

# We've got GREAT EXPECTATIONS



The chance  
of a lifetime  
for children  
with autism

By Beth Reid



The National  
Autistic Society

Accept difference. Not indifference.

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We include a number of examples of good practice in this report, from NAS and non-NAS services. Practice is as reported by the individual services.

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## Foreword

In 2006 The National Autistic Society (NAS) carried out the biggest ever survey of autism and education in the UK, as part of its *make school make sense* campaign – a campaign with which I was heavily involved.

Since then a lot has happened: special educational needs (SEN) and disability have become bigger issues for Government; there have been many reviews and initiatives attempting to improve provision and support for children with SEN, including those with autism; it's now mandatory for SENCOs in schools to have training in SEN – one of the key recommendations of the *make school make sense* campaign; there are new SEN modules for trainee teachers, which cover autism, as well as the Autism Inclusion Development Programme for professionals working in schools and nurseries; the Autism Education Trust has been established to help improve education support for children with autism; lastly, the Autism Act in 2009 creates legal duties around the needs of people with autism as they reach adulthood.

With the promise of further changes to the system through the Green Paper on SEN and disability, we wanted to find out what the experiences of those affected are now, five years on from our campaign, and how they feel about some of the proposed changes. We have been round the country talking to the real experts: families of children with autism, young people with the condition themselves and professionals, including specialists from across the NAS.

Sadly, we found that even now there are far too many children who are not getting the support they need, and far too many parents who face a daily battle to get them that support. There is much still to do.

We have *Great Expectations* that the necessary changes can and will be made. The Government recognises that action is needed, and says that it wants to reform a system which is letting children and young people down. Our report sets out the practical, often simple, steps that the Government can take to create a system that works for everyone.

The most important voices to listen to in shaping those changes are those of the people who rely on them. And their message is clear: children expect an education that sets them up for life; parents expect a system that works with, not against, them. Our report will demonstrate how we can make these aspirations a reality. We expect the Government to listen, and to act.

These reforms will shape the future of a generation of children with autism. We must take this chance to strengthen the voices of parents, improve outcomes for children, and transform families' lives.

Let's work together. Let's get it right.

A handwritten signature in purple ink that reads "Jane". The signature is written in a cursive, flowing style.

**Jane Asher**  
**President, The National Autistic Society**



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## Executive summary

Education is a fundamental part of every child's life. But far too many children with autism<sup>1</sup> are not getting the education they need and deserve.

### Our research found that:

- just half of parents in our survey (52%) feel their child is making good educational progress
- 30% of parents feel that their child's educational placement is not adequate
- a quarter of children are not happy at school, and one in five does not feel safe
- 43% of young people feel teachers don't know enough about autism.

### Too many parents have to fight the system to make it work:

- 7 out of 10 parents (68%) say it has not been easy to get the educational support their child needs
- 48% of parents say they have waited over a year to get the right support for their child; over a quarter (27%) have waited more than two years
- 18% of parents have had to go to tribunal to get the right support for their children. On average, they go to tribunal three to four times each.

Something needs to change. The Government's special educational needs (SEN) and disability Green Paper<sup>2</sup> will shape the future of a generation of children with autism.

## Key recommendations

An education that sets children up for life and a system that works with, not against, parents.

### Children with autism expect:

- to get the support they need quickly and easily, regardless of whether they have a statement or an EHCP
- teachers who understand how to support them and who have easy access to autism specialists for help.

### Parents of children with autism expect:

- to have robust, simple ways to challenge the system if their child doesn't get the support they need
- local authorities to have a thorough understanding of the needs of children with autism in their area, and to plan provision accordingly
- to be equal partners in the system and genuinely involved in decisions about their child's education and the planning of local services
- local information that empowers them to make the right decisions for their child.

### We expect the Government to listen and to act.

Let's work together.  
Let's get it right.

<sup>1</sup> In this report we use the term 'autism' to refer to all conditions on the autism spectrum, including Asperger syndrome and high-functioning autism

<sup>2</sup> Department for Education (2011). *Support and aspiration: a new approach to special educational needs and disability: a consultation*

# Autism: a brief overview

Autism is a developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means it affects different people in different ways. But everyone with autism shares three main areas of difficulty.

- > **Social interaction:** children with autism can have difficulties recognising and understanding their own and other people's feelings. They may sometimes find it hard to manage stress and frustration. At school, they may not always understand the 'social rules' and how to interact appropriately with their peers. This can make it hard to form friendships and many experience bullying as a result of these difficulties.
- > **Social communication:** children with autism may have difficulties understanding both verbal and non-verbal language, such as people's gestures, facial expressions and tone of voice. They may need support with understanding and to express themselves.
- > **Social imagination:** this affects children's ability to imagine situations outside of their normal daily routine, to plan ahead and to cope with change. Many children with autism have special interests or a repetitive range of activities which as well as being enjoyable, can be a way to deal with uncertainty, change or stress. They generally like set routines, familiar people and environments and may find unexpected changes to the school timetable, for example, hard to cope with. Unstructured time during the school day – such as break times, lunchtime and moving between lessons – can be particularly difficult. They may also struggle to understand and predict other people's intentions.

Children with autism may also have sensory sensitivity, and be over- or under-sensitive to stimuli such as sound, touch, taste, smell, light or colour. This can make busy, brightly lit or noisy environments such as classrooms, playgrounds and dinner halls difficult to cope with.

"Sometimes it's too noisy, especially in the hall at lunchtime. I wish I could have a quiet place to go at lunchtime. I find it hard to concentrate and the teacher does not understand that I can't always look and listen at the same time. My brain is different but not bad. Some people think I'm stupid. I wish there was someone else like me that I knew."

### Child with autism<sup>3</sup>

Some children with autism have a learning disability or specific learning difficulties, such as dyslexia, but can make good progress with the right support. Many are academically able, but will still need some support to cope with school life and realise their potential.

One in 100 people in England has autism.<sup>4</sup> It is a lifelong condition: children with autism grow up to be adults with autism, and a good education can equip them with the skills and confidence they need in life. It is imperative that – no matter where a child lives in England or what kind of school they go to – our education system can identify, understand and respond to their needs.

<sup>3</sup> All the quotes in this report are from research we carried out with parents, and children and young people with autism. Quotes attributed to a 'Child with autism' are from children under the age of 11; those attributed to a 'Young person with autism' are from those over the age of 11.

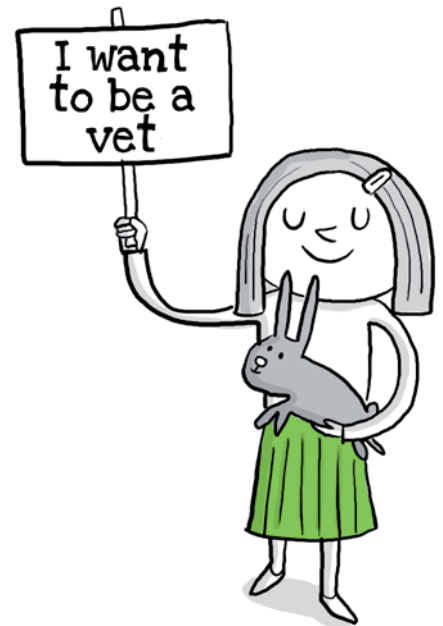
<sup>4</sup> Baird, G. et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, **368**, pp.210-215.



## Supporting children, parents and teachers

With the right support, every child has the opportunity to succeed. The NAS runs six autism-specialist schools and our outreach and student support services help people get the most out of school or college. Our schools are acknowledged as excellent provision by inspectors, and staff from our schools provide training and support to other education professionals.

Our Education Rights Service provides information, advice and support to around 2,000 callers every year, including support for families taking cases to tribunal. We also run a range of out of school clubs and social groups for children and young people with autism.





## Chapter 1: The fight

Education is a fundamental part of every child's life. It gives children the opportunity to learn about the world they live in, and how they can play a part in that world. It should be a time when children feel safe and happy, confident about building relationships and friendships, and able to make the most of their abilities and talents. It should help them to develop independence and prepare them for the future.

Children with autism expect an education that sets them up for life. But our research shows that the reality is very different.





## The reality for families affected by autism

Parents of children with autism tell us they want an education system that gives their children similar opportunities to other children.

They want an education system that understands their children's individual needs, that allows them to develop friendships, and to enjoy good mental health.

They want an education system that, as well as encouraging children academically, helps them to develop social, emotional and life skills. Many young people with autism are able to, and would like to, work. Their parents want them to be prepared for the world of work.

But our research found that one in four young people with autism in our survey (26%) doesn't feel happy at school. One in five (21%) doesn't feel safe. Thirty-one per cent have only one friend, or no friends at all. A third (34%) say that one of the worst things about school is being picked on. Just half of parents (52%) feel their child is making good educational progress. And when they reach adulthood, research indicates that just 15% of people with autism are in full-time, paid employment.<sup>5</sup>

"It's really hard to go to school. People don't understand how hard it is. They judge me for doing things I can't help."

**Young person with autism**

## The battle to get support

Parents have to fight every step of the way to get the support that their children need. When asked if it had been easy to get support, nearly seven in ten respondents to our survey (68%) said it had not been easy.

Forty-eight per cent of parents had to wait over a year to get appropriate support; more than a quarter (27%) have waited over two years. Fifteen per cent have waited more than three years.

"I found that if, as a parent, I had not been prepared to fight for my child, he would not have got where he is now, let alone got the specialised help that he needed. The sooner help is received the quicker the child can begin to fulfil their potential." **Parent**

Children with a diagnosis of Asperger syndrome or high-functioning autism are more likely to have waited a longer time to get the right support, for a number of reasons. Their needs may not be understood and sometimes they are overlooked. Often, there is limited provision for this group. A child may appear to be 'coping' quite well at school but this can take an immense amount of effort. A number of parents tell us their child comes home and 'explodes' as all the tension and stress of the day is released.

"Our problem is that our son is too bright for special school and too stressed for mainstream school. Although he is bright he cannot cope with the stress of mainstream school and his teachers do not understand autism." **Parent**

<sup>5</sup> Reid, B. (2006). *Moving on up?*  
London: The National Autistic Society

## Excluded from education?

Many parents who responded to our survey told us that their children have missed out on parts of their education.

