

All children with autism are individuals with differing strengths and needs: autism is a spectrum disorder. The autistic spectrum includes children with profound learning disabilities with little or no verbal communication, through to those with an average or high IQ, including those with Asperger syndrome. Moreover, the barriers faced by children with autism are social, so the support they need cannot be determined just by a medical model of disability. It is not surprising, therefore, that parents want a wide spectrum of educational provision including mainstream schools, special schools, resource bases in mainstream schools and dual placements.

Although the high profile inclusion debate relates to the type of school where children with autism should be educated, it is expertise in autism that is important to parents, irrespective of the setting. Of the 36% of parents who think a resource base in a mainstream school is the ideal option, 95% want the base to be autism-specific. Similarly, of the 36% of parents who feel a special school would be best, 83% want an autism-specific special school.

Can parents exercise their choice?

Unfortunately, the answer for over half of parents is no. 55% of parents say they had no choice over whether their child attended a mainstream or special school. Only 31% of parents of children in mainstream schools feel they were given the opportunity to choose for them to be there. Our survey also reveals that parents feel their choice becomes more limited as their child grows older, with 59% of parents of secondary school age children reporting that they were not able to exercise their choice over the type of school. This could indicate that the absence of a range of provision for pupils with autism at secondary level is particularly acute. Families from black or minority ethnic backgrounds are 25% less likely than white British families to feel as if they had a choice.

The lack of choice is not just a perception. Comparing parental preference with the type of school their son or daughter actually attends reveals that over 50% of children are not in the kind of school their parents believe would be best for them.

These findings are particularly significant as our survey also found that being able to exercise meaningful choice correlates strongly with overall satisfaction. 80% of people who are dissatisfied with their son or daughter's education overall also felt that they had no say over the type of school he or she attends.

Parents are most satisfied where their children are in autism-specific provision. 72% of parents of children in autism resource bases in mainstream education, and 83% of parents of children in autism-specific special schools believe this is the ideal option for their child. The majority of those in special schools and bases which are not autism-specific would have chosen the same kind of placement but with an autism specialism if the option had been available to them. Where children attend a special needs base in a mainstream setting, 59% of their parents think an autism-specific base would be preferable, whilst none of the parents would have preferred a special school catering for a range of children with special educational needs (SEN). 43% of parents whose children are in mainstream thought an autism base in a mainstream school would better support their child.

> "I thought it would be easy. The educational psychologist said special school was the best option, so did the primary school. In reality it took me nearly two years of letter writing and telephone calls, assessments and tears." [5]

The barriers to choice

The absence of a 'flexible continuum of provision'
In order to make a choice, parents need to have a range of options to choose from.

According to Government policy there should be a 'flexible continuum of provision' available at a local level.[6] However, the majority of parents feel that this is not available where they live. 66% of parents say their choice is limited by a lack of appropriate placements for children with autism in their local area. Parents of children described as 'less able'[7] feel their choice is even more limited locally by a lack of options.

> "I was allowed to 'choose' from what was available but what was available meant, in fact, there was little or no real choice."

> "My current college should be divided into various units according to special needs, so that it improves sociality and so that each individual person can learn better. In fact I think every school and college should have something like that. This is really something I've thought up."

Edward, 18, further education college

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[5] All quotes in this report are from parents of children with autism, unless otherwise specified.

[6] DfES memorandum to the Education and Skills Select Committee inquiry into Special Education Needs (2005).

[7] For example, limited speech and self-care skills.

Sam is 12 years old and has Asperger syndrome. There are no specialist places for children with Asperger syndrome in his local authority. Sam is currently out of school.

Q: Why did you leave your last school?

Sam: Because they did not want to keep me…Because I was too much trouble…No the bullies were too much trouble. Going to other schools didn't work…Because it was arranged quite quickly and it didn't work…I feel that they should just get on with it…I just want to go to a school, actually!

The LEA won't let me go into a mainstream school…my theory is because we have failed at one mainstream school. On the other hand we have already failed at two specialist schools.

Q: How does it feel being out of school for a whole term?

Sam: I'm very frustrated. Well actually it is a bit more than a term. If you can call three lessons a day in the learning support room…well I don't think it is actually an education.

Q: Would you like a school where there is more staff, maybe where the classes are smaller?

Sam: I dunno, I just want to go to a school.

Q: Would you like to go to a school, where there are others like you?

Sam: Yes probably, but as I said, I just want to go to a school.

Q: If you could choose, what then?

Sam: Whichever one I could go to quicker!

Mum: It's a shocker isn't it, Sam?

Sam: Yes

Mum: We will sort it out.

Parents highlight a lack of specialist placements for children with autism in their local area, both in special schools and in resource bases in mainstream schools.

> "Choice was limited as the nearest special school is over an hour away from home. No schools available locally with specialist base attached."

Parents who describe their children as being 'more able'[8] or as having Asperger syndrome, are even more likely to feel that they had no say over what type of school their son or daughter attends (61%). These parents highlight an acute shortfall in specialist provision for children with Asperger syndrome, which may coincide with a lack of tailored support for these children in mainstream schools.

> "There were no special schools or units to meet the needs of such able yet disabled children. There were no meaningful choices, yet we are never away from the mainstream school with one issue or another."

> "There is no suitable specialist provision for high-functioning autistic/ Asperger's children either within or anywhere near our borough. To try and get my son into such a provision further afield would mean a battle with the local authority to get funding and if we succeeded approximately two to three hours travelling a day."

In order for parents to have a choice over the type of school their child attends both specialist and mainstream placements must be available locally. With the implementation of the *Special Educational Needs and Disability Act* in September 2002, parents secured an increased right to a mainstream place. However, the comments from parents show how illegal disability discrimination still limits their choice of school. These experiences demonstrate the need for stronger safeguards in admission procedures to ensure equal access, and improved monitoring of the way schools put these procedures into practice.

> "Mainstream school dismissed any intention of educating my son when they discovered he had autism."

> "One school refused to take her as it would make their SATs league table placement drop!"

In addition to the need for more equitable access to specialist provision, mainstream education has to be a viable option in order for choice to exist. If a parent feels that a mainstream school is not an option because of the lack of training or support available for their child, then the freedom to choose that school is meaningless. A lack of appropriate placements in mainstream schools curtails choice and means that parents feel that specialist provision is the only practicable option. Although 32% of parents feel that a special school will always be the best option for their child, 58% of parents of children who are currently in special schools say their child would be better off in mainstream if he or she was properly supported and included.

> "No choice, mainstream local schools at the time said they could not meet his needs or cope with him. We were heartbroken."

> "We agreed to send Sam to special school only because the mainstream school was not well enough equipped or trained and because we were aware that the LEA would only provide untrained classroom assistant support at mainstream."

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[8] For example, average IQ and verbal.

"My son attended a mainstream school for a short while, but because of his autism the school/staff could not cope with him and he could not cope with that school. He has no choice but to attend a special school which suits him best and where he is happiest."

It is clear that building capacity in mainstream schools will extend parental choice. Local authorities need to ensure that their provision for children with autism includes ring-fenced funding for autism outreach teams or equivalent sources of specialist advice and support for mainstream schools. Partnership working between mainstream and special schools must also be promoted at a national and local level so that expertise can be shared.

A lack of support for parents choosing a school

Choosing a school is a big decision for any parent, but the additional support needs of a child with autism mean that access to information and support is particularly vital to help their parents find a suitable school. However, 45% of parents say they did not receive adequate support or information to choose a school. As the sample of parents responding to this survey are all members of The National Autistic Society, and therefore could be expected to be more aware of sources of support and information, the experience may be even worse for other families.

"We had a choice, but with no help to make a decision, we found it very difficult.

After diagnosis all support staff pushed mainstream school. Nobody would help us decide or give us plus or minus points to consider. All we were given was a list of schools with no history on which ones had autism experience."

Although examples of good practice were much more limited in our survey, where support was provided it was highly valued by parents.

"The LEA has included and consulted parents – offering options and making recommendations. I feel we have been given well-researched advice and ample opportunity to contribute to decision making."

Many parents in our survey feel that they needed to fight to get an appropriate placement and support for their son or daughter. This indicates that for many children with autism, access to a good education is still dependent on their parents' time and resources. In particular, our survey shows that parents feel they need to fight to secure autism-specific provision, which is the most popular type of placement. 62% of parents whose children attend an autism-specific special school say it was hard to get a place.

"We had to pay £20,000 a year for a special school for three years until we won the legal battle with our LEA. We had the money to make a choice."

What types of school do children with autism in this survey go to?

Mainstream school	47%
Resource base in mainstream (autism-specific)	7%
Resource base in mainstream (not autism-specific)	4%
Special school (autism-specific)	15%
Special school (not autism-specific)	22%
Dual placement at a special and mainstream school	2%
Other (specified)	3%*

*half of which home-educate

"I am due to move to a new school next September, but they have not decided where. My parents were supposed to have decided by my birthday, which is 1 November. I think they might think that the school we want will be too expensive. I think we might have to convince them that they have got to pay for it. It is taking them so long…I would like to tell them to hurry up."

Jamie, mainstream primary school

"You are constantly worrying about your child with autism with regard to their education. You have less time and energy for your other children and partner. You are continually fighting for appropriate provision. This is depressing and emotionally like being on a roller coaster. We are presently worrying about secondary education. We are looking around different types of provision, but have seen nothing suitable."

The right school for every child with autism: what are the consequences of getting it wrong?

Where children with autism are not able to access the support they need there are negative consequences for them, their families and their school, as well as potential long-term financial implications for their local authority. The only economic analysis of autism in the UK concluded that the estimated lifetime costs of autism could be sharply reduced with investment in early intervention and education services.[9] For children with autism it is not just their educational outcomes that are at risk, but also their broader development, mental health and well-being.

"Our son deteriorated so alarmingly in year 7 that he had to stop attending in June of that year. This was in spite of the best efforts of the school. The SENCO, LSAs[10] and teachers were excellent and really tried to help. The SENCO felt our son needed a different environment, so did the psychiatrist seeing him and we felt he could not cope at mainstream. He spent nine weeks as an in-patient at an adolescent psychiatric unit – the lowest point."

"My son attended a special school until June 2005 (secondary) and although they provided social support I felt that his all-round education suffered as they did not provide a full curriculum. It seems very unfair that I had to choose either social skills or education and that both are not readily available."

We cannot fully assess the long-term cost of a lack of appropriate school placements for children with autism in this report. However, we asked parents to tell us about the immediate impact of a lack of choice and some of the issues they raised are outlined below.

A disrupted education

One in three children (33%) in our survey has changed school in the last five years, in addition to the usual changes that their peers might make such as moving from primary to secondary. A significant minority of pupils, 10%, have changed school three times or more in the last five years in addition to the usual changes. This reflects a high level of disruption to their education.

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[9] Knapp, M. and Jarbrink, K. (2001). The economic impact of autism in Britain. *Autism* 5(1), pp7-22.

[10] Learning support assistants.

Out of authority placements

Out of authority placements are necessary where there is inadequate provision locally. Our survey reveals that 21% of children with autism attend a school located outside their local authority. 13% of children who live in Wales go to school outside Wales. Whilst 11% of children travel out of their local authority to go to primary school, this rises to 30% of secondary school pupils. These figures reflect parental perception that provision is more limited at secondary school level.

Of those children who attend a special school, it is notable that pupils who are described as ‘more able’ are much more likely to be in an independent special school. This indicates a shortfall of specialist provision for this group in the maintained special school sector.

Where there is not adequate provision locally, it is vital that children are able to access an appropriate school placement outside their local authority or in the independent sector. Where access to out of authority and independent sector placements is denied in these circumstances, children with autism are prevented from accessing a suitable education at all.

Long journeys to school

A lack of appropriate provision locally results in children having to travel further than other children to get to a suitable school. 81% of those travelling over ten miles or more to get to school attend a special school, alluding to a lack of specialist provision locally. Moreover, 20% of children attending an autism-specific school have to travel over 50 miles to attend. The number of secondary school age children travelling over ten miles to get to school (31%) is almost double the number of primary school age children who travel this distance. This indicates that fewer children with autism are attending local schools at secondary level.

The *Education Act (1996)* makes it clear that children must arrive at school in a fit state to learn, and where children experience long journeys this can impact on their tiredness in school and their ability to concentrate. Factors associated with transport arrangements such as sharing transport, exposure to bullying, sensory problems, changes in routine and long journeys impact on anxiety and fatigue levels for children with autism. This could lead to behavioural problems either during the journey or in school time. 19% of two to five-year-olds in our survey travel over 45 minutes each way to and from school every day. Overall 27% of children described as less able have to travel over 45 minutes to get to school each day.

Long journeys to school have additional consequences for a family, for example 49% of families do not receive any contribution from their local authority towards the cost of school transport.

Focus on home education

Home education is a preference for some parents and a route they always intended to take. However, this is not the case for the 20 families in our survey who home educate. When asked why they home educate, parents highlight a lack of adequate provision for their child in the local area. Most are concerned that the ‘system’ can be inflexible, and struggles to respond to the individual needs of children with autism. This view is largely shared by the 11 families who had home educated in the past, and the five parents who were seriously considering home educating in the future.

> “My daughter became very distressed at school and her behaviour was appalling at home. After three years at school she still had no communication. Now, after four years of home education, she can talk in sentences, communicate and she is doing well academically.”

> “At the moment we don’t home educate, but it is something we are seriously considering for next year (secondary) because there are no suitable placements in our county for high-functioning children with autism.”

Over half of the parents who have experience of home educating say they received no support from their local authority. However, some experiences were positive, and several parents report that speech therapy and home tuition services were provided.

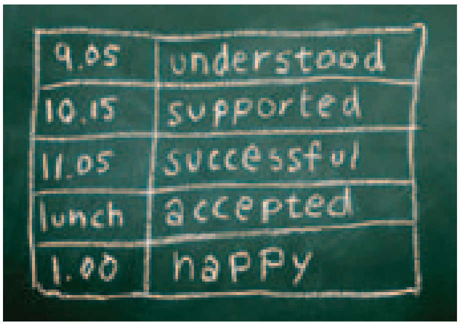
Recommendations

The Government and the Welsh Assembly Government should:

- **Enshrine in law a duty upon local authorities to ensure that every child with autism has local access to a diverse range of mainstream and specialist educational provision, including autism-specific resource bases attached to mainstream schools, special schools and specialist outreach support.**
- Ensure that the progress of children with SEN is monitored and reflected in school performance indicators.
- Ensure that choice advisers[11] in England are adequately trained in autism to support parents to choose a school.
- Take action to break down barriers between special and mainstream schools, including independent special schools.

Local authorities should:

- **Work to ensure that every child with autism has local access to a diverse range of mainstream and specialist educational provision, including autism-specific resource bases attached to mainstream schools, special schools and specialist outreach support. They must also report publicly on the range of provision that is provided.**
- Ensure that if a child has highly complex needs which cannot be met locally, they are able to access appropriate provision outside the local authority. Local authorities should collaborate with neighbouring authorities to co-ordinate provision of suitable placements for children with more complex needs.
- Monitor the admission of children with SEN to schools in their area, including Academies and Trust schools in England, and report publicly on this each year.
- Secure the provision of autism support and advisory services to mainstream schools. This should include ring fencing resources for outreach services so that the delegation of SEN funding to schools does not erode such services.
- Increase the capacity of specialist services for children with Asperger syndrome, including outreach services and tailored placements in resource bases and special schools.
- Increase the proportion of autism-specific placements (schools or resource bases) for secondary school age children with autism.
- Secure good quality, independent advice for parents about local SEN provision: not just a list of schools but advice regarding their experience and training in autism.



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[11] The White Paper *Higher standards, better schools for all* (2005) outlines proposals for the creation of choice advisers to support parents in England in choosing a school.

2 The right training for every teacher

- **Teachers are not required to have any autism training, although 1 in 110 children have autism.**
- **72% of schools are dissatisfied with their teachers' training in autism.**[12]
- **98% of the general public think that teachers in mainstream schools should be trained in autism.**
- **Only 30% of parents of children with autism in mainstream education are satisfied with the level of understanding of autism across the school.**
- **In mainstream schools only 27% of parents say that all their child's teachers could adjust their approach and teaching materials – and therefore meet their legal duties under the *SEN and Disability Act (2001)*.**
- **Special Educational Needs Co-ordinators (SENCOs) are responsible for co-ordinating provision for children with autism in schools, yet 23% of parents are dissatisfied with SENCOs' level of understanding of autism.**
- **Over 40% of children with autism have been bullied at school.**

With an estimated autism prevalence rate of 1 in 110 children, all schools should expect to teach children with autism and have the understanding, training, resources and specialist support to do so. Without an understanding of autism, staff cannot be expected to know how to adjust the curriculum and school environment so that learning and the rest of school life is accessible to pupils with autism. These adjustments can be very straightforward and simple to make where staff have an understanding of this 'hidden disability'.

We asked schools what they thought about their level of training in autism in 2002. 72% of schools said they were dissatisfied with the extent of their teachers' training in autism. This was not surprising: even in schools where there were pupils with autism, only 22% of teachers had received any autism training, the majority for just one to four hours.

We asked the general public what they thought in the biggest ever national autism survey: of over 28,700 responses, 98% believed that all teachers in mainstream schools should be trained in autism.[13]

Now we ask what parents think, and look at the difference training can make from the perspective of the child and the teacher.

Why is training important?

"Our son's teachers do not understand that his perception is different from other children's but as he is quiet and polite nobody sees he has a problem – they think he is an underachiever."

"It doesn't appear that mainstream teachers have had access to training. The fundamental issues relating to communication, behaviour and language disorder continue to be misinterpreted as 'bad behaviour', 'not listening' and so on."

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[12] Barnard et al (2002). *Autism in schools: crisis or challenge?* London: NAS.

[13] *Autism Counts* survey (2005). London: NAS.

"The learning assistant is really brilliant. She's just really, really efficient. She makes sure that everything works all right. It's hard to explain but she just makes everything sort of work all right."

Ben, age 12, mainstream school

"We allow children with autism to use different coping strategies. So for example one lad has real problems concentrating and looking, he hides under his jacket while he is listening and does so much better. It is just too much for him otherwise.

"Gradually teachers are allowing the kids to do things like that in class – they tend to react with 'I can't let him do that, they will all want to', but of course the rest of the kids don't want to hide under their blazers!"

Secondary school teacher

When we asked parents what one change would most improve their child's learning or experience in school, they overwhelmingly chose teacher training. The high levels of satisfaction which parents report when their children are in autism-specific settings are no doubt due in part to the autism-specific knowledge of professionals in these settings. In comparison, only 30% of parents of children in mainstream education are satisfied with the level of understanding of autism across the whole school. For some parents, the expertise of an individual member of staff is enough to determine their choice of school.

> "It was recommended that he attended a school with a resource base attached, but we felt he would do better at the primary school in our village where the SENCO had special knowledge and skills in ASD."

The Government's strategy for special educational needs in England states that 'all schools should expect to teach children with SEN' and proposes a tiered approach to training, whereby all teachers have core skills, some teachers in all schools have specialist skills and some teachers in some local schools have advanced skills. Our recommendations on page 18 concur with this model. All teachers need the skills to differentiate their lessons, all SENCOs should be supported to build up and pass on expertise to other staff, and all local authorities should ensure autism outreach teams are available to provide specialist support where schools need it.

Teachers

> "In our experience our daughter's progress relies on the teacher's ability to engage with the children, understand their needs and choose appropriate teaching materials. We have, however, encountered over the last eight years a number of teachers who have been inflexible with both their approach and teaching materials, which has stalled our child's progress."

There is still no requirement for either trainee teachers or practising teachers to undertake any training in autism, even though they are required by law to make 'reasonable adjustments' to their lessons to enable children with autism to learn.[14] A lack of training puts unfair pressure on the child with autism, their peers and the teachers themselves. It can be argued that this current lack of teacher training contributes directly to the high exclusion rates of children with autism revealed in this survey.

On a positive note, the majority of parents think that the staff at their child's school has received some autism training. However, if this is the case it is evident that the training is inadequate, as only 20% of parents of children in mainstream education feel that their child's teachers have received the professional training they need in order to meet the special needs of children with autism. This demonstrates that basic awareness training in autism, although essential, will not adequately equip teachers to work with children on the spectrum.

In mainstream primary schools, 51% of parents are satisfied with the teacher's understanding of autism. The picture becomes bleaker at mainstream secondary school level, where only 40% of parents are satisfied with the understanding their child's form teacher has of autism. Of all staff considered in our survey, including non-teaching staff, parents are most dissatisfied with

[14] *Special Educational Needs and Disability Act (2001).*

the level of understanding demonstrated by secondary school subject teachers. In mainstream schools only 23% of parents are satisfied with the level of understanding demonstrated by subject teachers, and almost double this figure (42%) say they are dissatisfied.

> "A few teachers in particular have made an effort to understand him and his disability, helping with warning systems, breaking down instructions, ensuring he was understood and encouraging him to express himself. The number of teachers involved at secondary makes it difficult – they change each year, including two changes of SENCO."

It is a matter of huge concern that a significant proportion of teachers are not sufficiently trained or supported to meet their legal duties under the *SEN and Disability Act (2001)* to differentiate the curriculum and school environment for children with autism. In mainstream schools only 27% of parents say that all their child's teachers have been able to adjust their approach and teaching materials so that their child could learn. 13% of parents do not believe that adjustments are made in any of their child's lessons. The remainder of parents (52%[15]) report a mixed picture, where some teachers do make adjustments in the classroom but others do not. The experience of secondary school age children[16] with autism in mainstream schools is particularly poor. In this age group only 13% of parents say all their child's teachers adapt their approach, and 16% do not believe that any of their child's teachers adapt their approach at all.

> "Some are more prepared to make 'allowances' but few make 'adjustments'."

> "I am constantly challenging the teachers to provide my daughter with an environment to learn in, not just one in which she attends. In such an environment it is not surprising she becomes frustrated."

> "The two teachers Sam has this year, and last year's teacher, were wonderful. They give him differentiated work and a lot of support. It hasn't always been this way. One teacher put Sam in the corner because he didn't answer him, because he didn't know what to say. Another didn't let him go to the loo, when his LSA had tried for months to get him to ask."

The following quotes from parents demonstrate that where there is an understanding of the individual child's condition, making adjustments in order to include children with autism can be both straightforward and effective, and can have a dramatic positive impact on the child's progress.

> "The school has an excellent reception teacher. She uses 'visual cards' to reinforce 'listening', 'sitting' etc, and uses a reward chart for good/positive reinforcement."

> "My son is now experiencing real differentiation in classroom – previously this only happened in theory. My son can now say when things are getting too much for him and politely ask to leave the room for five to ten minutes. Before he could not and usually resorted to violence to have himself removed. They are actually listening to him."

> "Some teachers who are new to my son this year have stopped using 'humour' and 'sarcasm' with him following requests and information from us in the home/school diary. In Food Technology, staff do not now put pressure on my son to taste certain foods after I explained sensory sensitivities (and after he was sick!)."

"I like her [my teacher] because she is nice and kind…she understands me."

Jamie, age 11, mainstream primary school

"Training is so important. Not just one-off but ongoing training. It has to be not just theoretical, general stuff, but practical HOW TO – how to do social stories, how to use visual supports, what does it really mean to talk clearly and unambiguously – how do you do it. Each session builds on and reinforces all the other work."

Primary school teacher

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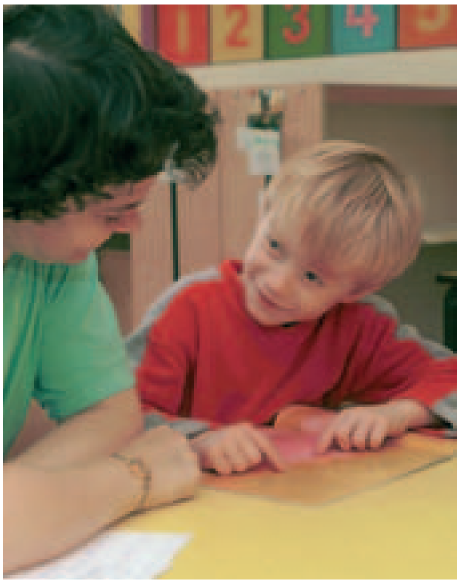
[15] An additional 8% of parents answered 'don't know'.

[16] Age 11 to 16 years.



“I go to a happy school…I don’t find any of it difficult. I do need adults…all the adults…Wendy is a special one…She teaches – she is a teaching cover. She doesn’t lecture me.”

Rachel, age 11, special school

If teachers are to meet their legal requirement to make adjustments they must receive the training that will enable them to do so, via both initial teacher training and opportunities for continued professional development. Given that a significant proportion of teachers are unable to adjust their approach and materials to make classes accessible, a resource pack of practical teaching strategies should be developed by the Government(s) and distributed to schools to aid teachers in meeting their legal duties to children with autism.