Seventeen per cent of children have been suspended from school. For half of these children (48%) this has happened on three or more occasions, and 4% have been expelled from one or more schools. Parents' views echo our own: that exclusions often happen because a child's needs are not well understood and therefore, not being met appropriately.

"I am a single parent and the school told me that following a fixed-term exclusion they would only accept him back in school if I was on call during school hours, which meant I had to give up work." **Parent**

One in three (32%) parents who responded to our survey has been asked to pick their child up early or take them home at lunchtime – but not because their child was ill. One in five (19%) has been asked to do this on more than four occasions.

"My family and I have been on tenterhooks since our son started primary school. At the ring of the phone I have become nervous, wondering whether I shall be asked to pick up my son. I am unable to plan anything as I am expected to be 'on call' all day. The phone rings, I am expected to drop everything and pick him up by 12 o'clock as

there is NO provision for him... I have become reliant on medication to deal with my situation [and] am unable to work." **Parent**

"I was contacted at least once every single week to go and collect my child... now he is in specialist provision, I am not contacted at all other than illness." **Parent**

In the focus groups we held with parents, exclusion was a common theme. One mum described having to pick up her son every lunchtime for weeks on end because the challenges he was facing were not addressed; others spoke of their child being excluded from school trips or having to go on trips themselves to provide support – booking into B&Bs nearby at their own expense. Children with autism really benefit from practical, hands-on learning so exclusion from school trips is of great concern.

"Our son was excluded from his school trip (with all the subsequent effects of that exclusion on his school work). We were told that it was 'too much of a risk' to take [him] to the seaside, despite an offer of parental accompaniment on the trip." **Parent**



"I only go to school in the mornings. I need somebody to help me all the time but teachers just ignore me and the other kids pick on me. I don't get enough help and they always ring my mummy and I have to go home. I just want to be like the other kids but they are better than me. I'm not allowed to stay for lunch breaks and if I have a meltdown I can't go on school trips - but when I panic that I'll miss out I have a meltdown and then I miss out anyway. The teachers don't listen to me, they always blame stuff on me and then I get angry because no-one is listening. I hate school."

#### **Child with autism**

These 'informal exclusions' are illegal, although many parents are not aware of this, and continue despite Government guidance to the contrary. Parents should be made aware that this is illegal.

Forty-four school-age young people in our survey – 6% – are not being educated in school. Of these, 23 are being home educated by their parents. While some parents choose to home-educate their children, none of the parents we spoke to said it had been their preferred choice.

Most of the calls to our Education Rights Service about home education tell a similar story. Parents feel pushed into home education because no suitable provision is available, or because they feel the

## **Good practice**

### **Supporting pupils with very complex needs**

The NAS Robert Ogden School in South Yorkshire provides education and full-time and term-time residential care for pupils aged seven to 19.

According to Ofsted, the school provides an outstanding quality of education, with particular expertise in supporting children with autism with very complex behaviour, including mental health problems, attachment disorder and pathological demand avoidance.

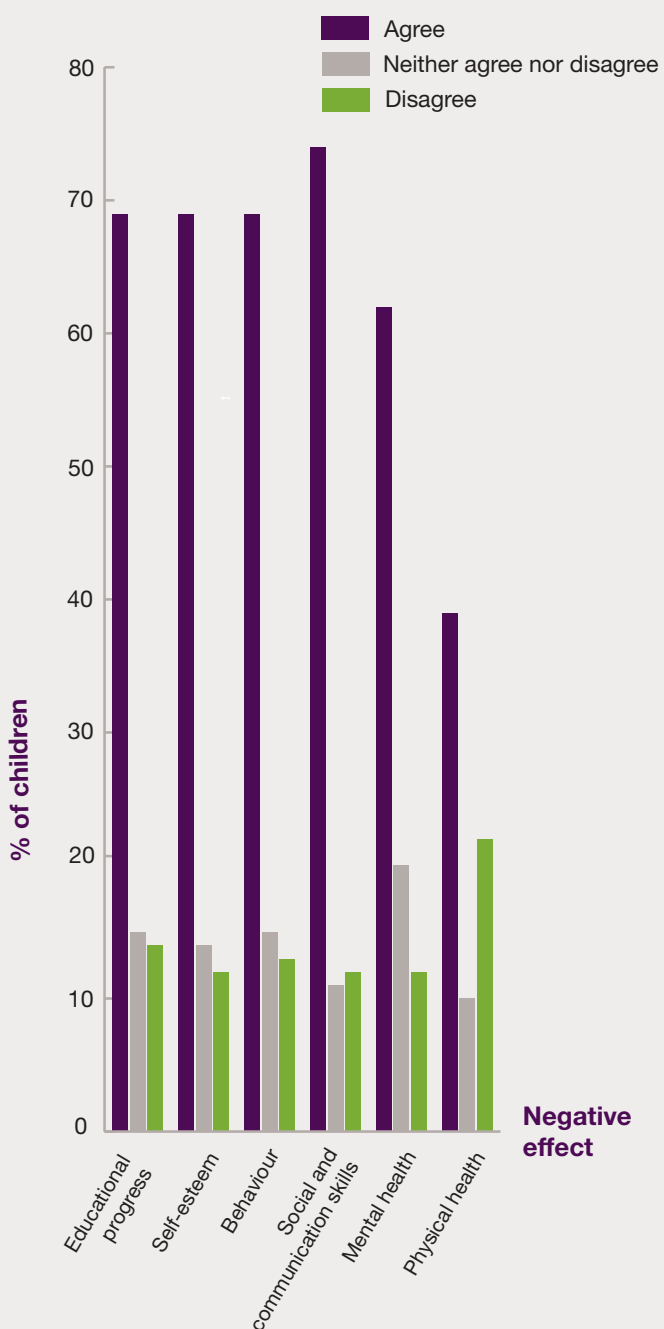
In order to support pupils effectively, staff know that they have to be flexible, understand pupils' individual needs, their behaviour and the motivation behind it – which is often different to children who do not have autism. They take any opportunity to encourage learning and see parents as partners in their children's education.

Approximately one-quarter of pupils at The Robert Ogden School were without education for up to two years before they came to the school. The school established an 'inclusion resource' to support these pupils: through it, they build up their tolerance of group learning and have a personalised learning programme. The resource has been so successful it is now being rolled out in other NAS schools.

One pupil had been to six different mainstream schools and a 52-week autism-specific school before coming to The Robert Ogden School. Following support through the inclusion resource, he settled in well at school and went onto higher education, eventually doing a Masters degree in engineering programming.

provision that is available is harming their child. And when they take their child out of the school system they may find their local authority refuses to provide any further support to educate their child.

### Lack of timely support: has it had a negative effect on your child?



*"If you take your child out of the school system because you feel there isn't adequate support, then you're not eligible for any further support because you're not in school."* Parent

Twelve of the children in our survey are not in education at all because their placement has broken down and no other provision is available. One young person has been expelled and is waiting for a new placement to start.

*"My son has classic autism. He was out of school for two-and-a-half years. Nobody visited us but we did fight for him to go to a school for children with autism. He showed them all he could do well if he had the right education."* Parent

### The consequences of getting it wrong

A lack of support can have a profound effect on children's lives (see the chart opposite).

Seven in ten (69%) parents in our survey say their child's education progress has suffered because of a lack of timely support. Nearly half (48%) say there has been a strong negative impact on their child's progress. Critically for children with autism, three-quarters of parents say that a lack of support has harmed their child's social and communication skills.

Social and communication skills help all of us to learn, and to cope with day-to-day life. Yet they are also the things that all people with autism experience difficulty with. It is essential that children with autism get appropriate support to develop these skills.

When a child finds it difficult to communicate verbally, they may have no other way to express themselves other than through their behaviour. Two-thirds of parents say their child's behaviour has suffered as a result of a lack of support.

"Behaviours that were coping strategies before he had appropriate support have become embedded and are difficult to undo." **Parent**

Meanwhile, a child who has difficulties with social interaction may struggle to make friends and to take part in everyday school life. They may also be bullied. A lack of timely support can affect not only children's academic progress but also their physical and mental health. Shockingly, three in five of the parents who responded to our survey said that a lack of support has affected their child's mental health, and two in five said it has harmed their physical health. Some children refuse to go to school altogether because it becomes such a detrimental experience.

"I don't like going to school. I don't have any friends. People laugh at me when I do P.E. Thinking about going to school makes me feel poorly." **Child with autism**

"By the time my son stopped going to school because the placement had completely broken down he had become mentally ill, suffering from severe anxiety, depression and at times suicidal... Intensive work with a psychologist has

confirmed that many of these problems had their root in lack of appropriate support in school."

**Parent**

Through our research for this report and our work with families across England, we know there is some excellent autism education practice, often led by individuals in local areas. We want to acknowledge and celebrate their hard work. But the message from families is that despite the best efforts of individuals, the system as a whole is still failing too many children with autism. Appropriate, timely support just isn't there when they need it.

"This whole experience has been utterly destructive for the family. An ongoing, uphill daily battle, trying to help a child who is becoming increasingly socially isolated." **Parent**

In the rest of this report, we look at why the support isn't there and what can be done to give children with autism the education they need and deserve.

The Government's reforms will shape the future of a generation of children with autism. We have *Great Expectations* of a better future for these children and their families.

Children expect an education that sets them up for life. Parents expect a system that works with, not against, them. We expect the Government to listen to what families want, to work with us, and to get it right.



## Chapter 2: Giving confidence and control back to families

Parents want to know that their child will get a good education. Without them having to fight for it.

Unfortunately, too many parents of children with autism do have to fight every step of the way to get the right support for their child.

"It shouldn't have to be like this, we shouldn't have to battle for every crumb available." **Parent**

"It was such a long, lonely battle to get him some form of support." **Parent**

Parents expect a system that works with, not against, them. In our research, we asked parents what needs to change to make this happen.



## Parents as partners

Nearly half the parents in our survey (47%) say that their child's special educational needs were not picked up in a timely way after concerns were first raised. This in turn leads to delays in getting appropriate support.

We asked parents what would help to prevent delays. Top of the list was professionals listening to parents' concerns and taking them seriously. We then asked parents who or what had made the biggest difference in getting the right education for their child, and the overwhelming answer was 'Me!' One young person echoed this:

*"Q: What else could make school better?"*

*A: If they believed my parents more... I can't show my true feelings at school, only home, and so they just don't believe I have a problem."*



As children's most ardent advocates, parents should be at the heart of their child's education. But too often parents feel that they have to fight the system to get their child the support, understanding and education they need.

*"A great deal of parental determination was necessary to obtain what my son needed, and it took far too many years to get it. If I had been less well-educated, less well-informed, and less assertive, he would still be floundering in the wilderness with rock-bottom self-esteem and no prospect of being able to capitalise on the positive aspects of Asperger syndrome."* **Parent**

Parents want professionals to work in partnership with them, to recognise that their knowledge of their own child is valuable, to listen when they have concerns, and to communicate with them so they feel fully involved. Parents of children with autism particularly value this, as many children need support to apply what they learn in school in other areas of their life. They may also find it difficult to manage the transition between home and school, and the differences in 'ground rules'.

## Good practice

### Autism Accreditation: a mark of quality

NAS Autism Accreditation is the world's only autism accreditation programme. It was founded 18 years ago in response to parents' concerns about the ability of non-specialist schools to meet their children's needs. Today, it helps parents make informed choices about which school or service is right for their child.

Accreditation confirms that a school or service meets independently defined standards of good practice in supporting people with autism. By creating 'quality action groups' in schools, accreditation also helps non-autism specialist schools to develop, share and retain autism knowledge and practice.

The Autism Accreditation programme is operated at arm's length by The National Autistic Society to ensure independence. Parental feedback is an important part of the review process that leads to a service becoming accredited.

"Adequate and appropriate care should be there without parents having to exhaust themselves fighting for it. If relationships between the parents/carers and providers of services are good then this can help greatly in getting appropriate provision." **Parent**

In our experience, parents greatly value professionals who are willing to discuss issues frankly and honestly with them. Furthermore, our work with young people shows that many children with autism also value the opportunity to share their views and play an active part in decisions about their education.

### Information and support

In order for parents to be partners in the system, they need better information and advice about their child's education, the options available to them and what they should be able to expect for their child.

Half (52%) of parents we surveyed felt they didn't have enough support or information when choosing their child's school placement. They may also get conflicting advice from different professionals.

"The thing we have found most helpful has been our support group, who not only support us through the hard times but provide all the information and help you could get." **Parent**



"The only real, positive support we received was from the NAS Advocacy for Education Service. This was invaluable and gave me as a parent the strength to fight the local authority." **Parent<sup>6</sup>**

The Government's proposal for improved information through the Local Offer and through an SEN quality mark for schools is therefore to be welcomed. This information should be accessible, but detailed enough that parents can understand which services may meet their child's needs and how to access them. It will need to be backed up with support and advice where necessary to help parents make the right choices for their child.

Parents in our survey told us about the services they had used to get information and support, including parent partnership services (PPSs).

Views on PPSs and other services are mixed around the country. Sometimes they are not seen as being independent enough; sometimes parents feel they are under-resourced. On the other hand, some parents saw PPSs as a body that was on their side.

But information and support is only one part of the solution. Parents may be well-informed and supported, but still struggle to get the support their child needs because it is simply not available locally.

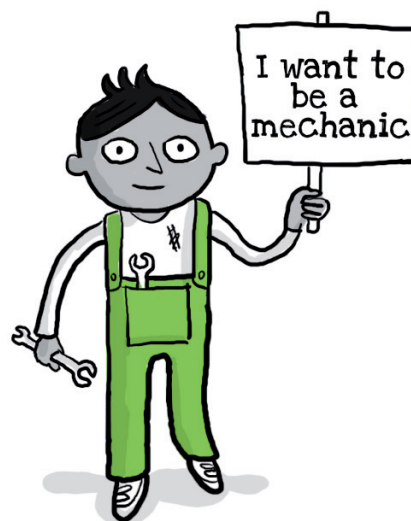
<sup>6</sup> The NAS Education Rights Service (formerly the Advocacy for Education Service) provides information, support and advice on educational rights and entitlements to parents of children with autism.

## Good practice

### Involving students in their education

Each term, all students at the NAS Broomhayes School have an individual planning meeting (IPM). It's an opportunity for students to say what they enjoy at school and what they would like to change. They can also tell us about the type of support they need and the skills they would like their key worker to have. The school can then match students to a key worker.

The IPM uses a person-centred and 'Team Around the Child' approach, involving students in setting their own targets, which cover education, health and social care. These targets emphasise students' skills and the various goals that they will be working towards.



## A local choice of education

Parents want a real choice of education provision. This means an education which meets their child's needs. And choice means more than one option being available for every child locally.

Our research found that fewer than two in five (37%) children are in their parents' preferred type of provision. Thirty per cent of parents feel that their child's current education placement is not adequate.

Fifteen per cent of parents who answered our survey told us that their child is being educated outside their local authority area. Some children with extremely complex needs require highly specialised support, which is only likely to be available in a very small number of specialist settings such as the schools run by the NAS. But often there is a lack of choice locally: for example, parents from one large local authority report that there is no autism-specific provision at all in that area. Overall, 43% of children in autism-specific schools have to go out of area.

This is far from ideal. Children who travel long distances to school have longer days and often become more tired, making it harder for them to concentrate at school. They may also have fewer opportunities to develop friendships and social skills, exacerbating the difficulties they already face.

"The worst part was having to travel on the school bus and getting stressed before even getting to school, with people teasing me and picking on me. I had to go in a taxi in the end." **Young person with autism**

It can also put pressure on families. Local authorities may be reluctant to pay for education in other areas, and parents may have to fight to get the right provision, as well as suitable transport to get there.

"Many local secondary schools are simply not appropriate to the needs of [children with autism] and so being transported to an appropriate setting is the only real alternative." **Parent**



## Good practice

### Supporting families, developing local provision

ASSIST is a service that is run as part of Wokingham Borough Council's Learning Difficulties and Disabilities Service. The four ASSIST staff have worked with people with autism in a variety of settings, and bring a wealth of experience to their roles.

The team works closely with local professionals, running autism awareness workshops, providing training, and directly supporting schools and practitioners. ASSIST has produced a transitions toolkit which is used by parents, schools and local agencies.

ASSIST also offers information, support and advice to people with autism and their families, including a social group for young people, social skills programmes, and parent programmes.

Feedback on the ASSIST programme has been very positive. One family, who took a slightly

different approach to their daily routine following guidance from ASSIST, commented on their son's improved behaviour after 'putting the world into little bite-sized chunks that he can easily cope with.'

A secondary school SENCO said:

"Thank you for all your work with R. I really felt that you understood her and helped her to take responsibility for her transition to college. Her mother also felt that your work made a real contribution and has resulted in her being so happy at college."

The manager of ASSIST also coordinates Wokingham Children's Autism Partnership, a multi-agency planning group which aims to ensure a strategic approach to developing the right services and support for children and young people with autism locally.

"[My school should] be nearer to home as it is 40km away. I travel each day on the minibus one hour to school and one hour to home. My school is excellent but far away." **Young person with autism**

Genuine local choice means a choice of mainstream or special provision, according to a child's needs. Yet at present only children who have a statement of

special educational needs have access to provision in special schools.

Some of the parents in our focus groups wondered whether the Government's proposal to remove the bias towards inclusion would mean their child could access special provision without a statement. This could help to make parental choice a reality.

However, any return to the assumption that all children with autism should be in special provision would be extremely concerning to parents, as well as highly impractical.

## The inclusion debate

With fewer than two in five children in the type of provision parents think is best, we wanted to know where children actually are, and where parents would prefer them to be.

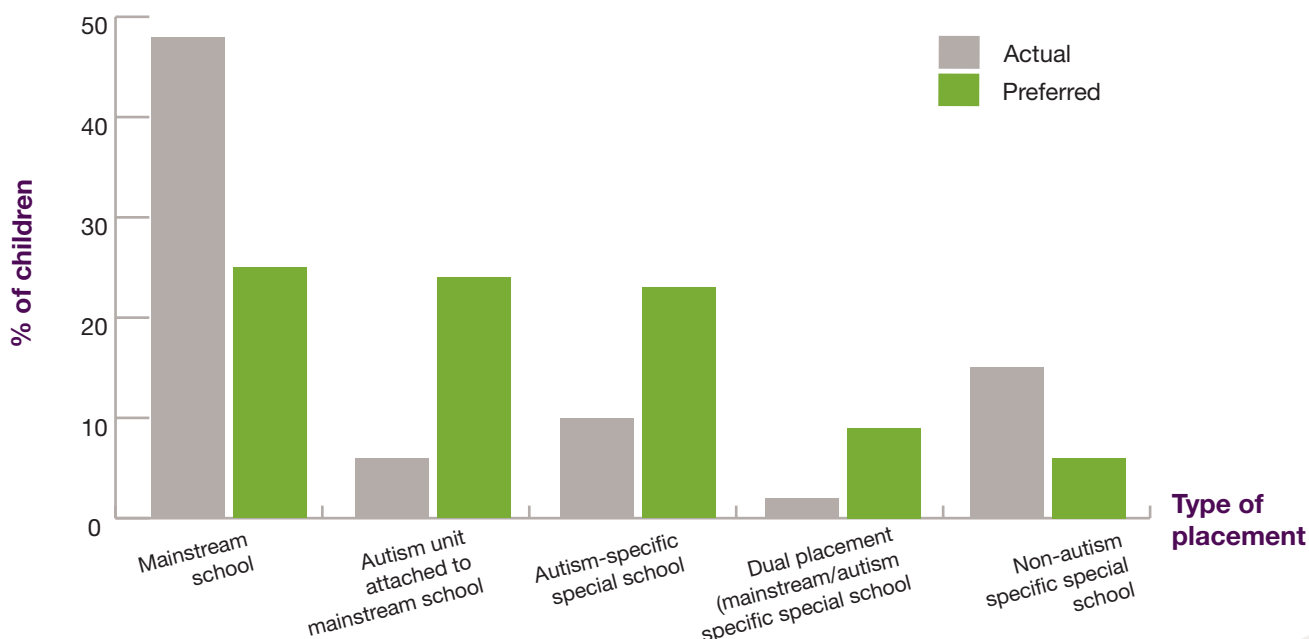
Parents report that their children are most likely to be in mainstream provision (48% overall), particularly children with diagnoses of Asperger syndrome, high-functioning autism or autism spectrum disorder. Children with autism and additional learning difficulties are most likely to be in non-autism-specific special schools.