Special Educational Needs Co-ordinators (SENCOs)

The role of the SENCO is critical in ensuring that children with autism receive the support they need. It is the SENCO’s responsibility to ensure the day-to-day operation of the school’s SEN policy; co-ordinate appropriate provision for pupils with autism; undertake SEN assessments and liaise with staff, parents and external agencies.

With such a specialised role it might be expected that all SENCOs would have a good understanding of autism. But 23% of parents of children in mainstream schools are dissatisfied with the SENCO’s knowledge and a considerable number (11%) make no comment, stating that they do not know enough about what the SENCO is doing.

It is vital that teachers have access to advice and support, particularly in light of the inadequacy of teacher training. The SENCO has a key role in disseminating practical strategies to support other school staff.

> “I felt mainstream teachers were left to their own devices with no, or little, senior help. Jamie was extremely distressed at school but often hugged the teacher – senior staff’s response was to exclude him – why can’t they help us?”

> “The school has had a lack of understanding – the new SENCO has made a big difference.”

It is essential that all SENCOs have ongoing training in autism and adequate non-contact time to enable them to keep their knowledge up-to-date. They must be supported to disseminate their expertise through the school and must be involved in decision-making at senior management level.

Leadership

Strong leadership is central to a school’s inclusive ethos, which affects the way children with autism are included both in and out of the classroom. Just 40% of parents of children in mainstream schools are satisfied with their head teacher’s understanding of autism. However, satisfaction levels vary significantly depending on the age of the child, and tail off as the child grows older.

> “There is not a ‘whole-school’ strategy for supporting children with autism which has led to difficulties with some teachers who have withdrawn helpful support materials such as visual timetables.”

> “The class teacher shows a willingness to learn but support is not resourced, and there isn’t a whole-school approach.”

Focus on bullying

Bullying is a major problem for children with autism. Over 40% of children with autism have been bullied at school. Children with Asperger syndrome are particularly vulnerable, with 59% of their parents reporting that they have been bullied.

"Alex doesn't tell me when he is being bullied. I have to figure it out, sometimes from bruises. His teachers don't seem to notice – perhaps because of inadequate playtime supervision."

The impact of bullying can be devastating. Where children have been bullied, 83% of parents report a negative impact on their child's self-esteem and 63% say that the bullying led to mental health difficulties. Many parents say that bullying led their child to self-harm or to feel suicidal.

"My son was bullied to the point of wanting to end his life and has self harmed. He attends therapy to help him deal with this. We feel he will never recover from these feelings."

"We moved him at the end of year five because of bullying, which had resulted in physical injury. The bullying in secondary school was classified by the staff as 'regular teasing' and was therefore ignored. When he reacted to it, first by school refusal, then by minor acts of violence, then by significant self-harm issues, he was classed as having emotional and behavioural difficulties and was excluded."

"She wouldn't eat for a week. She wanted to die. She head banged on the wall before I took her to school."

Because of the nature of autism, children on the spectrum may not be able to understand the motives of other children or may not have the social skills to handle difficult situations. This can mean they are easily led or provoked by bullies, which further compounds their difficulties with social communication and interaction, as highlighted by 74% of parents.

"Jenny suffered extreme mental bullying about her severely autistic sister, and because of her poor social and language skills she lashed out. The school refused to address the issue and just excluded her for her retaliation."

Bullying can also severely disrupt a child's education. Where children have been bullied, 62% of their parents say that the bullying led to them having to miss or change schools or to their child refusing to go to school at all.

44% of parents of children who have been bullied feel that the school did not take action to stop the bullying. However, in some cases schools acted promptly and effectively.

"The school handles bullying sensitively and as far as we know bullying has significantly reduced. They have whole-school meetings when any incident takes place."

"They were teasing me, and hitting sometimes, trying to get me into trouble. I tend to know what these people try to do. They attack and tease you and try to get you to lash out and then go and tell the teacher…

People see that autistic people are different and just because they are different, they start teasing them…This man in a wheelchair came in…he gave us this little phrase to remember: 'It's OK to be different'."

Toby, age 11, mainstream school

"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."

Jamie, age 11, mainstream primary school

Recommendations

The Government and the Welsh Assembly Government should:

- **Fund, develop and distribute resource packs on autism for teachers and support staff, which provide practical information, ideas and support on how best to support the differing needs of children with autism.**
- Work with the Training and Development Agency for Schools (and the Higher Education Funding Council in Wales) to incorporate autism into initial teacher training.
- Ensure that Qualified Teacher Status is only awarded to teachers who can demonstrate an awareness of autism.
- Ensure that Advanced Skills Teacher Status is only awarded to teachers who can implement strategies to ensure successful inclusion of children with autism.
- Work with the National College for School Leadership to ensure that the Head Teacher Induction Programme and the National Standards for Head Teachers, promote inclusive practice with explicit reference to autism.
- Ensure that all Special Educational Needs Co-ordinators (SENCOs) are qualified teachers, and work with local authorities to ensure that all SENCOs receive training in autism.

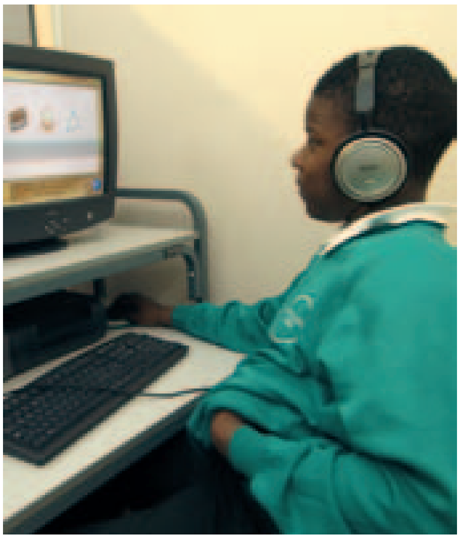
Local authorities should:

- **Work with the Government or Welsh Assembly Government to ensure that all SENCOs receive training in autism. This training must be sufficiently in depth that they are able to meet the needs of children with autism, and can disseminate best practice to other staff in the school.**
- Set out in their SEN policy action to ensure all SENCOs are adequately monitored and supported in their roles.
- Review implementation of the National Standards for SENCOs (1998).
- Ensure that school governors with responsibility for SEN receive appropriate training in autism.
- Provide regular opportunities for teachers to address their skills gaps and develop their knowledge of autism, working with schools to facilitate attendance at training sessions.

3 The right support for every child

- **45% of parents say it took over a year for their child to start receiving any support.**
- **66% of parents say a delay in accessing support had a negative impact on their child's behaviour and 34% say it had a negative impact on their child's mental health.**
- **There are more appeals to the SEN and Disability Tribunal in England about autism than any other type of SEN. 79% of parents who appealed to the Tribunal in this survey won their case.**
- **Parents say the biggest gap in provision is the lack of social skills programmes.**
- **Only 55% of children receive the speech and language therapy specified in their statement.**
- **46% of parents rate communication and information sharing with their local education authority to be poor or very poor.**
- **1 in 5 children with autism have been excluded from school, and 67% of these have been excluded more than once.**

Everyone with autism shares a difficulty in making sense of the world around them. The nature of the condition means that all children on the autistic spectrum will have some level of special educational need.



The right support at the right time

The benefits of early intervention for children with autism are widely acknowledged. In a 2005 statement, the Government pledged 'a firm commitment to ensuring that early intervention is central to future policy development in supporting young disabled children'.[17]

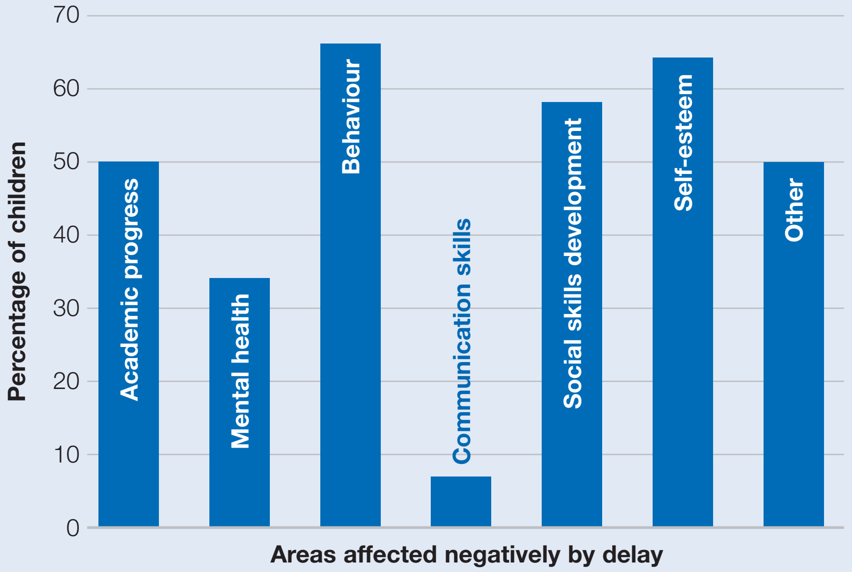
However, our survey found that the length of time it takes to get support in place to meet a child's special educational needs is hugely variable. 66% of parents say that, from the point when concerns were first raised about their child's progress in school, it took over six months for their child to start receiving any support. 45% of parents say it took more than a year before any support was in place, and parents of more able children are over-represented in this group.

> "We originally had to pay for the extra staff member at my son's mainstream nursery – he couldn't have gone without this! It will now be funded by his statement so if we hadn't funded this, my son would have missed a year's valuable learning in a social group."

30% of parents feel that support was delayed because of a lack of ready access to relevant professionals or diagnostic services. Parents highlight long waiting times for appointments, a shortage of therapists and the length of time it took for their child to be diagnosed.

[17] www.surestart.gov.uk

The negative effect of delays in support on children with autism



> "I have a helper who sits with me and if I'm stuck on a word she helps me. It makes a big difference. Mum says she keeps me on track. I used to have my own timetable but not now. I don't want to be different."
>
> **Ruaraidh, age 9, mainstream primary school**

"I'm not sure how long is normal. It seemed an eternity between me realising there was something wrong and gaining a diagnosis."

25% of parents feel that the delay was the result of a lack of understanding at their child's school, highlighting poor communication and a lack of awareness of autism.

"I was told it was my parenting, and that Andrew was out of control and attention-seeking. No one would listen to me!"

"Because my son was very quiet, he basically did what he was told and he 'fitted in' to the class. No one noticed he actually had a problem."

"The school did not see special needs as a priority and did all it could to resist providing extra support. It took many representations before the head agreed to spend extra money on a year 1 class with five children on the spectrum."

23% feel that their local authority was responsible for the delays, citing communication problems, bureaucracy and a perceived lack of readiness to help.

"Our delay was due to the refusal of the LEA to assess our child. It was a frantic and desperate time for us."

66% of parents surveyed claim that the delay had a significant negative impact on their child's behaviour, and 64% feel it was detrimental to their child's self-esteem. A further 34% say that the delay in securing support directly affected their child's mental health. Parents of more able children most commonly identify a negative impact on academic progress, whereas 60% of parents of children described as 'less able' highlight the development of social skills as a particular area for concern.

Delivering support

83% of children in this survey have a statement of special education needs, with 3% of children receiving extra support at Action stage and 7% at Action Plus.[18] Comparing these figures with our membership survey in 2000 reveals a small drop in the proportion of children with statements.

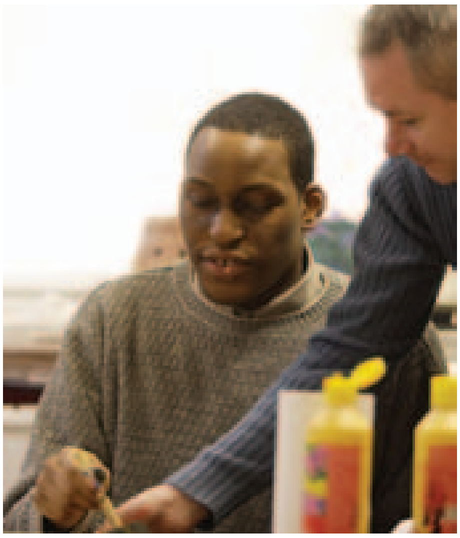
Of those who do not have a statement, and are not currently going through the statementing or assessment process, 33% say this was because the local authority refused to carry out a statutory assessment. In 14% of cases an assessment had been carried out but the local authority decided not to issue a statement. This is reflected in an increase in appeals to the SEN and Disability Tribunal on the grounds of refusal to assess, the majority of which are upheld.[19]

In our survey, 72% of parents who appealed to the Tribunal on the grounds of a refusal to assess won their case and 70% of parents appealing against the decision not to issue a statement won their cases, showing that their concern was justified. It is important that the Government ensures that its intention to reduce reliance on statements by delegating resources directly to schools does not translate into reduced access to assessment and support. Where parents have to go to Tribunal to get their child's needs assessed or to get a statement issued, access to support is delayed and the benefits of early intervention may be lost.