The chart below shows that parents want a range of provision, and what is very apparent is that the majority of parents (58%) want some kind of autism-specific provision (such as an autism-specific special school or a resource base in a mainstream school). However, just 18% of children are currently in this type of provision.

"I am leaving my present school as they do not understand autism at all. I get treated pretty much the same as other children although I don't think I act like them. I am different but they don't take much notice of me at my school. My mum has found me a much better school that has a unit for children with Asperger's. Although I won't be in there, my mum says that the teachers and teaching assistants have more knowledge and a better understanding of my problems. I hope I will finally find a school I am happy in." **Young person with Asperger syndrome**

syndrome

### What type of school placement is your child in, and what placement would you like them to be in?



"Special schools are vital to children such as mine. My son simply would not cope in a mainstream environment. His considerable needs simply could not be provided for in a mainstream setting. The small classes with high staff ratio and autism experience are essential." **Parent**

Children with autism have a wide range of ability and need access to a variety of curricula to suit their needs. Most parents of children with autism and learning difficulties surveyed have a clear preference for special schools, while many other parents think it is important for their child to be able to access a mainstream curriculum, whether or not that is in a mainstream setting. For children in mainstream, inclusion must be genuine and effective. Parents do not always feel it is.

"My child attends mainstream school and has mainstream lessons. When meltdown occurs he is supported and given help." **Parent**

"Now he is at special school they seem to cover up most things like poor behaviour and don't contact me like they did in mainstream, where they were in constant touch. I only find out he's done something months later and don't feel we are working together on any issues." **Parent**

Some parents in our focus groups have children in special schools who used to be in mainstream ones. They changed to special schools after mainstream placements broke down, but felt their children had fallen behind while they tried to arrange new provision and that there has been a negative impact on things such as self-esteem, social skills and other consequences described in chapter 1. Often special schools are further away than mainstream schools.

Sadly, the views of young people reinforce this point. Children in mainstream schools are twice as likely to say that going home is one of the best things about school. Forty-three per cent say one of the worst things is teachers who don't understand them.

Every area needs to have education provision which understands autism, both equipped mainstream and more specialist provision. Children with autism must be able to access provision that meets their needs, and they must be able to do it promptly. This will prevent delays in education, which at the moment are yet another challenge for children and families to deal with.



## Making it real

Parents are clear. They want to feel confident about their child's education, that they're able to make the most of their time in school. They want information and advice to make informed choices and speak up for their child. They want a system that works with them, that offers real choice, and which feels fair.

So how do we make this happen?

### The Local Offer

The Green Paper proposes a 'Local Offer' to provide clear information, set out by local authorities, about what support is available locally and from whom. In relation to school provision this may include, for example, how a school will tailor the curriculum to meet a child's needs, carry out assessments or access specialist expertise.

The Local Offer has the potential to overcome many of the barriers families face when trying to find out how local schools can support children with autism. It is important that the Local Offer is developed in consultation with families, and that it is clear how families can hold services to account.

#### For the Local Offer to be effective:

- parents should be consulted during the development of the Local Offer, as local areas are currently required to do when developing their short breaks services statement<sup>7</sup>
- the local offer must be available in a clear and accessible format, with independent support and advice to help parents make the right choices for their children. It should be reviewed every year in consultation with local families
- the information provided must be genuinely transparent
- in relation to school provision, the information set out in the Local Offer should include:
  - ~ a named member of the school's senior management and school governor with responsibility for SEN
  - ~ details of how provision is made for children with autism in the school, including the training available to staff
  - ~ details of specialist autism expertise available to the school
  - ~ details of the school's SEN budget and how this is spent
  - ~ information about the experiences of children with SEN in the school, including annual progress against objectives (see page 32) and rates of exclusion for children with SEN
- Ofsted should assess the quality and accuracy of the Local Offer set out by schools as part of its inspection framework.

<sup>7</sup> Under the Breaks for Carers of Disabled Children Regulations 2011, "in preparing and revising their [short breaks services] statement, the local authority must have regard to the views of carers in their area" - [www.legislation.gov.uk/uksi/2011/707/made](http://www.legislation.gov.uk/uksi/2011/707/made)

## Local authorities as coordinators

The Green Paper proposes that local authorities retain responsibility for making sure that the necessary range of services is available. This means a stronger focus for local authorities on planning and commissioning, so that a range of services is in place.

Local authorities are clearly the key to planning and securing local provision, and getting different agencies to work together. As the Government has recognised, services for disabled children are too often disparate and uncoordinated.

### **To make sure that local authorities' roles are effective, we recommend that:**

- the proposed Health and Wellbeing Boards include greater representation from schools, to help ensure joined-up, more cost-effective work when planning and commissioning services
- local authorities should use autism-specific data such as the Pupil Level Census, Joint Strategic Needs Assessments (JSNAs) and information from statements or the new Education, Health and Care Plans (EHCPs) to inform their planning
- the Department of Health should make sure, as part of its review of data collection, that local authorities are collecting sufficient information on people with autism in their area
- proposed guidelines on JSNAs should help local authorities to better identify the needs of people with autism in their area, in line with the commitment in the Adult Autism Strategy
- parents should be consulted about what local provision is needed and this information should feed into the planning and commissioning of local services.

## Local authorities as champions for parents

The Green Paper proposes that local authorities take on the role of parents' champion, helping parents to make informed choices and exercise greater control.

We would welcome a role for local authorities in championing and supporting parents, although in some areas work will be needed to build the trusting relationship between the local authority and parents and carers which will allow them to perform this role effectively.

### **We believe that:**

- as part of their role as parents' champion and to increase transparency, local authorities should publish their strategic plans for children with SEN
- the Government should work with local authorities, parents, the voluntary sector and other stakeholders to develop further details of how they see the role of local authorities changing to become the parents' champion. This information should be made available to parents, local government officials and elected representatives
- local authorities should work with parents as they develop their role of parents' champion, and their approach should be set out in the Local Offer
- local parent carer forums should have an increased focus on education, such as an education group. To support local authorities in their new role as parents' champion, this group should feed into strategic planning and report back to the local authority on education services locally
- the Government should continue to support local authorities in their role as parents' champion, and to support local parent forums to act as a strong voice for all parents of disabled children in their area.

## Confronting the system

Unfortunately, too many families find that information and support are not enough. To get the support their children need, they have to fight. And fight. It can feel like the system is working against them. They feel they need to know the system inside out to understand their rights and in the words of one parent, 'avoid being pushed from pillar to post'. Some feel that without such knowledge they could be taken advantage of. And so the system becomes adversarial.

"In his early years the understanding and help were not necessarily adequate despite individuals trying. My knowledge was also far less then. If I were able to re-live the time, my son may well be a different person."

**Parent**

## Challenging the school


Some of the Government's proposals suggest a stronger role for parents in challenging local services. We asked parents how they would feel about challenging their child's school if they had to. Fifty-eight per cent said that they would feel confident about doing this. But when we look at their comments in more detail it becomes clear that many of these parents only feel confident about challenging a school because of experience. They have challenged the school before, often repeatedly, but may still not feel able to effect change. This comment is typical of many:

"I wasn't [confident] to start with and was very meek, but as time rolled on and I realised I was getting fobbed off I became stronger. I had to for my son's sake." **Parent**

"[I want] teachers to remember what they told my mum: that they would tell other teachers about me not liking too much noise and to help me write down homework because I am slow at writing. But they promise and forget to tell the teachers and my mum has to keep telling the school again." **Young person with autism**

Several parents say they feel better-equipped to challenge a school because of other experience, such as being education or legal professionals themselves. Others have even undertaken qualifications to better equip themselves. These parents expressed considerable concern for others who didn't share their background.





"I have felt very able to challenge the school and have done so repeatedly. I am very aware that other parents may find it harder to do this." **Parent**

However, 31% of parents told us that they don't feel confident about challenging their child's school. Some expressed concern that doing so would sour their relationship with the school. They worried about striking a balance between trying to get their child's needs met and maintaining a positive relationship with the school.

"You have to be very diplomatic when approaching schools about their provision and are very quickly labelled an over-anxious parent, even when things are clearly very wrong. Most schools do not give parents much info or a clear route on who to contact in the case of having issues, or a feeling that things will be dealt with." **Parent**

Some parents expressed concerns about local authority SEN departments not having power over school decisions in the future, especially if a child does not have a statement or an EHCP. When the Government's plans are developed in more detail, they must address this issue.

"Although statements are legally binding, there seems to be no way of enforcing them on a rogue school. They are not worth the paper they are written on unless the culture of the school is inclusive." **Parent**

Some parents in our focus groups felt that their child's school did not understand or see the need for the support detailed in a statement, and didn't put it in place effectively. We have occasionally heard of cases where schools find ways to get round implementing a tribunal judgement, leaving a child without the support their family has fought so hard for.

### Invoking the legal system

In a system which is supposed to provide an adequate education for every child, it should not be necessary for parents to have to take legal action to get the right education for their child. But ultimately, many parents find this step is necessary to get the support they feel is needed.

Autism cases make up the largest proportion of cases going to the Special Educational Needs and Disability Tribunal (31% in 2009-10), and the proportion seems to be increasing over time.<sup>8</sup> One in five parents (18%) in our survey has appealed to tribunal and on average, they have appealed three-and-a-half times each to get the right education for their child. In the majority of cases parents won their appeal, or the case was settled before being heard.

<sup>8</sup> Special Educational Needs and Disability Tribunal annual report 2009-10: [www.justice.gov.uk/downloads/guidance/courts-and-tribunals/tribunals/special-educational-needs-and-disability/SEND\\_AnnualReport\\_09\\_10.pdf](http://www.justice.gov.uk/downloads/guidance/courts-and-tribunals/tribunals/special-educational-needs-and-disability/SEND_AnnualReport_09_10.pdf)

"It still upsets me to think of the amount of time, effort and expense involved in preparing a case even though it was settled a few days before we were due to appear at the tribunal." **Parent**

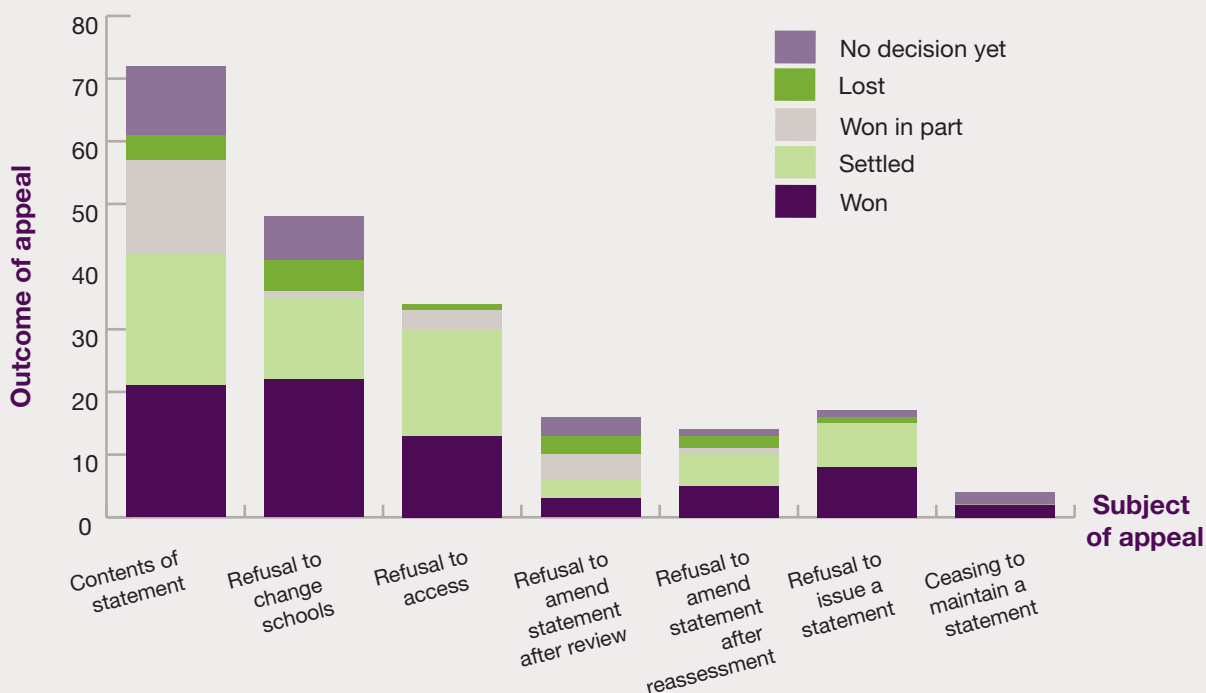
"We were put through the wringer as a family and in the end the local authority backed down two weeks before the date of the tribunal hearing." **Parent**

The process of going to tribunal can be very daunting for parents, involving lots of time, effort and distress.<sup>9</sup> Some parents in our focus groups had considered going to tribunal but said they did not have the energy to keep fighting.

"It was extremely stressful on my son and our family... We all suffered as he continued to struggle with school and life, while time was being wasted having to go to tribunal to prove to our LEA what was very clear to everyone else."

**Parent**

### What was the subject and outcome of your appeal (s) to tribunal?



<sup>9</sup> Some parents point out that it is not the tribunal session itself, but the process leading up to it, that feels so draining.

## Mediation

The Green Paper proposes that in case of a dispute, mediation would have to be the first port of call before parents could go to tribunal.

One way to make challenging the system easier is to introduce mediation to resolve disputes. Some parents in our survey have used mediation and they told us they valued having a third party involved. They thought it helped their discussions with the local authority and with the school. One mum described how her local authority had provided mediation between her family and her child's school, where the school was not communicating effectively.

*"I'm using the agreed points from mediation to hold the school to account for the support they agreed."* **Parent**

We asked parents whether they should have to go to mediation before going to tribunal. While a significant proportion (42%) agreed, there seems to be some confusion as to the difference between mediation and information and support services. Many raised concerns about the independence of mediation services, the non-binding nature of mediation decisions, and whether mediation would simply be another hoop to jump through before they could take a local authority to tribunal. Any move to mandatory mediation must tackle these concerns.

### For mandatory mediation to work the following steps need to be taken:

- parents should be able to take a supporter with them if they choose to
- mediation should be available between parents and schools where necessary, as well as between parents and local authorities
- mediation should happen as quickly as possible to prevent unnecessary delays to a child's education
- any introduction of mandatory mediation must not delay the time it takes to get to tribunal
- professionals who attend mediation must be able to make commitments on behalf of the school or local authority they represent
- parents must have ways of making sure that the decisions made during mediation are stuck to.

### Giving confidence back to parents

With some parents having to go to tribunal three or four times to get the right support for their child, it is not surprising that families do not have confidence in the system.

To feel confident in their child's education, parents need an SEN system where their child has clear entitlements and rights and is well-understood by the professionals who work with them. Families need to know who is accountable if appropriate support isn't forthcoming. And they need a quick, simple system which is answerable to parents and young people. These are the themes of the rest of this report.



## Chapter 3: A system that supports individuals

At the heart of the Green Paper are proposals to change the process of getting support for SEN, including statements, School Action Plus and School Action.<sup>10</sup>

This process must be thorough, identifying and assessing individual need so that each child gets appropriate provision and support. Children expect an education that sets them up for life. Families need to be clear about what their rights and entitlements are, so that they feel confident that the system will meet their child's needs.

<sup>10</sup> School Action Plus is the non-statutory level of support where a school draws in additional resources to support a child's SEN. School Action is the level below this, where a child receives support using in-school resources. A statement of special educational needs is a statutory document setting out all of a child's educational needs and the provision required to meet those needs. Local authorities are responsible for ensuring that the support outlined in a statement is delivered. Statements tend to be for children with more complex needs. They are drawn up following a statutory assessment, and parents have the right to challenge them at various points at the Special Educational Needs and Disability Tribunal. Currently, a child has to have a statement before they can go to a special school. Statements, School Action Plus and other aspects of SEN support are set out in the SEN Code of Practice (2001).

## Early identification

The Government's plans place a strong emphasis on identifying children's needs, as this is the crucial first step towards getting the right support. When a child's needs are identified early on, and accurately, the right support can be put in place and prevent more difficulties developing later.

In this report, we have seen how many families experience delays in accessing support after first raising concerns about their child. Ofsted has found that children with autism generally find it less straightforward to access services than children with more obvious needs do. In some areas, support is only available after a formal diagnosis. This means that support may not be put in place in a timely manner, particularly as over half of all areas take longer than 30 weeks to complete a diagnostic assessment.<sup>11</sup>

Parents who took part in our research feel that the needs of children who are academically able in particular are too often overlooked, despite the fact that these children often have clear social difficulties which, left unsupported, may have a profound impact on their well-being and educational progress. A number of parents also feel that sometimes, a child who acts out their difficulties through their behaviour is more likely to get help than a child who is quieter or tries to mask their difficulties – when both are in equal need of support. Professionals need to be able to identify the many ways that autism may present.

"Because my son is high-functioning and his behaviour is not difficult there is a misconception that he will be able to cope and just get on with things." **Parent**

"Our initial requests for a statement were rejected until we eventually got an assessment, and my child is now recognised with severe learning difficulties and severe autism. The initial delay was completely unnecessary as our application was backed by education providers." **Parent**

"Because I am well-behaved in school, I get overlooked when I am requiring help."

**Young person with autism**



<sup>11</sup> Ofsted (2010). *Special educational needs and disability review: a statement is not enough*. Manchester: Ofsted

## Good practice

### Identification and assessment leading to support

Manchester's multi-agency Social Communication Assessment and Intervention Team (SCAIT) supports children with autism and their families. Once a referral is accepted, children are assessed in different settings such as clinics and assessment units, and at nursery or school.

The team includes educational psychologists, speech and language therapists, clinical psychologists, child and adolescent psychiatrists and child mental health practitioners/nurse therapists. Together, it develops interventions and strategies to support children with autism in all settings, including school. To this end, outreach teachers are part of the wider SCAIT team.

The team provides autism training to schools across Manchester, which helps to make sure the strategies they put in place are used consistently by everyone who supports a particular child. SCAIT is also piloting joint training sessions that include parents, teaching assistants and SENCOs.



## Assessments

Parents want professionals to see their child as an individual, and look at their needs as a whole. Many children end up undergoing multiple assessments to get the help they need. The Government proposes introducing a single assessment process. Our research shows that most people are in favour of this approach: nearly three quarters (73%) feel it would be helpful. However, people are less sure that it would be right to combine this with an assessment for Disability Living Allowance: 62% supported this proposal.

*"I agree that the medical and educational assessment could be more coordinated to avoid repetition."* **Parent**

More details are needed on how the different professional assessments can be better integrated, so that all relevant professionals can feed into the process. Moreover, mechanisms to resolve conflict between professionals will be vital: parents tell us about professionals from different services giving different advice about the support their child may need. This means that parents aren't sure what advice is 'right', and that sometimes one service won't accept the opinions of another. Through our Education Rights Service, we sometimes hear of cases where schools and local education authorities refuse to accept a medical diagnosis of autism, instead wrongly attributing behavioural issues to naughtiness or bad parenting.

### Separation of assessment and funding

One issue which has been debated a lot in recent years is whether there should be greater separation between assessment of needs and the funding of SEN provision. At the moment, both are done by local authorities. The Government is proposing to introduce a greater degree of separation. Four in five parents (79%) feel that separating funding and assessment would be helpful: they perceive a conflict of interest, where support is only recommended if an authority

knows it can be paid for. But other parents see it as less of an issue about conflict of interest, and more as an issue about allocating limited resources fairly.

*"The same professionals who decide whether a child gets a statement also grant funding. There is a conflict of interest. The system is based around whether there is money available rather than starting from the point of view of what a child needs. This has to change."* **Parent**

### Statements: the key to support?

Sixty-five per cent of parents who responded to our survey said their child has a statement – a legal document that sets out in detail the support they need and will receive. A further 18% of children get support through School Action Plus. Five per cent get no support.