Despite the fact that a local education authority is legally responsible for delivering the support outlined in a statement of SEN, 31% of children who have a statement do not receive all the support outlined in it, and this is true for 40% of children in mainstream schools.

> "My child's statement specified changes which the school could not make and has never attempted to make, despite what the school's representative said on behalf of the authority at the tribunal hearing. Luckily for them, my child has learned to cope!"

It is most common for children not to receive the speech and language therapy detailed in their statement, followed by social skills programme delivery. Where there is a recognised need in the statement for occupational therapy and support at break times and outside the classroom, figures for failure to deliver are also high.



> "You don't get told anything unless you know your child's rights and fight every step of the way."
>
> **Parent**

The gaps in support

Social skills programmes

Social skills programmes help children with autism learn the social skills that other children develop naturally. This may include how to listen and take turns in a conversation or activity, how to deal with real-life situations and how to recognise the thoughts and intentions of other people.

Parents feel the biggest single gap in support is the lack of social skills programmes. Social skills training came top of the list when we asked parents if there were other forms of support they felt their children needed, but were not getting. 35% of parents say this is the area of greatest need, particularly parents of more able children, including those with Asperger syndrome.

[18] Once it has been decided that a child has special educational needs, they move onto 'School Action' or 'Early Years Action', which means they receive extra or special help. If the pupil continues to have difficulties despite all the interventions and the putting in place of an Individual Education Plan (IEP), then they move on to the School Action Plus stage of the *SEN Code of Practice*, DfES, 2001.

[19] *Special Educational Needs and Disability Tribunal (SENDIST) Annual Report 2004-05* (2005) and the *Special Educational Needs Tribunal for Wales (SENTW) Annual Report 2004-05* (2005) suggest that 39.9 % of appeals to tribunal in England and 25% of appeals in Wales were on the grounds of refusal to assess.

> “Sometimes I get extra minutes to do my work and sometimes I need that, I sit by the computers. It is a desk by the computers just by the door, with Jane (support assistant).”
>
> **Jamie, age 11, mainstream primary school**

This increases to 41% of parents of children in mainstream schools. A further 5% also identified a form of social support, specifying a buddy system or a mentor.

Even when social skills training is specifically provided for in a child’s statement, 38% still do not receive it.

> “Academically, my son was achieving the right goals so he was left alone. Socially he was really struggling but teachers seemed less concerned about this.”

Speech and language therapy

All children with autism have difficulty with both verbal and non-verbal communication. Speech and language therapy (SALT) is therefore an important intervention, and provision correlates with overall parental satisfaction. 55% of the children in our survey receive SALT in some form. However, a further 29% of parents believe that their children would benefit from SALT, but are not able to access it.

Children who need speech and language therapy are more likely to get it if they attend a special school. Our findings indicate that 38% of children in mainstream schools who need SALT do not get it. However, even in specialist autism placements a significant proportion of children do not get the therapy their parents think they need.

Where children receive SALT, it is written into the statements in 75% of cases. The SEN Code of Practice states that speech and language therapy should be specified and quantified in a statement, and this is reinforced by case law.[20] Despite this, our survey found that it was not quantified or specified in 51% of cases. Moreover, only 58% of children who have SALT written into their statements actually receive it.

Our survey found that SALT is delivered by a speech and language therapist in the majority of cases. However, 36% of children have some or all of their therapy delivered by a Learning Support Assistant (LSA). It is much more common for teachers in special schools or resource bases to deliver SALT than it is for teachers in mainstream schools to do so. 34% of children in special schools or resource bases receive some or all of their SALT from a teacher, compared to only 5% of children in mainstream schools.

The average length of time between the need for SALT being agreed and the children in our survey receiving the therapy is just over seven months. However, our findings indicate a high degree of variance in waiting times that is not accounted for by age, school, ethnicity, gender or the nature of the child’s autism. Therefore, it is likely that where you live is a significant factor in accessing SALT, and that a postcode lottery persists.

Delayed access to SALT means that opportunities for early intervention are lost and that children are at risk of developing behavioural difficulties, deteriorating social relationships, and being unable to access the curriculum and their learning potential. Workforce recruitment, retention and training issues for SALTs must be addressed in order to improve access, and progress towards meeting the relevant standards in the *National service framework* at a local level needs to be resourced and monitored.

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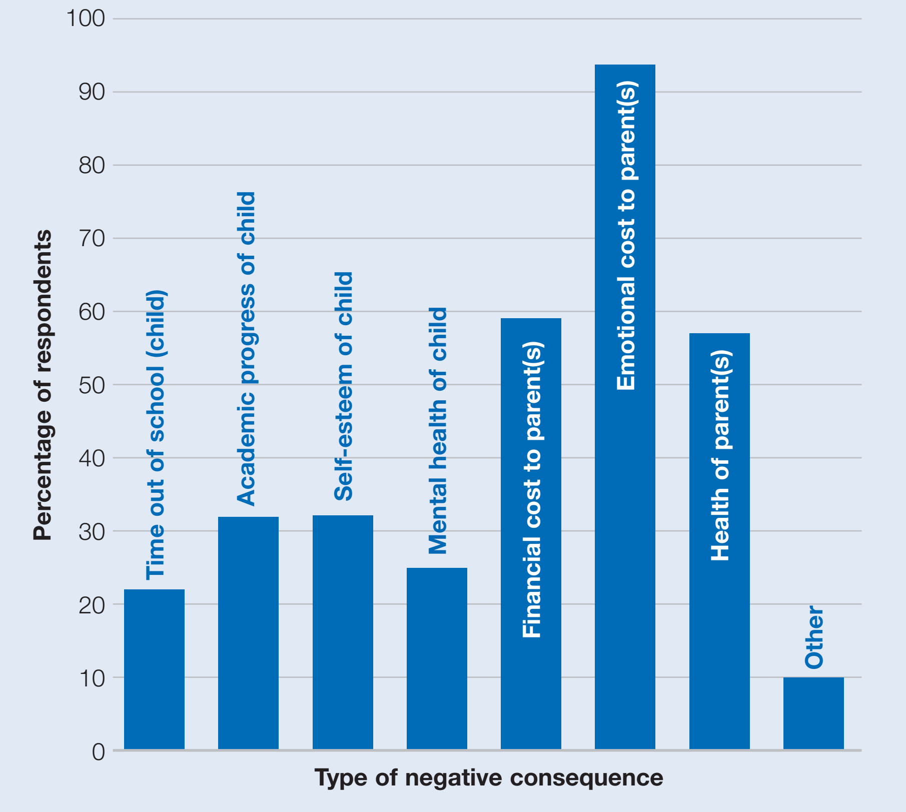
[20] *R-v-Lancashire County Council ex parte M 1989 2 FLR 279.*

The negative consequences of having to appeal to tribunal



The impact on families of struggling to secure support

> "So much time has been taken up attending meetings, phoning people and chasing up paperwork. When my son was smaller I had to organise childcare for him so I could do this. It has caused a lot of stress and worry – my son needs a calm environment to help him – the stress and aggravation of organising appropriate provision is not conducive to this."

Many parents feel they have to struggle to get their child the support they need to access an education. A lack of understanding of the support needs of children with autism, budgetary constraints and bureaucracy can often mean that necessary support is not available. Parents can quickly feel in conflict with their local authority.

> "Getting the original statement several years ago was a horrible, exasperating experience."

46% of respondents rate communication and information sharing with their local education authority to be poor or very poor. Only 16% of parents of children in mainstream schools rate their communication with the local education authority to be good or very good.

Communication- and information-sharing appears to deteriorate as the child gets older, with dissatisfaction hitting its highest point when the child is in secondary school, where only 15% of parents find communication to be good or very good. Even many of those who are satisfied with their children's education overall rank their communication with their local authority as less

than adequate. Parents highlight a need for independent advocates and impartial information on rights and entitlements.

"The procedure for getting any support for my children in school has been very combative and exhausting. There is a great need for an independent advocate or care co-ordinator."

"As an independent parental supporter with Parent Partnership, I am aware of some of the problems during the statementing process, and I felt confident challenging certain points. I'm not sure other parents have the appropriate knowledge or experience."

However, where good practice exists it is evident that good relationships have very positive consequences for all concerned.

"The local authority was instrumental in resolving difficulties with the school."

The adversarial relationship that can build up between local authorities and parents is reflected by the fact that there were more appeals concerning children with autistic spectrum disorder than children with any other category of SEN in 2004-05.[21] Between 2004 and 2005, 23.7% of the total number of appeals to the SEN and Disability Tribunal in England and 29.6% of appeals to the SEN Disability Tribunal in Wales (SENTW) concerned autism, despite the fact that autism only accounts for 5.8%[22] of the population of children with SEN.

In our survey, 17% of parents had appealed to the SEN and Disability Tribunal, some more than once. Of these, 79% of parents report that they won their case, either entirely or in part, which demonstrates that their concerns over a lack of appropriate support were justified. Although parents highly value the role of the Tribunal, having to appeal in order to get appropriate support in place has consequences for the family and the child. The graph on page 23 illustrates the impact that parents feel that having to go to Tribunal had on them and their child.

In 66% of these cases the local authority complied with the Tribunal ruling, and complied in part in 17% of cases. This indicates that a significant minority of children are still denied the support they are entitled to even after their needs have been recognised at Tribunal.

> "It has all led to divorce. My husband couldn't cope with the stress of disability and fighting for what our child deserved. I constantly feel the stress of the 'battle.' You spend too much time on fighting which could be spent on one-to-one with your child. You also feel isolated from other parents."
>
> **Parent**

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[21] *Special Educational Needs and Disability Tribunal (2005). Annual Report 2004/2005.*

[22] Table 9 of Department for Education and Skills (2005). *Special educational needs in England, January 2005*. London: DfES. Estimate based on percentage of children with autistic spectrum disorders being supported in school in England at school action plus stage or with a statement.

Focus on exclusion

Our survey found that one in five children with autism has been excluded from school and one in four children with Asperger syndrome has been excluded. Children from black and minority ethnic backgrounds are more likely to have been excluded than their white peers, and boys are twice as likely to have been excluded than girls.

> "The school said there was not enough support available to keep Tom safe and to protect the rest of the class from being disrupted."

Of these children, 67% have had more than one fixed term exclusion and 16% had either been excluded more than ten times or so many times that their parents had lost count. 24% of excluded children were excluded permanently.

> "Hamet's behaviour was a consequence of his needs not being met rather than him being naughty. This behaviour is not displayed now he is in a specialist school."

> "The school was unable to cope: they did not want to adjust their teaching to accommodate him, and wanted him to change to become neuro-typical."

Of the children in our survey who have been excluded from school, 34% had missed a term or more of school and 10% had missed more than a whole school year, over the last two years alone. Moreover, 71% of parents say that their local authority did not put any support in place for their child whilst they were excluded from school, although they are required to do so after 15 days.

> "Jake never – despite repeated requests – got a report of the incidents, but once a plan was put in place and he went back, the problem never recurred."

> "Danny would not have been excluded if the school had understood the difference between 'normal' behaviour and Asperger syndrome. They inflamed situations because they didn't understand that my son finds physical contact, or being touched by teachers, really difficult."

In addition to formal exclusion, many parents report that their child has been excluded from school on an ad hoc or informal basis. This amounts to 'less favourable treatment' under the *Disability Discrimination Act (1995)*, unless the school can give a material and substantial reason for the exclusion. Over half of the parents who highlighted that this had happened to their child, said it had happened more than ten times or that they had lost count of the number of times their child had been excluded in this way.

> "Chris was excluded from primary school during an OFSTED inspection – we were told not to bring him in. He was excluded from a school activity trip due to a 'health and safety issue'. I offered to accompany him but this was refused."

> "Joshua has generally been excluded on sports days and other events, the reason being that he 'wouldn't cope with it'. Occasionally, it's been when the classroom assistant has been absent."

> "I sometimes get into trouble and get shouted at and told off for saying stuff I wasn't saying…the older children don't like me…my teacher doesn't do a lot to stop it and she shouts at me…but it doesn't happen when my helper is there. I feel safe then."