While the main reason for requesting a statement among the parents we surveyed is to get additional support, nearly one on five (18%) say they requested a statement to get the school they felt their child needed.<sup>12</sup>

Thirty per cent feel they needed a statement to give them stronger rights: one person said that a statement 'gives you peace of mind that your child does have rights and that if they are not being met then you can do something about it and get things changed.' In our experience, parents do not generally start by trying to get a statement, but eventually come to the conclusion that one is needed to make sure their child gets the necessary support.

Following the proposed new single assessment, children who are assessed as needing significant additional support will get an Education, Health and Care Plan (EHCP). This will set out the support a child needs in education, health and social care. EHCPs will replace statements.

Parents are strongly in favour of single assessments and services working more closely together to take a holistic approach to their child's needs. The system needs to work smoothly and quickly, from effective identification and assessment through to putting the right support in place and reviewing it regularly. This means that local agencies, including education, health and social care services, need to work together closely so that children can get the start they need in life.



<sup>12</sup> This did not necessarily mean special provision (for which a statement is currently required), but usually autism-specific provision, whether in a mainstream or special school.

"The current systems are so complicated (for everything from getting diagnosed, education, DLA, support, etc)... You have to fight for everything, which is exhausting, time-consuming and extremely stressful (especially as I work full-time). The processes should be simplified and more family-friendly." **Parent**

"I wish we had specialist support not just for the educational side of it but things like getting my son to school in the morning or dealing with meltdowns. I feel like we, as a family, and the school have no one to turn to for help." **Parent**

While a reduction in bureaucracy may help to free up professionals' time, the challenges of joint working should not be underestimated. Shared objectives and pooled budgets will help services to work together effectively. Parents and professionals alike will need information about how local services are expected to work together and who is accountable for what.

It is essential to keep the same legal protections to EHCPs that are currently in place for statements. To help with joint working, the health and social care parts of EHCPs should carry the same 'weight' as the education parts, and all agencies should be equally accountable.

However, all families – not just those whose children have a statement or an EHCP – need to know they have rights and entitlements. Otherwise, they will feel that a statement or an EHCP is the only way to get the protection they need.

Parents told us about the additional support their children receive, and where they think more support is needed (see the chart opposite). The biggest need is perceived to be for speech and language therapy, buddying, befriending and support to develop living skills.

It should also be remembered that children with autism who do not have an EHCP will still benefit from health and social care services. As reforms are taken forward, it should be made clear through the Local Offer how children without an EHCP can access the services they need.

## Personal budgets

The proposal to offer personal budgets to families entitled to a statement or an EHCP has two main aims: to make it more clear what services cost; and to help families to get the services they choose.

However, it does not seem to be clear how those who do not have an EHCP will be able to understand the funding their child is receiving.

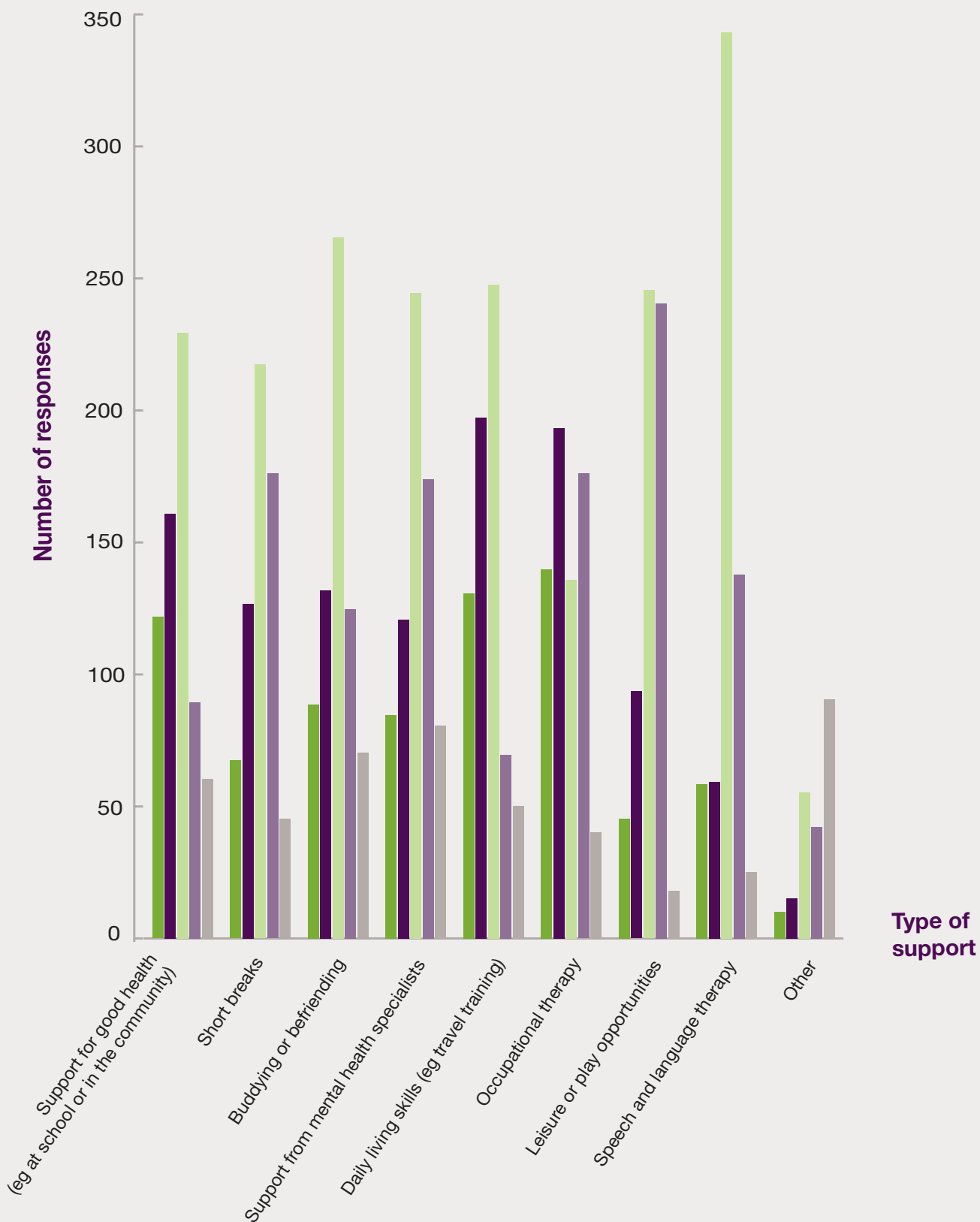
We asked parents what experience they have had of personal budgets. Around 14% had used an individual budget<sup>13</sup>, mainly for social care services. For some, the budgets have worked well – they felt they had gained control and were happy about using them. For others, experiences were more mixed: some highlighted the challenges of finding staff and services with the specialist skills and expertise needed to work with children with autism. Others encountered unmanageable levels of paperwork.

<sup>13</sup> The families we spoke to had used individual budgets, rather than personal budgets. These include funding for social care services but not additional funding streams such as those relating to educational support.



**Which of the following types of support does your child have enough of, and which do they need?**

- Receive sufficient
- Receive but need more
- Want but don't receive
- Don't need this type of support
- Don't know



## Good practice

### Improving access to social support

The NAS Radlett Lodge School in Hertfordshire provides 'exceptionally high quality' education and weekly boarding for children aged four to 16 with autism and complex learning and behavioural difficulties.

The school works with the London Borough of Tower Hamlets to help young people with autism access mainstream youth groups and leisure activities – and by doing so, gives them the chance to form friendships and take part in community life. Joining a new club or meeting new people can be stressful, so each young person has a 'personal inclusion plan' to help with this.

In turn, Radlett Lodge offers autism-specific training and support to youth clubs and other mainstream provision, covering everything from the basics of autism to behaviour management.

As youth workers in Tower Hamlets gain more awareness of the issues facing young people with autism and adapt their clubs accordingly, parents are increasingly confident about their children going to mainstream youth projects.

Through the scheme, young people's confidence also grows. For example, one young person with autism had been reluctant to socialise after school and spent his time in front of the TV. However, after being supported to go to a local theatre group, he now enjoys taking part in drama sessions every Tuesday evening.

While individual budgets will be good for some families, they are clearly not the answer for everyone. It will be important to learn from the experiences of the personal budgets pilots, due to be published in September 2012, and to consider within that evaluation how local authorities can help develop a market of different provision so that a range of services is available for families to choose from.

"Would really welcome [a personal budget] as it would enable parents to buy services that the children really need." **Parent**

### Results, not just processes

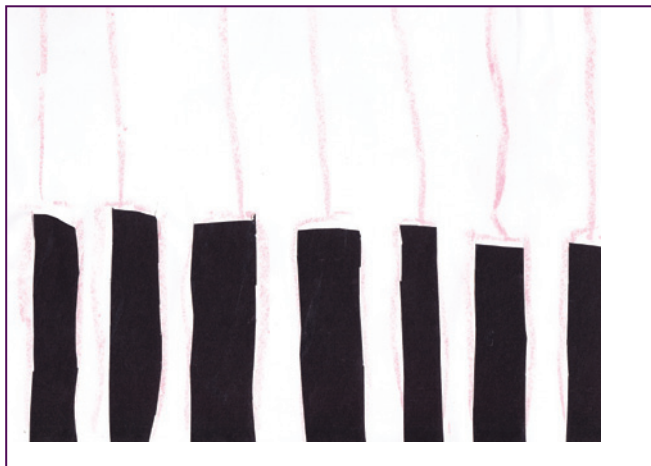
EHCPs are intended to have a strong focus on outcomes – what is actually achieved – and this is to be greatly welcomed.

All children with autism (including those who do not have an EHCP or a statement) should have an action plan that is regularly updated and sets appropriate objectives, and their progress should be measured against those objectives.

We welcome the Government's proposal to introduce a new measure of performance for the lowest attaining 20% of pupils in schools. Some children with autism will fall within this band, and an action plan would help schools to make sure that they are making the best possible academic progress.

For children with autism a good school will develop their confidence, their social skills, their skills for independent living and in many cases for employment. In order to deliver on its vision to give every child the very best opportunity to succeed, the Government should consider how schools will be recognised for delivering these outcomes for all children with SEN, not just those who fall within the lowest attaining 20%.

"I want to be a musician."



"I want to be a mechanic."



*Illustrations: artwork by pupils Miguel and Romy at our Radlett Lodge School. They were asked, "What do you want to do when you grow up?"*



## Good practice

### Planning for the future: work experience and transition

The NAS Sybil Elgar School in Middlesex recently worked together with Prospects, our employment service, to pilot a work experience programme for young people with autism.

For many young people with autism, it can be difficult to imagine life beyond school and what being in the workplace will actually involve. Good quality work experience placements can be particularly beneficial, yet few have the opportunity to do such placements.

The project started with school-based workshops with six students. The workshops looked at what work experience involves, including sessions on finding a work experience placement, learning new skills, dealing with new environments, and self-advocacy. These sessions aimed to build students' confidence, communication and social skills.

After the workshops, a work placement was planned with each student. Prospects provided autism awareness training for the employers and along with the school, sought to support young people while on their placements. They also worked closely with parents and carers so that the students had support at home during this period of change and transition.

## Making it real

Children's needs should be identified early and appropriate local provision put in place to meet those needs. Local agencies should work together when carrying out assessments and supporting families. A re-written Code of Practice must set out everyone's rights, entitlements and responsibilities in a clear, accessible way, and retain those aspects of the current Code which families and professionals value greatly.

### Early identification

The Green Paper proposes that all two-year-olds will be offered a health and development review so that they can get any support they need quickly. It also says that where a pupil faces exclusion, multi-agency assessments will be piloted to see whether they help identify any factors behind this, such as unidentified SEN.

We welcome the piloting of assessments related to exclusions, something that the NAS has called for over many years.

**For the needs of children with autism to be identified as early as possible, we recommend that:**

- health visitors should have training in autism to ensure that they can identify the early signs of autism as part of the health and development review. However, it is essential to recognise that many difficulties relating to autism do not become apparent until after the age of two
- school staff should receive training so that they can identify possible signs of autism, and work with the local NHS so that they know where to refer children for assessment and diagnosis
- local NHS bodies should follow the NICE guidelines on recognition, referral and diagnosis of autism in children and adolescents<sup>14</sup>, so that there is a clear route to getting a diagnosis in every area.

### Coordinating support through EHCPs

The Green Paper proposes that statements should be replaced with EHCPs and a single assessment process for EHCPs introduced. EHCPs would provide the same education rights as statements currently do, but be better integrated with health, social care and other services. The Green Paper also proposes reducing the maximum time limit for the statutory assessment process from 26 to 20 weeks.

We agree that services need to work more closely together so that support for children with autism can be better coordinated. A streamlined process would be welcomed by parents, as would a shorter waiting time: 90% of parents we surveyed are in favour of reduced time limits for statutory assessment.

<sup>14</sup> National Institute for Health and Clinical Excellence (NICE) (2011). *Autism spectrum disorders in children and young people: recognition, referral and diagnosis*. London: National Institute for Clinical Excellence

### To make sure that the new system works:

- the test areas for the new assessments should look at how local authorities might work with other organisations, such as voluntary organisations, to develop an assessment process which parents feel is more independent
- the health and social care elements of EHCPs should have the same weight and accountability as the education parts
- streamlined assessments must not mean that relevant professionals are excluded from the assessment process
- all children with autism should have an action plan that is regularly updated and sets appropriate objectives. This includes children who do not have a statement or an EHCP
- children's progress should be measured against these objectives, and this information should be used when evaluating school performance.

### Personal budgets

The Green Paper says that personal budgets will be offered to everyone eligible for an EHCP, giving parents greater control and making it clear what funding levels are available.

Personal budgets will only work if they are optional, and if there is a real choice of appropriate services for families to choose from.

#### For personal budgets to work:

- evaluation of the personal budget pilots, due to be published in October 2012 should look at the role of local authorities in developing the market so that parents can have an appropriate range of services to choose from.

### Clear and accessible guidance for families and professionals

The Green Paper proposes re-writing the SEN Code of Practice to make it shorter, clearer and with a focus on identifying SEN more accurately, and integrated with guidance for other children's services.

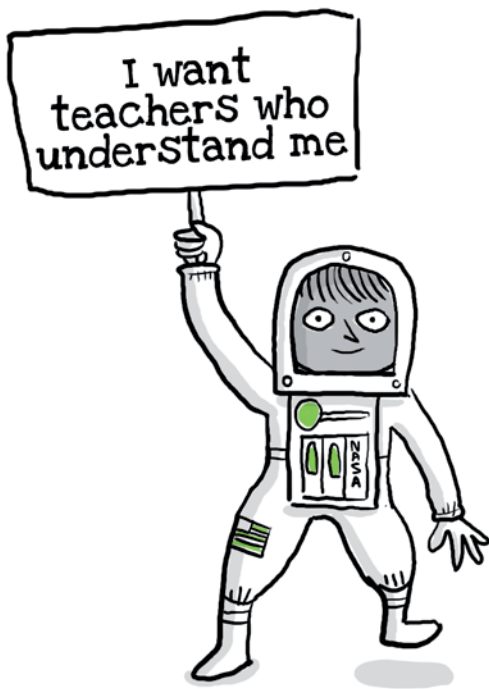
The current SEN Code of Practice is incredibly useful to parents and professionals alike.

What comes through very strongly in our research is that whatever system is in place, parents want and need a way of making sure their child's needs are met, that progress is being made, and that support cannot be removed without proper consultation with parents and staff working with the child, whether or not they have a statement or an EHCP.

A re-written Code of Practice should remain clear, accessible and set out parents' and children's rights.

#### These rights must include:

- clear timescales and processes, including communication between agencies
- a named and trained senior person in each school with responsibility for SEN
- an identified teacher, with relevant training, in each school who has responsibility for coordinating SEN provision
- ways for parents to challenge the system, including clear and accessible complaints and appeals processes
- rights for children without EHCPs or statements
- clear and enforceable lines of accountability between schools, local authorities and other agencies involved in providing support
- regular objective-setting for individual pupils.



## Chapter 4: The knowledge

Parents and young people agree that knowledge of autism, more than anything, helps children's needs to be met. Conversely, many teachers say that developing autism knowledge is their biggest challenge in teaching children with autism.<sup>15</sup> According to our research, when a teacher has a good understanding of autism, 86% of children feel happy at school, compared with 53% generally.

"My son thrives best with teachers and assistants who know about autism and understand his needs." **Parent**

<sup>15</sup> Jones, G, et al. (2008). *Educational provision for children and young people on the autism spectrum living in England*. London: Autism Education Trust. A report by the NUT in 2006 (*SEN survey on the provision of training to teachers in relation to pupils with special educational needs – evaluation*) also found that 44% of teachers in their survey did not feel confident teaching children with autism



### Autism knowledge in schools

We know there are many professionals who are extremely well-equipped to support children with autism. Some have received specialist training, others have even undertaken research in their own time so they can support these children more effectively.

But our research indicates that autism knowledge and expertise across all schools, and sometimes within individual schools, remains patchy. Too many teachers are trying their best but are being let down by a system that doesn't give them the training, knowledge or resources they need to help children with autism thrive at school.

"The thing that would make the most difference for children with SEN would be much more training for staff. The staff at school are all kind and have been very concerned that they have not known how to teach our child."

Parent

"[School would be better] if there was a way which everybody could find out about autism without asking me or the TAs [teaching assistants] in the base."

Young person with autism

For parents, good training and teaching practice is of great concern. Fewer than half of parents in our survey are satisfied with class teachers' understanding of autism. Many expressed their frustration at having to explain repeatedly what autism is. Autism is a hidden disability and without a good understanding of it, a child's needs may be overlooked, or teachers may be

unsure what adjustments they should make to support pupils. A number of parents' comments echoed this one: 'Because they don't visually **see** a disability they tend to treat it as non-existent.'

### Parent satisfaction with mainstream teachers' understanding of autism<sup>16</sup>

	Satisfied	Not satisfied
Primary teacher	52%	25%
Secondary form teacher	45%	18%
Secondary subject teacher	29%	30%
SENCO	59%	24%
Head teacher	37%	26%

Young people themselves are even less satisfied. More than two in five (43%) feel teachers don't know enough about autism and for pupils in mainstream schools, the majority (57%) feel that this is the case. This is particularly worrying because when we asked young people what the worst thing about school is, the most common answer is 'when teachers don't understand me'. A lack of knowledge of autism has a direct impact on the lives of young people.



<sup>16</sup> Remainder made up of 'neither satisfied nor dissatisfied' or don't know.

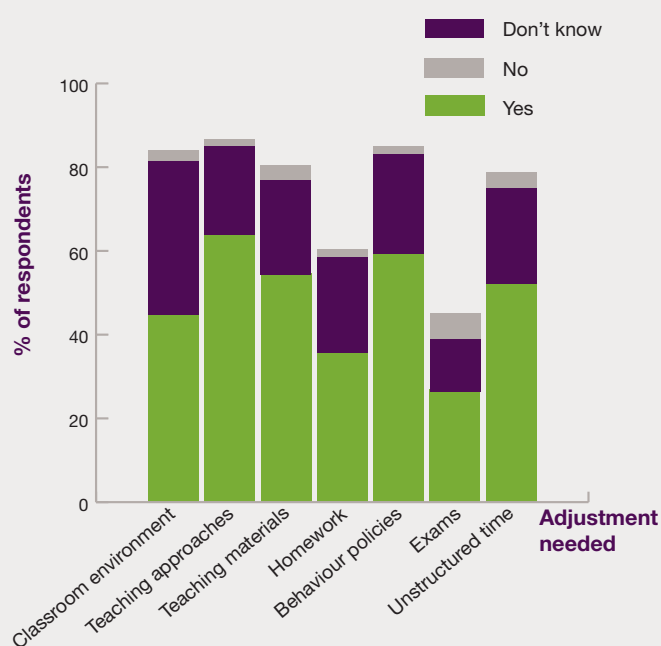
"I'm lucky that I now go to a brilliant school. But when I was in mainstream primary, things were VERY different. I hated school, I self-harmed and I refused sometimes to go to school. I was badly bullied. Teachers had no idea how to teach me and often gave up although I have since found out at my new school that I am very bright and I am taking nine GCSEs, all predicted Bs and As." **Young person with autism**

In a significant number of cases, adjustments and adaptations that are required by law and necessary to meet a child's needs, are not made (see chart below).