Ruaraidh, age 9, mainstream school

Recommendations

The Government and the Welsh Assembly Government should:

- **Resource and deliver their ten-year strategy for SEN in England: *Removing barriers to achievement* (DfES 2004).**
- Ensure that reducing reliance on statements by delegating resources directly to schools does not translate into reduced access to assessment and support.
- Resource and monitor implementation of the speech and language therapy elements in the *National service framework for children, young people and maternity services* standard 8 in England.
- Require schools and local authorities to review provision and adjustments for a pupil with SEN or a disability, before disciplinary action is taken against the child or before action is taken against the child's parents.
- Work with the relevant inspectorates to investigate local authorities with high levels of appeals concerning autism, and non-implementation of Tribunal orders.
- Resource and inspect implementation of speech and language therapy actions 5.25 and 5.26 in the *National service framework for children, young people and maternity services (NSF)* in Wales.
- Identify NSF action 5.26 as a priority action for delivery in Wales.

Local authorities should:

- **Strategically plan to address the shortfall in social skills programmes for children with autism.**
- Secure access to impartial advice and advocacy services for parents.
- Implement government guidance on the *Management of SEN expenditure* in England.[23]
- Take action towards achieving the standards set out in the *National service framework for children, young people and maternity services* on services for disabled children and speech and language therapy.
- Establish a multi-agency autistic spectrum disorder co-ordinating group to lead strategic planning of services in accordance with the *National Autism Plan for Children.*[24]
- Review transition planning for young people with autism, and monitor how they are meeting their responsibilities under the *Special educational needs Code of Practice (2001)* and the *Learning and Skills Act (2000).*
- Ensure that extended school provision is accessible and appropriate for children with autism in the local area.

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[23] *Management of SEN expenditure* (2004) London: DfES.

[24] *National Autism Plan for Children* (2003) London: NAS.

4 The right approach in every school

- → **The support and adjustments children with autism need can be straightforward and can enable a child with autism to play a full role in their school.**
- → **44% of parents say their child has not been able to take part in activities before or after school, where these are provided.**
- → **45% of parents of children in mainstream schools say that the school environment is not adequately accessible.**
- → **36% of parents of children at mainstream schools feel that their child does not get the support or adjustments they need at break times.**
- → **Only 53% of young people aged 14 to 19 years have a transition plan, falling to just 34% of students in mainstream schools.**

> "The LEA and other professionals are just so keen on 'inclusion' but they really don't know what inclusion means – he takes part in lessons but that's it. Education is much more than that."

School life extends beyond the classroom. Inclusion is about the quality of a child's experience; how a child develops his or her skills; participates in the life of the school and learns and plays with children from a range of backgrounds.

In practice, free time, lunch, school trips, assembly, extra curricular activities and the like can be the most testing times in the school day for children with autism, who all find changes to routine and social interaction difficult. The stress and anxiety that can build up often leads to official or unofficial exclusion from certain activities and may have consequences for a child's behaviour and ability to learn back in the classroom

The *Special Educational Needs and Disability Act (2001)* places duties on schools not to treat disabled pupils 'less favourably' than other pupils, and to make 'reasonable adjustments' to ensure that they are not disadvantaged. Just as a child's experience at school extends beyond the classroom, so does this duty. We asked parents if reasonable adjustments had been made or if any extra support had been provided to help their child get through the school day. The graph on page 28 indicates those areas where parents feel that necessary adjustments are not in place. The graph reveals that access to breakfast or after school clubs is a particular area of concern for parents of children in both special and mainstream schools.

→ Sensory difficulties

Some children with autism are particularly sensitive to sensory stimuli. Seemingly incidental environmental factors such as background noise, strip lighting or bright colours can cause stress or physical pain, making it difficult for the child to concentrate, with implications for behaviour. Children with autism can find it difficult to block out background noise or visual information and can be overwhelmed by all the sensory information in their environment. Many parents highlight the importance of a quiet space or a calm working environment. However, in mainstream schools 45% of parents feel that the school environment is not adequately accessible, and this is reinforced by 33% of parents saying that their child does not get the support he or she needs to move around the school.

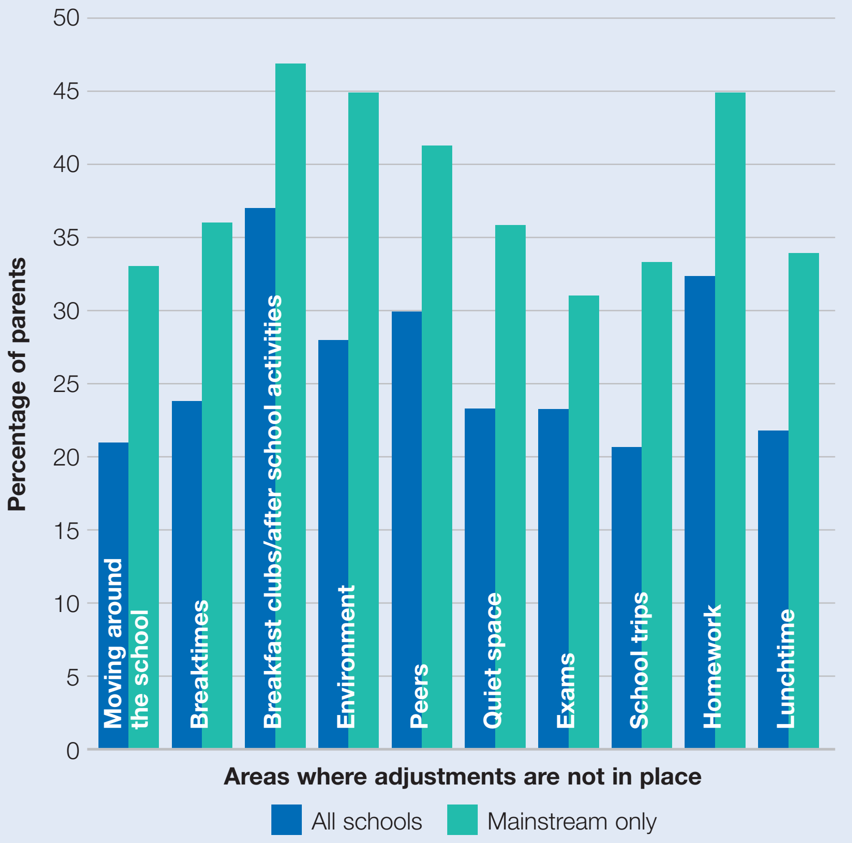
> "At my old school…it was hard…I was left out. They would not play with me. They chatted with each other but not to me."

Anna, age 14, special school

> "At break times it's really crowded because they allow everyone out at the same time. At lunch its not so bad because there are two separate lunch lots and everyone is split up according to that…But I still don't like sitting there…There's something so intimidating when you are sitting on your own at a table, everyone else is in groups, and someone comes up and says, 'Can I take this chair?' – telling you they've got lots of friends but you haven't."

Chloe, age 16, mainstream sixth form

Areas where parents believe necessary adjustments are not in place



"There is a bright fluorescent overhead light. He sits on his own next to a hot radiator with his back to class, facing the yellow wall! Given his sensory issues it couldn't be any worse."

→ Break times

Children with autism find unstructured time difficult to manage and break times or free periods can be particularly challenging. In mainstream schools, 36% of parents feel that their children do not get the support or adjustments they need at break times and only 25% of parents are satisfied with the level of understanding demonstrated by lunchtime supervisors and other support staff. These statistics are particularly worrying, given that 41% of children in this survey have been bullied at school and that bullying often takes place during break times.

"We were encouraged to take him home for lunch. All the other pupils stay in school and taking him home involves driving 12 miles each day. However, when he started staying for lunch again, he was allowed to eat lunch in peace and quiet in the headmaster's office. He is now encouraged to attend lunchtime clubs – drama, chess, etc."

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

[26] SENDIST (2003) *Annual Report 2002-03*. London: SENDIST.

[27] DfES (2005). *Extended schools: access to opportunities and services for all – a prospectus*. London: DfES.

→ Peer support

Overall, 30% of parents say that there is not adequate support to enable their child to build friendships or feel part of their peer group. In mainstream schools 42% of parents cite a need for support with peer relationships that is not met. This reflects the unmet demand for social skills programmes highlighted in Chapter 3. Children with autism have difficulty with social communication and interaction and can therefore find it difficult to build relationships. A survey by the Office for National Statistics found that over 70% of children with autism found it harder than average to make and keep friends.[25] Action to increase understanding of autism across the whole school and to provide support with social activities can make a huge difference to whether a child with autism feels included at school.

→ Home-school communication

Parents in our survey really value good home-school communication, and the standard of communication correlates closely with how satisfied parents are overall with their child's education. 64% of parents say that communication with their child's school is good or very good. Autism-specific settings, both special schools and resource bases, rank highest for good communication with parents. Regrettably, parental satisfaction with communication- and information-sharing falls as a child gets older.

Parents say that home-school diaries are very useful when completed properly. Children with autism may not communicate their experiences well, and stresses built up during the school day can explode once they get home.

> "They don't always make contact if something goes wrong and it is very difficult to untangle the version that comes home via Robert."

> "Communication could be very much improved if all involved with my son used the home-school contact book to note problems or events that have caused him some anxiety, as he explodes when he cannot re-tell events of the day. It would help if they could inform me of a change to his routine no matter how trivial it seems."

Caring for a child with autism involves additional pressures and responsibilities, so it is vital that already over-stretched families are not relied upon to provide the support their children are entitled to at school. However, many parents report that they are called in to support their child or to pick them up when they are excluded from particular activities or periods during the school day. This may amount to 'less favourable treatment' under the *Disability Discrimination Act (1995)*, which is illegal. However, only a small proportion of cases are taken forward to the SEN and Disability Tribunal, which in the Tribunal's view represents a lack of awareness of the role they can play in discrimination cases, rather than a near absence of discrimination.[26]

> "We ended up having to pay for extra cover at lunchtime to make sure he was OK."

> "If my son is keeping himself safe at school and listening to the teacher (behaving good) they will take him on school trips out. If not, they ask me to go with them. My son does not want me there so sometimes he misses out."

Breakfast and after school clubs

> "I used to have this person who helped me during the football club. This person called Catherine who was 19 used to help me. When I got distracted I could chill out. She's gone to university now. I can't go to any football club anymore."

Toby, age 11, mainstream primary

The Government wants all children in England to have access to a variety of activities beyond the school day by 2010.[27] Our survey found that action needs to be taken to increase access for children with autism if this target is to be met.

44% of parents say their child has not been able to take part in activities before or after school, where these are provided. Within mainstream schools 54% of children were able to take part, compared to only 22% in autism-specific bases, indicating the need for a whole-school approach to developing after school facilities. However, participation rates were highest in special schools, with 63% of children in an autism-specific special school taking part in after school clubs.

In fact breakfast and after school clubs came top of the list when we asked parents where they felt their child was not getting the support or adjustments he or she needed to access school life outside the classroom. This was consistent across special and mainstream schools.

Good practice

Making school make sense for children with autism

Our survey highlights the ongoing barriers faced by children with autism in school. However, it also uncovers good practice in schools that has transformed the experiences of the children concerned. These adjustments are often very simple but they all reflect an understanding of autism and a flexible approach. Action to support children with autism can have benefits for their peers and for the whole school community. The following section illustrates some of this good practice from the perspective of parents, teachers and children.

Adjusting to school life

"In Year 1 we have four children on the autistic spectrum who were finding it difficult to cope. To improve things we arranged for them to start the day separately. They come straight to my room, and we do the same things that they would do in class: hang up coats and bags, sit on the carpet, wait quietly, answer questions by putting up your hand and so on. We also do some reading work, and then they have a bit of time on the computer. We had a very tight routine at the beginning but that is lessening a little now as they are more able to cope. At the end of this session I take them back into class. Their class teacher makes sure the classroom is really quiet so the children can go straight to their seats and they don't have to cope with the chaos. The positive start sets everyone up for the day."

Secondary school SENCO

"When Alexander started school, his LSA stayed with him at lunchtimes. After the first term he was able to cope on his own and her time was then used during lessons. She still monitors him and if there is a problem (such as him not eating for several days) the LSA will go and sit with him during lunch."

Parent

"We make little transition books if children are moving to a new teacher or new class. We take a photo of the empty classroom, and then the pupil visits it when it's empty, so that they can ask questions and wander round quietly."

Primary school teacher

Visual supports

"We had one child with autism who had really challenging behaviour, and would hit out at others. We created a 'how am I feeling?' set of visual symbols for him so, if he is getting very anxious or annoyed and needs some quiet time, he can show the appropriate card. He also has sets of symbols for specific tasks, with a card for each stage of the task so he knows when he has finished each stage and puts that card in the box. We have screened off a little part of the classroom for him to use as a quiet space, and he uses a timer to know when his five minutes of 'time out' is up. He has full-time support but we really had to fight for it. Overall, it has taken a long time – from nursery through to Year 1 – but he is calm now and he sits in the class in his own space. All our classes have a visually-based timetable with symbols for the different activities. It helps everyone and does not make the children with autism feel different."

Secondary school SENCO

"Every class has some sort of visual component to the timetable for the whole class, but if the child needs more we will do an individual timetable and a task timetable."

Primary school teacher

"We are in introducing 'communicators' at the moment. These are brief profiles of each child with autism, which include: what I am really good at; what I enjoy (and could motivate me); what I find difficult; what I am likely to do when things get difficult/boring/can't cope; what will help me stop. The 'communicators' are small enough to fit in each child's blazer pocket."

Primary school teacher

Social stories™

Social stories™, written according to guidelines devised by Carol Gray, can help explain specific social situations to young people with autism. The goal of a social story is to share accurate social information in a patient and reassuring manner that is easily understood by children.[28]

"I was a little sceptical when I first heard about social stories, but we use them a lot now in all sorts of situations. For example, we had a little boy who had started pulling his shorts down in the playground. We needed to stop it quickly, so we discussed it with his parents and drew up a short social story. He couldn't read so we did a few lines about what to do in the playground and a picture of a little boy pulling his shorts down with a big red cross through the middle of it. We read the story to him before every playtime and within two weeks he had stopped."

Primary school teacher

"PE has been a big problem for a lot of the children on the spectrum. It creates lots of anxieties and the children are daunted by getting changed, the feel of the floor, the size of the hall and the way it echoes. We used social stories to help the children understand the situation. We let the children watch PE lessons for a couple of weeks and then allowed some of them to come in already in their trainers so they just had to change their tops. Most of the children are fine now. One member of staff has been trained in writing social stories and will support others, using picture symbols where necessary."

Secondary school SENCO

Time out

"This is my red card and my red card helps me when I am very stressed but sometimes it isn't enough. Sometimes I have to walk out of lessons. My red card says 'Urgent, please be aware that Ben sometimes has difficulty coping with social situations. If he puts this card on your table he is feeling very stressed and needs some extra monitoring during the lesson.'"

Ben, age 12, mainstream school

"We run regular withdrawal sessions for children with an ASD at our school. Some of them are on an individual basis and some are for groups. The sessions look at social situations and are very practical. They cover topics such as turn-taking – what to do and how, how to reach across the table to get something and how to get through the door if there are lots of other people all waiting or someone is coming the other way. The sessions also work well as a quiet time for the children. We use visual timetables for these sessions so they know exactly what we are going to do."

Primary school teacher

"My daughter can use 'time out cards' for 15 minutes of time in the library when she needs a break. She has three cards for use in the day."

Parent

"When I am anxious I have to stay seated…[I] bite my nails…If I get anxious I get in a tizz…They tell me not to worry…I write down my feelings…they help me to see what I have to do next…otherwise I get confused…I can go to another room. I can go to another room to talk. If I need to talk I like to talk to Wendy. She is not my teacher, I just like her. I don't know why I like her."

Anna, age 14, special school

"When she couldn't cope with her SATs at age 14 they took her out, helped her to calm down and arranged for her to finish the test later that day. They were so kind."

Parent

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[28] Gray, C. (2002). *My social stories book* London: Jessica Kingsley Publishers.

Good practice

Home-school communication

"There is a book for daily communication between home and school; this way those in charge of the children are aware of developments as they happen and many anxieties and sources of distress have already been lessened or avoided in this way."

Parent

"There are lots of photographs taken of him at school to help us try to talk to him about what he has been doing. I get daily feedback when I collect him."

Parent

"Working with parents can seem expensive and time consuming, but pays dividends. We meet with parents at the beginning of every term to set Individual Education Plans – the meeting lasts about an hour, usually. Then I write it up and agree the targets with everyone. This helps reduce parents' worries because they know they have a regular opportunity to talk with teachers, although they can talk at other times too."

Primary school teacher

"We run a smiley face good work chart which the parents keep at home. Every member of staff writes in the home-school book every day, to say – good day, not so good, did this really well, etc. Each child has six opportunities to win a smiley face each day. We concentrate on the positive, congratulating them lots and lots of times to reinforce the good."

Secondary school SENCO

Breaks and lunchtime

"The school set up a club in a special quiet zone at lunchtime, where other children can come too."

Parent

"There is a lunch menu on the main door. Sam chooses his lunch first thing in the morning. Unfortunately, if he was last in and what he had chosen was gone, he would not eat. After discussions with school he now goes in first every day."

Parent

"The school has a separate building for children to use at lunchtime if they cannot cope with the main school."

Parent

"My son has been supported to move around the school by sending him on errands with incremental increases in the distance and reasons for these errands. He has been supported at breaks and lunchtimes from highly supervised play within the unit playground to more loosely supervised play within the mainstream playground."

Parent

Social skills

"We run regular groups where the aim is to help the children learn and cope with social situations. The children meet once a week and each session starts with an information-sharing session which helps them to learn to listen to others. We do different tasks, like making a sandwich or chocolate fruit fondue. The group has to explain exactly what to do. If someone says put the butter on the bread, they are likely just to pick up the whole piece of butter and put it on the bread. This helps them really think about what is being said and what they are saying – how to follow instructions and how to listen."

Secondary school teacher

Support from other children

"There are peer mediators and playground leaders wearing special bibs and working in the playgrounds at lunchtime. Any child who is lonely needs help or wants to join in a game is supported by these volunteers."

Parent

"A group of children are encouraged to include my child in activities if he is wants to do so."

Parent

Circles of Friends

Circles of Friends is an approach used in schools to support children with autism. One SENCO describes how it works below:

"First you identify a child and ask them whether a group of people might be useful to help them get into trouble less and not annoy people. If they think it would, you inform their parents. The person co-ordinating the circle arranges a session with the child's classmates and their class teacher, but not the child. They talk with the class about friendship and people who help us and tell the class that someone in their class needs friendship (the class usually recognises who this is). Using smiley and not-so-happy faces they encourage the class to talk about all the good and not-so-good things they can think of for that child. They then ask the children to volunteer to be part of the circle – there is usually a very good response. Two volunteers are suggested by the class teacher, the SENCO and the class. The group of six then immediately meet the child and say why they volunteered and what they can do to help. Weekly meetings last around 15 minutes and the children review the week using smiley and not-so-happy faces."

Secondary school SENCO

"We now run several Circles of Friends. They have been a huge success and have had a phenomenal impact on the children. We set one up with one child who was driving everyone in his class nuts. They all had about six or seven negative things to say about him and his behaviour.

But once we had gone through the process and talked about friendship and not having friends they all volunteered. Within about two to three weeks there was a huge change. The class supported the lad and picked up on what they were not doing. For example, one boy used to be sick every Monday and Tuesday because of PE. His classmates identified the problem and worked out that he really hated rugby and did not understand it. He couldn't understand the rules or the team stuff, and he hated the noise. So the class went to the PE teacher and suggested that he be a substitute and sit on the bench. That way he got to participate, but he felt happier because he hadn't made them lose. They felt great because they in fact won. Everyone was happy."

Secondary school teacher

"We have used Circle of Friends for seven children to address a whole range of issues, including lack of friends, isolation, annoying classmates, getting into trouble, bullying, and behaviour in general. One child with ASD was obsessed with his book. It was almost impossible to get him away from it so his teacher had to constantly tell him to put it away. Now the kids remind him and usually that works. Also, they give him thumbs up when things go well, look out for him in the playground, talk to him, and take him to a teacher if there is a problem."

Primary school SENCO

Planning autism-friendly schools

The approach and the planning that underpins an autism-friendly school is the glue that holds it all together. Good practice clearly exists, but all schools now need to take a strategic approach to including children with autism so that current good practice can become standard practice in all schools. Wherever they live, all families should be able to expect a baseline of provision so that their child can access an appropriate education. However, not only does a postcode lottery persist, but practice varies from school to school and within schools.

In 2002 the Department for Education and Skills (DfES) and the Department for Health (DH) produced excellent guidance for schools and local authorities on best practice in supporting the needs of children with autism in school.[29] The guidance sets out to provide an impetus for raising standards of support, and its suggestions are based on examples of good practice drawn from parent support organisations, practitioners, government agencies, LEAs and researchers. Unfortunately, implementation of this guidance has been patchy and in too many areas professionals and parents are not even aware of its existence.

The *Special Educational Needs and Disability Act (2001)* requires schools and local authorities to plan to increase access to education for disabled pupils, and this planning duty applies to access to both the premises and the curriculum. In carrying out this duty schools need to consider their current pupils and pupils who might attend the school in the future. Although schools were required to produce their first accessibility plans by April 2003, 18 months after this deadline, OFSTED (the Office for Standards in Education) found that over half of schools had no disability accessibility plans in place. Where schools did have plans in place, OFSTED reported that in too many cases they were merely paper exercises.[30] This must be addressed with urgency. Given the prevalence rate of autism of 1 in 110, all schools should be planning the steps they need to take to break down barriers for children with autism.

The *Disability Discrimination Act (2005)* goes further and places a welcome duty on public bodies to promote equality of opportunity for disabled people. This duty aims to ensure that local authorities and schools build disability equality into all aspects of their work. Schools and local authorities also have a specific duty which requires them to produce a disability equality scheme to help them meet the general duty. This means that schools need to take the views of disabled children, including those with autism, into account when they are setting school priorities. Schools and local authorities will also need to report on the measures they are taking to ensure that disabled children are given the same opportunities as everyone else.[31] This new duty provides an opportunity for schools and local authorities to review outcomes for children with autism and take their interests into account from the outset. This opportunity must not be lost.

[29] DfES (2002). *Autistic spectrum disorders: good practice guidance*. DfES: London.

[30] Ofsted (2004). *Towards inclusive schools*. Ofsted: London.

[31] The general duty comes into force on 5 December 2006. The specific duty applies to schools and local authorities and they must publish their Disability Equality Schemes by 4 December 2006. However, primary schools in England have until 3 December 2007, and all schools in Wales have until 1 April 2007, to publish their Disability Equality Scheme.

Focus on transition

The move from school to adulthood is widely acknowledged to be a particularly difficult time for young people with autism. For young people with a statement, transition planning should start when the child reaches year 9 (age 14 years) and should involve input from a range of agencies. Young people without a statement should also be offered guidance and support with transition.[32]

Whilst it is recognised that support through transition is crucial to maximise the life chances of young people with autism, in reality many do not receive appropriate support. Our survey reveals that only 53% of young people were issued with transition plans during the course of their education, falling to just 34% of students in mainstream schools. The input of adult social services is crucial to the viability of the transition plan, and yet adult social services were only involved in planning in 17% of cases.

Young people with autism have the same aspirations for the future as their peers, and with varying levels of support they can live full and independent lives. The aspirations of children in this report contrast sharply with the reality experienced by many adults with autism. Only 6% of people with autism, and 12% of people with Asperger syndrome, are in full-time paid employment.[33] This failure in the system to support people with autism has repercussions for the individual, their families and for public expenditure. With appropriate support during and after school and timely multi-agency planning, young people with autism can realise their ambitions. Making school make sense for young people with autism, will help equip them to make sense of their future.

"I was put off by my careers adviser, she was horribly patronising. I'd be telling her my ideas about what I want to do when I grow up…working at home doing art…and she'd say, 'Well it's very hard for someone with your problem…' Well if you'd seen my work you'd see that my autism is what makes me good at art in the first place. She'd never ever seen my work but she kind of put me off having a career, so I don't know what to do… If I'd said I don't want a career she'd have still raised her eyebrows, so you couldn't win with her."

Chloe, age 16, mainstream sixth form

"I want to go to Oxford University…Maybe in astrophysics, something to do with space science. I also want a degree obviously. I feel that I have a very full future in front of me and I want to become a space scientist, as I just said."

Ben, age 12, mainstream school

"I want to be an 'oddqulianaire'…An oddqulianaire is a posh name for a businessman (entrepreneur)…and I want to be a part-time campaigner… I want to do the same thing that you are campaigning about now – rules for people who can't get a proper education."

Sam, age 12, out of school

"Society expects the autistic person to learn to 'fit in' and, whatever their problems are, to get over them especially if no physical signs of the autistic spectrum are present. If you look normal, you can't be autistic seems to be the message."

Parent

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[32] DfES (2001). *Special Educational Needs: Code of Practice.*

[33] Barnard et al (2001). *Ignored or ineligible: the reality for adults with autism spectrum disorders.* NAS: London.

Recommendations

The Government and the Welsh Assembly Government should:

- **Review implementation of *Autistic spectrum disorders: good practice guidance*, and promote its use in England.**
- Work with local authorities to raise awareness of disability rights in education, including the role of the SEN and Disability Tribunal.
- Adopt the DfES *Good practice guidance* or develop an equivalent for use by local authorities in Wales.

Local authorities should:

- **Ensure schools' disability accessibility plans refer to the specific needs of children with autism and are implemented effectively.**
- **Embrace the opportunity presented by the new Disability Equality Duty to ensure that schools in their area promote and provide a positive environment for children with autism now and in the future.**
- Review implementation and promote the use of the *Autistic spectrum disorders: Good practice guidance* (in England).

5 The changing picture across Great Britain

- **Parents' experiences have not changed significantly over the last five years.**
- **The experiences of black and minority ethnic families are consistently worse than those of white British families.**
- **Parents in Wales report a more negative experience than parents in England, particularly with regard to availability of speech and language therapy and communication with the LEA.**
- **Parents in Scotland report a more positive experience with regard to speech and language therapy; but participation in after-school activities is limited.**

In 2000 The National Autistic Society conducted a membership survey on autism and inclusion.[34] Since then, there have been significant policy developments relating to autism and special education needs. In 2001 the Government launched *Removing barriers to achievement*[35] their ten-year strategy for special educational needs in England, and in 2002 *Autistic spectrum disorders: Good practice guidance*[36] was published. The devolved administrations in Wales and Scotland have also taken their own paths on education policy.

Five years on we compare our report in 2000 with our current survey to see whether the views and experiences of families have changed. We also study the differences between results from Scotland and Wales, and between children from different ethnic backgrounds.

A picture over time

When we compare the answers given in this report with those given in 2000, we find that little has changed.[37]

Parents continue to believe that arguing their case makes a difference to the provision received, with 48% strongly agreeing with this statement compared to 42% in 2000.There has been a small drop in the proportion of children with statements between 2000 and this survey. More children in England and Wales have Individual Education Plans (IEPs) now: 88% compared to 81% in 2000, and fewer people do not know whether or not their child has an IEP.

There is a worrying trend which could suggest that more children are missing out on education for longer periods as a result of exclusion from school. While a similar proportion of children were excluded from school in 2000 and in this survey, there was a striking difference in terms of time out of school. Of 165 who were excluded and answered the question, 16 were out of school for more than a year, compared to just one of 106 in 2000.

Progress since 2000 is most marked in the field of diagnosis. 42% of children in the current report were diagnosed at age three or under. A large majority (69%) were diagnosed between the ages of two and five, compared to just 53% in our survey in 2000. Another indicator that children in the current survey are being diagnosed earlier is that 24% of 16 to 19-year-olds were diagnosed after age 12, compared to just 4% of 11 to 16-year-olds.

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[34] Barnard et al (2000). *Inclusion and autism: is it working?* NAS: London.

[35] DfES (2004). *Removing barriers to achievement.*

[36] DfES and DH (2002). *Autistic spectrum disorders: good practice guidance.*

[37] Barnard et al (2000). *Inclusion and autism: is it working?* NAS: London.

Even accounting for the fact that the older group will include some additional people who have had late diagnoses, this is a sizeable difference.

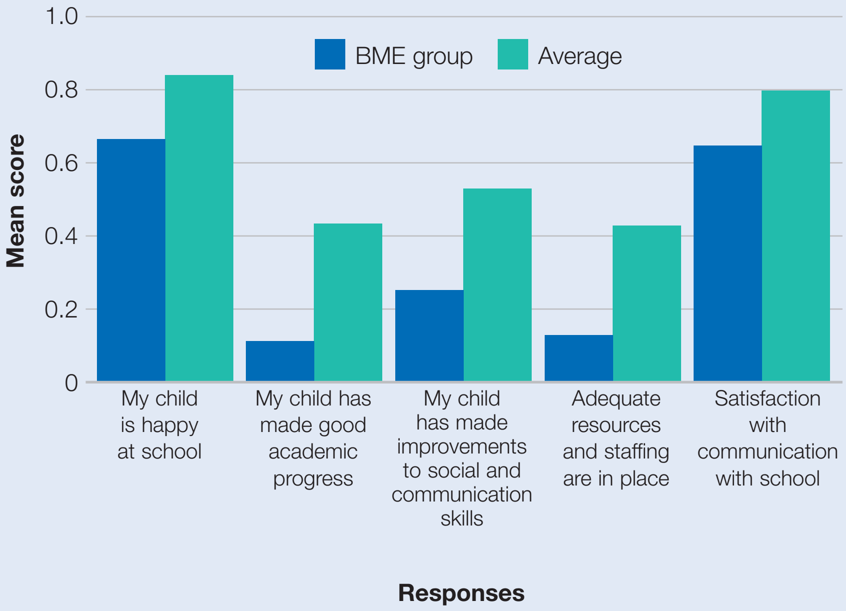
As the sampling frame for both surveys was the NAS membership, it should be noted that both samples are less likely to include children whose autism has yet to be recognised or diagnosed. Therefore, in both surveys the level of diagnosis may reflect a more positive picture than reality. Nonetheless, progress towards earlier diagnosis of autism opens up opportunities for early intervention to maximize outcomes for children. It is therefore vital that government policy on early intervention for disabled children addresses the needs of children with autism.

Ethnicity

The outcomes for children from black and minority ethnic families are consistently worse than the average. Elsewhere in this report we note that black and minority ethnic children are more likely to be excluded from school, and their parents are less likely to feel as if they had a choice of school. In addition, white British respondents were 15% more likely to rate themselves as satisfied overall.

Further disparity of provision is illustrated in the graph below. The graph shows how strongly parents agree with statements where 1.0 indicates that they agree. The black and minority ethnic group rated markedly lower on the indicators of the child's academic and social progress, and on whether adequate staffing and resources were in place. This is despite the fact that most children in this survey from black and minority ethnic backgrounds are of mixed race, and therefore may be less likely to face strong cultural and language barriers to satisfactory provision.

Disparity between the experiences of white British children and children from black or minority ethnic backgrounds



The picture across Great Britain

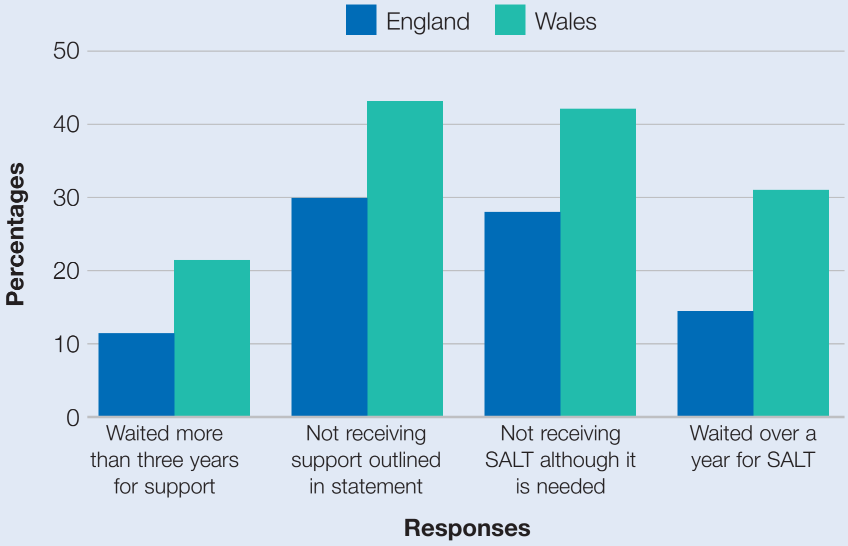
The survey findings display some interesting contrasts between the experiences of parents in England, Scotland and Wales.[38]

Parents from Wales present on the whole a gloomier situation. Communication with their local authority is deemed to be much worse by parents in Wales, with 64% rating this poor or very poor, compared to 45% in England. A greater proportion, 75% compared to 67%, agrees that arguing their case made a difference to the provision their child received.

A higher proportion of children in Wales go to a school outside their local authority area, with 27% compared to an average of 20% in England. In addition, 13% go to school outside Wales. In line with these trends, a greater proportion of parents in Wales said their choice of school was limited by a lack of adequate placements. The rural and remote nature of large parts of Wales contributes to this, and reinforces the need for local provision in all areas.

Our survey also suggests that the nationwide lack of professionals is even more acute in Wales. As the diagram below shows, parents in Wales wait longer for their child to start receiving support; and more children did not receive the support outlined in their statement. Speech and language therapy (SALT) appears to be especially scarce in Wales: of those who have SALT specified in their statement, fewer children in Wales actually receive it and they wait longer for therapy.

Disparity of provision between England and Wales



The results from Scotland reveal some aspects of education for children with autism which are better than the general picture, as well as some less positive areas; some structural differences are also revealed, as would be expected.[39] A greater proportion of Scottish parents indicate that their child is taught in a mainstream school, or in a resource base in mainstream – 74% compared to 58% in England and Wales. This is largely due to the legal requirement that, except in specific circumstances, education in Scotland should be provided in mainstream schools.[40]

[38] This report is based on data from England and Wales apart from specific results from Scotland in this chapter. Results from Scotland and Northern Ireland were analysed separately. The number of responses received from Northern Ireland was too small to enable a meaningful comparison between Northern Ireland and the rest of the UK to be made.

[39] In June 2004, the Scottish Parliament passed legislation that transformed the teaching of special educational needs in Scotland, introducing a much broader concept of 'additional support needs' and replacing the Record of Needs (RoN) with a Co-ordinated Support Plan. Since this only came into force in November 2005, the changes will not impact on this survey; rather, the report offers a reflection of families' experiences under the previous system.

[40] *Mainstreaming pupils with special educational needs: an evaluation* (2005). Edinburgh: Information and Analytical Services Division, Scottish Executive Education Department.

Despite this, only 49% of Scottish parents feel that their child can take part in activities or clubs before or after school, compared with 52% in England and Wales. Similarly, 42% of parents in Scotland say that their child's school has made no adjustments to allow their children to participate in breakfast clubs or after-school activities, compared with 37% in England and Wales.

In terms of autism awareness, parents in Scotland are much more likely to be satisfied with primary teachers' understanding of autism than parents in England and Wales. However they were also significantly less likely to be satisfied with the level of understanding of secondary school subject teachers, compared to parents in England and Wales.

Provision for speech and language therapy (SALT) seems to be better in Scotland than in Great Britain as a whole. Overall, 72% of parents report that their child receives SALT, compared to 55% in England and Wales. Of those who have provision quantified in their Record of Need, 66% of children receive this, as opposed to 58% of the children in England and Wales who have it quantified in their statement. Nevertheless, SALT and Occupational Therapy are still the form of support which is most often not provided, although outlined in the Record of Need.

A greater proportion of parents in Scotland, 73% compared to 67% in England and Wales, agree or strongly agree that arguing their case resulted in better service provision.

Although it is difficult to assess the impact of devolution, these results at least illustrate the variation in different aspects of provision across Great Britain. The gaps in provision that have been highlighted must be addressed by the Welsh Assembly Government, Scottish Executive and UK Government. The experiences of black and minority ethnic children who generally fared less well than their white British counterparts, require further investigation and must be addressed in all three nations of Great Britain.

6 Conclusion

This report demonstrates that the right approach, training and support can *make school make sense* for children with autism. Currently, families encounter very different levels of support and understanding in the education system. This disparity is particularly evident when comparing the experiences of those who are dissatisfied overall with their child's education with those who are satisfied.

Parents who are dissatisfied with their child's education have a poorer experience across all ten indicators listed in the table below, from access to diagnosis through to a lack of support as they leave school. This demonstrates that parents who are dissatisfied overall with their child's education have strong grounds for their dissatisfaction. Although parents who are satisfied report a much more positive picture, a high proportion of their children have still experienced bullying and exclusion.

Local and central government need to take action to ensure that all children have access to an appropriate education.

Disparity of provision

Factor	Dissatisfied group	Overall	Satisfied group
Age of diagnosis	6.6 years	5 years	4.5 years
No choice in type of school attended	80%	55%	47%
Dissatisfied with level of understanding of ASD of school overall	68%	23%	9%
Do not have an IEP	13%	7%	5%
Do not receive SALT although it is needed	43%	29%	23%
Been to SENDIST	25%	17%	15%
Feel staffing and resources are adequate	4%	57%	77%
Have been bullied	65%	41%	35%
Have been excluded	27%	20%	19%
Supported to express views during transition planning	16%	40%	47%

Many families who are now satisfied with their child's education feel that they had to struggle to get to this point. Overall 67% of families strongly agree or agree that arguing their case made a significant difference to the services that were provided.

It is evident that too many children with autism are reliant on the emotional, educational and financial resources of their parents when it comes to accessing an appropriate education. Parents report an ongoing struggle for support, which takes its toll on the whole family.

"Looking after a child with autism is stressful enough and the added strain of constantly fighting for an effective education for him impacted on all our lives. It was at times all-consuming."

"You are constantly worrying about your child with autism with regard to their education. You have less time and energy for your other children and partner because you are continually fighting for appropriate provision. This is depressing, and emotionally it is like being on a roller coaster. We are presently worrying about secondary education and are looking around different types of provision, but have seen nothing suitable."

If you could make just one change, what would it be?

This report has highlighted the barriers that families face as they struggle to secure an appropriate education for their child. We asked parents, wherever they were on this journey, to look to the future and identify the one single change that would make the biggest difference to their son or daughter.

→ Improved training and understanding of autism was the biggest single response from families.

"**If I could make one change…** I would ensure compulsory, thorough training about autism and how it affects learning is given to all school staff. Plus, ongoing support for all schools from well-resourced autism advisory teams at local authority level."

"**If I could make one change…** every person who comes into contact with my daughter would have some form of training in autism."

The right training for every teacher: In mainstream schools 41% of parents say more understanding or supportive staff would make the biggest difference to their child. This is not surprising given that this report found that only 30% of parents of children in mainstream education are satisfied with the level of understanding of autism across the school. Furthermore, in mainstream schools only 27% of parents say that all their child's teachers can adjust their approach and teaching materials – and therefore meet their legal duties under the *SEN and Disability Act (2001)*. 23% of parents are dissatisfied with the school SENCOs' level of understanding of autism, a worrying statistic given that a SENCO is responsible for coordinating provision for children with autism in schools.

→ A large proportion of parents voice the need for improved support in school, highlighting a range of gaps in provision.

"**If I could make one change…** schools would be obliged to put relevant support in place for all pupils with autism. This would involve a proper assessment of their abilities in all areas and may involve thinking 'outside the box' in terms of deciding how best to support them."

The right support for every child: This report found that it takes over a year for 45% of children to receive any support, from the time concerns were first raised. The biggest gap in provision highlighted by parents is in social skills programmes. The consequences of inadequate support are clearly evident.

We found that one in five children with autism has been excluded from school, and 67% of these have been excluded more than once. Furthermore, over 40% of children with autism have been bullied at school. There are more appeals to the SEN and Disability Tribunal in England about autism than any other type of SEN and 79% of parents who appealed to the Tribunal in this survey won their case.

→ Many parents say that their child needs to go to a different type of school, and highlighted the need for a range of provision to be made available in their local area.

"**If I could make one change…**I would attach an autism base to the school, so that there was more specialist knowledge available. To get help from the visiting teacher for autism takes weeks and then she's in the school for no more than one hour."

"**If we could make one change…**we would like our son to mix with mainstream children as well as special needs children."

The right school for every child: This report found that parents want a range of provision including mainstream schools, special schools, resource bases in mainstream schools and dual placements. However, 66% of parents say a lack of appropriate placements for children with autism limited their choice of school and 45% say they did not receive adequate support or information to help them make the decision. Therefore, over 50% of children in this survey are not in the kind of school their parents believe would best support them The consequences include disruption to education as school placements fail, with one in three children having to change school in the last five years in addition to the usual changes that their peers might make.

→ A significant proportion of parents highlight the need for the child's school to have a stronger inclusive ethos and a strategic approach.

"**If I could make one change…**I would put her in a quieter classroom – not sitting out in the corridor when the noise in the room is unbearable for her. The teacher looked utterly baffled by my comment 'Is this inclusion?'!!"

"**If I could make one change…**it would be more direct support at all free times at school, i.e. lunch and play time breaks."

The right approach in every school: Adjustments to enable children with autism to play a full role in school life can be straightforward and both schools and local authorities should be planning to breakdown barriers to meaningful inclusion. However, we found that 45% of parents of children in mainstream schools think that the school environment is not adequately accessible. 36% of parents of children in mainstream schools feel that their child does not get the support of adjustments they need at break times. Overall, 44% of parents say their child is not able to take part in activities before or after school. Looking to the future, only 53% of young people aged 14 to 19 years have transition plans, falling to just 34% of students in mainstream schools.

"Having an autistic child in the family is hard enough, but when you have to battle with the education system it's exhausting. When Emma is unhappy at school she is a nightmare to live with, withdrawn, clingy and tantrums – she can't go anywhere. Earlier this year I was off work for eight weeks suffering from depression because of trouble at her school. This affected the whole family and it's not fair on her sisters. Sometimes I feel like I am banging my head against a brick wall but I won't give up until there is more training and understanding and hopefully a better future for Emma."

Parent

The need for change

The education system is failing too many children with autism. Local and central government must take action now to increase access to education for children with autism by implementing the recommendations outlined in this report.

Access to an appropriate education can maximise the life chances of individuals with autism. Where children are not able to access the support they need, there are negative consequences for them, their families, their school and potential long-term financial implications for their local authority. The parents who responded to our survey told us about the negative impact on their families of the struggle to secure a meaningful education for their child with autism. They also shared their feelings of guilt and inadequacy where they feel they have failed to secure an education for their child that of course should be theirs by right.

> "I am clinically depressed and taking medication, and it has put a lot of stress on my relationship. I'm exhausted due to endless battle to get any provision. We feel isolated."

> "I have had to lose my job, so financially we cannot do the things we did. Looking after a child with autism can be hard in itself but then having to battle with the school and then the LEA can completely destroy a family. Over the past year we seem to have lost our adult friends who have found it difficult as we are always fighting for Sarah."

> "The whole family has become depressed, angry and resentful at the treatment of our daughter by the education system. I had to give up work because of constant school/college problems – which meant a decrease in income and my independence. With all the stress, I had a heart attack and my husband had a nervous breakdown. We can never leave her alone (for a meal, holiday etc) because she now self-harms and we're worried she will kill herself."

> "Perpetual fighting and endless meetings with ignorant schools and LEA officials, repeating the same format over and over, grinds you down. Terrible feelings of despair and inadequacy as you cannot access the help your child needs."

This report has demonstrated the extent of the struggle that many families face as they try to secure an appropriate education for their child. This needs to change. All children with autism have the potential to learn, achieve and make a positive contribution to school life, and this report highlights examples of good practice that enables them to do so. Local and central government now need to take action to ensure that good practice becomes standard practice for all children on the autistic spectrum. Professionals working with children with autism need to be trained and supported in their roles; a range of provision needs to be developed in every local area; and schools and local authorities need to plan strategically to break down barriers to inclusion. It is time for change. It is time to work together to make school make sense for children with autism.

Autism is complex.

Our demands are simple.

make school make sense

Appendix 1 Methodology

The survey

The survey was divided into sections along the same lines as this report: built around sections on choice, understanding and support, with questions on bullying, exclusions, transition and home education as well as background information and impact on the family. Respondents were asked about levels of satisfaction overall and in specific areas, and what one single change they would make to their child's learning or experience.

Surveys were sent to all members of The National Autistic Society (NAS) in October 2005. From 13,400 members at the time, 1,367 surveys were returned. Taking into account the 3,300 couple memberships, this represents a response rate of 13.5% of NAS members. Since the sampling frame was NAS members, not all of whom are parents of school-age children, the response rate from families of school-age children would in fact be higher than 13.5%.

There were 50 responses from Wales, 85 from Scotland, 11 from Northern Ireland and 1,221 from England. 70 respondents described their ethnicity as black or minority ethnic. The response rate from each nation corresponds approximately with the proportions of our membership in each of those nations.

It is important to bear in mind that NAS members are necessarily people who have found access to support and information mechanisms. 98% of respondents were able to specify the age their child was diagnosed; therefore this survey does not include those families still battling for answers about why their child is not developing typically.

The figures quoted in this report are based on the number of respondents who answered each question in the survey.

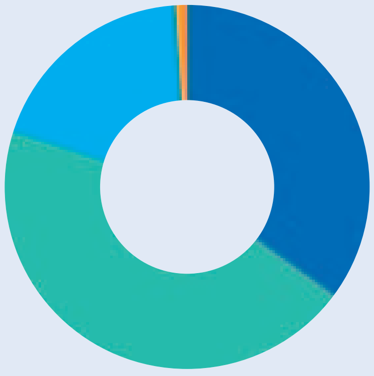
Profile of respondents

The variation in diagnosis broadly reflects the national picture, with just over half described as 'able'. The percentage of children with Asperger syndrome (35%) is close to the NAS estimate of prevalence in the general population – 40% of all people with an autistic spectrum disorder. The number diagnosed with autism is more difficult to compare, as it appears that many diagnoses have used a broad term of 'autism' or 'an autistic spectrum disorder'. Several respondents wrote caveats to the diagnosis and level of ability, referring to differing abilities in different aspects of life.

84% of respondents answered questions about a boy, compared to 14% about a girl, representing a 6:1 ratio. However, this ratio was consistent across the spectrum, which does not correlate with the difference in diagnosis by gender at a national level.[41] There was a balance of respondents across age groups, with most children aged between 5-16 years.

For a blank copy of the survey, please contact The National Autistic Society information centre on 0845 070 4004 (press 2) or email info@nas.org.uk

Diagnosis



35%	Asperger syndrome
45%	Autism
19%	High-functioning autism
1%	Other

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[41] The estimated ratio of boys to girls ranges from 2:1 to 15:1, but it is thought that while females are less likely to develop autism, when they do they are more severely impaired. For further information see the NAS website at: www.autism.org.uk/nas/jsp/polopoly.jsp?d=255&a=337

Interviews

To capture the opinions of children with autism, 25 boys and girls across the age range were interviewed about their experiences at school. The children and young people were selected to reflect a broad range of experiences, the interviewees were in different educational settings, with different needs and positions on the autistic spectrum; they came from different backgrounds and all parts of Great Britain.

Interviews were predominantly face-to-face, with some conducted by telephone. Children were asked about some or all of the following:

- which school they attend; the class they are in
- friends
- lessons and teachers they like/don’t like and why
- other activities, places, experiences they like and don’t like at school
- anything else that is good or not so good about school and if possible why
- how they feel at school – at different times
- whether they ever get/have got into trouble and if so for what, why, what happened and how did they feel
- have they ever been sent home/not been allowed to go to school; if so what happened and why etc and how did they feel
- hopes for the future, ambitions, aspirations, successes and interests.

In addition to providing a topic outline to the children before interviews, communication supports and visual prompts were used where children had limited or no verbal communication. Four teachers were also interviewed from a range of settings.

Appendix 2 Terminology

Type of school

The survey asked respondents which of the following best described the type of school their child goes to:

- mainstream school
- unit attached to mainstream (autism-specific)
- unit attached to mainstream (not autism-specific)
- special school (autism-specific)
- special school (not autism-specific)
- dual placement at a special and mainstream school
- other (specified).

There was a separate question asking whether the child was home educated.

It is recognised that the boundaries between these types of placement are not always clear: for example, some pan-disability special schools have specialist autism resource bases, and some children attending mainstream schools receive specialist or individual support, although this may not be in the form of a resource base. Nevertheless, the vast majority of respondents were able to select one of these categories. It was important to make the categories distinct enough to enable comparison of results between them.

It is particularly important to remember the distinction between autism-specific and non autism-specific or pan-disability placements in this report. Unless it is specified that a school or resource base is autism-specific, then ‘special school’ or ‘resource base’ refers to schools and bases that do not have an autism specialism.

Similarly, where ‘mainstream’ is mentioned, this always refers to responses about mainstream schools and does not include those in resource bases within mainstream school. Any reference to resource bases within mainstream is made explicit in the text.

> “Education is one of the most important issues facing children with autism and their parents. Please join the NAS *make school make sense* campaign today and help every child experience the education which is their right.”
>
> **Jane Asher, President**
> **The National Autistic Society**

To join the *make school make sense* campaign go to www.autism.org.uk/campaign, email campaign@nas.org.uk or call 020 7923 5799 (answer phone)

> “The National Autistic Society *make school make sense* campaign calls for the right school for every child, the right training for every teacher and the right approach in every school. Help the NAS to achieve its goals by joining the campaign today.”
>
> **Stephen Fry, Actor**

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