Most commonly missed are adjustments to the classroom environment (which may help a child to manage sensory sensitivity), homework and unstructured time, such as breaks and lunchtime: times that children with autism often find particularly difficult. However, these adjustments are often relatively easy to make.

"I think all schools should have a room to go to for quiet time and for kids like me to be able to concentrate away from the noise and clutter and just chill out or work in peace. Sometimes I have panic attacks at school in the cookery room; it's too smelly and there's not enough time to finish the food I'm cooking. My head needs time off from the noise and amount of people. Regular breaks in the day would be good." **Young person with autism**

Is school making adjustments or adaptations?<sup>17</sup>




**Young person with autism**

It's not just about teaching staff. Young people would also like other pupils to have a better understanding of autism, with one in three saying this would make school better. Lack of understanding can have consequences: 34% of young people say that people picking on them is the worst thing about school, the second most common answer after teachers not understanding them.

<sup>17</sup> Remaining respondents indicated that the adjustment was not applicable or not needed.





"It would be better if I was understood better by everyone, and other children at school weren't mean to me because I am a bit different." **Child with autism**

### Get it right for teachers, get it right for children

Everyone recognises that dedicated and capable school staff can make a big difference during a child's time at school – and beyond. With an estimated 88,000 children with autism in England, teachers need the right training so that they can feel confident about supporting these children, and schools can fulfil their legal obligations.

"Our son is very happy in his secondary school and they are very supportive. He had numerous opportunities to visit the school previous to him starting, including meetings with us. He is well-supported when needed and attends a nurture session twice a week and at lunchtimes... [He gets] excellent social skills training, he has regular supply staff when other staff are absent... He is very happy and is achieving well." **Parent**

When autism training works, families feel the benefits of it. Some of the parents in our focus groups said they are beginning to notice the effects of the recent initiatives around autism training for teachers, and could see the difference between teachers who had received training and those who had not.

"Some teachers were understanding and allowed me helpful concessions, for instance I could come straight into the classroom in the morning (with the 'job' of putting out the chairs) instead of waiting and lining up in the playground. This was useful as the busy, noisy playground full of parents and children was a very anxiety-provoking place for me."

**Young person with autism**

"I found [my son's] primary school to be fantastic. All the teachers and teaching assistants were very knowledgeable about autism and the problems or difficulties that it can bring. All his work was aimed at his level." **Parent**

These training initiatives must continue. In addition, the proposed SEN scholarships for teachers and support staff must include a scholarship which focuses specifically on autism, with incentives for teachers to take these scholarships up and share what they have learned with colleagues.

### Putting training into practice

Parents we spoke to in our focus groups highlighted the importance of teachers (and teaching assistants) having the opportunity to put training into practice, vital to make the investment in training worthwhile. But all too frequently, teachers do not have the time or support to do this.

## Good practice

### Supporting children with autism in mainstream school

The County Inclusive Resource (CIR) is a Suffolk County Council-based outreach service for mainstream schools who want to access support for pupils with autism. Schools refer pupils, who must have a medical diagnosis of autism but do not have to have a statement.

CIR teachers are based in schools across Suffolk. They work directly with pupils; train and advise school staff; and supply resources, such as visual prompts, learning aids and social stories. All their work is based on the individual needs of pupils and their schools.

In partnership with schools, the CIR works closely with parents and other agencies. Once a pupil has been successfully referred to the CIR, there is no need to re-refer, and they receive consistent support from Reception to the end of Year 11.

"The CIR intervention has been highly effective. It has provided us with a range of strategies to use to enhance learning and behaviour and has helped us to feel more confident in our management of children with autism."

We also need more than just generic awareness training. Some approaches, such as modifying language to make it more concise and literal, can be simple and effective for many children with autism (and, indeed, other children with communication difficulties). But autism is a complex condition and every child with autism is different. Training should emphasise this, and focus on how teachers can adapt strategies and approaches based on their knowledge and observation of a child. Combined with up-to-date information and clear action plans and objectives, this will help each child to make appropriate progress.

### Awareness and support across the school

#### SEN leads

Special educational needs co-ordinators (SENCOs) advise on provision for children with SEN, including autism. Three in five parents who we surveyed are happy with their SENCO's understanding of autism. It is a role which must be retained as the education system changes and develops.

However, a significant proportion of parents are not confident that their SENCO can advise other school staff on how to support their child.

"The support assistant assigned to me should be fully trained in autism, and most of them are not. The SENCO should also know about autism and the proper procedures to follow."

#### Young person with autism

But in part, this is because SENCOs have insufficient time to support all the children who need help. Parents in our focus groups argued that they should not have teaching responsibilities on top of their SEN responsibilities.

In our experience, having a person on a school's senior management team who represents SEN

issues is critical. Such a person can oversee the training and development needs of staff, make sure children are receiving appropriate support, help to set school policy about SEN, and build links with other professionals so that more specialist support is available when necessary.

### School leadership

Head teachers can take the lead on SEN in their school, identify areas for development, and set the whole tone and attitude of the school towards children with SEN. Just 38% of the parents we surveyed who have children in mainstream schools feel that the head's knowledge of autism is satisfactory. We strongly welcome the Government's proposal that training for head teachers will have a focus on SEN. This training should be available to newly appointed leaders and experienced head teachers.

"We are relatively satisfied with the support our son now receives at mainstream school because it has a fantastic SENCO who absolutely understands autism. The school has a strong ethos of inclusion, supported by the Head. The SENCO has taught us things we didn't know! Our experience at primary school was the opposite; a Head who not only didn't understand autism but chose not to learn about it." **Parent**

"The most important thing is staff who are properly informed and willing to help children on the spectrum maximise their talents

and handle the challenges posed by their autism. Strong leadership from a head teacher whose enlightened attitude percolates through all school staff is a major advantage." **Parent**

The Government envisages school governors having a much greater role in holding schools to account, and hence proposes to give them more information about the progress of children with SEN. However, nearly half of parents (48%) could not say whether their school governors have sufficient knowledge of autism to

## Good practice

### Sharing knowledge through local school 'clusters'

In Lincolnshire, there has been an increasing demand for advice and information on supporting pupils with autism. The Autism Inclusion Mark for Lincolnshire (AIM4Lincs) has led to the development of a network, through which schools can share autism knowledge and training opportunities.

Primary and secondary schools – both specialist and mainstream – submit evidence on their practice and are assessed by a team of professionals from the education and voluntary sector. They are marked against 13 'prompts' with three levels in each prompt – entry, developing, enhanced. Schools are judged on their environment and the adaptations they make, their strategies for training staff, and how they work with parents and outside agencies. Each applicant receives detailed advice and support to help them develop. To date, two schools have achieved an enhanced level, and a further five are very close to this.



## Good practice

### A centre of autism expertise

The NAS Helen Allison School, rated outstanding in its most recent Ofsted inspection, is a centre of expertise in autism education. It provides high-quality education to children with autism aged five to 19 and maintains close links with other schools in the area. Staff offer training to professionals, including the chance to observe teaching and best practice at Helen Allison.

Staff share their autism knowledge in other ways, too. Some teach on postgraduate autism courses at Canterbury Christ Church University and Sheffield Hallam University, while others are involved in research, including the specific issues around educating girls with autism; the development of social and self-management skills for children with high-functioning autism; and an international project looking at how smartphones may aid people's inclusion in society.

make sure children are supported effectively. Parents need to be confident that governors have sufficient knowledge to do their jobs well and hold schools to account. Training should be made available to governors.

*"The culture of inclusion is what makes school work for my child more than any other factor."* **Parent**

### Access to autism expertise

While improved training for teachers and school leaders is critical, it is not possible for every teacher to be an expert in autism: access to high-quality expertise and specialists will still be necessary. Yet often these are limited resources which have to cover large populations, and it is those children who do not have a diagnosis or a statement in particular who lose out. Teachers need to know what additional support is available and how and when they can access it.

*"Autism advisory teacher specialists are very effective but seem to be stretched to the limit."*

**Parent**

We welcome proposals in the Green Paper to give professionals more opportunities to learn from colleagues in specialist settings, and to develop 'clusters' of schools that share good practice. This could be very cost-effective: preventing mainstream school placements from breaking down, and reducing the need for more expensive out-of-area placements.

*"Some of my son's teachers have been outstanding - his current one in particular. We need to ask them more about what is needed."*

If they are doing [things] well we should be picking their brains!"

**Parent**

"From the Foundation Stage, [my son] was welcomed into school and practices were put in place to support him, eg visual timetables, flexible approaches. His school listened to the speech therapists and put all of their recommendations into practice. [My child] is now thriving." **Parent**

"I would like my very small school to work with a larger mainstream school so that I can have a chance to work in larger groups when I feel able to."

**Young person with autism**

We want all schools to have access to the autism specialist support that they need. Local authorities will need to work with schools and other partners to identify the kind of autism expertise that is needed in their area. They should then commission appropriate, specialist services. The Government has protected funding for these services in 2011-12 but a longer-term strategy is needed to make sure they are available across England.



## Good practice

### Sharing specialist expertise

Beverley School in Middlesbrough is a specialist technology college with places for 125 children and young people with autism aged three to 19 years. The pupils come from Middlesbrough and the neighbouring areas and have a range of academic ability. Some have severe and complex learning difficulties. Beverley pupils may go to mainstream school for some of their lessons and likewise, some pupils from other schools attend Beverley part-time.

Funded by the local authority, Beverley School shares its autism expertise with local mainstream schools. It provides specialist advice and training, making use of the Inclusion Development Programme resources on autism. As well as formal courses, mainstream staff benefit from mentoring, placements and the chance to work alongside Beverley School staff to develop strategies for individual pupils.

## Making it real

Children with autism will not thrive in school unless staff feel confident about identifying their needs and putting appropriate support in place, whether a child has a statement or an EHCP, or not.

### Getting training right

The Green Paper proposes better training and awareness around SEN:

- › more funding for teacher training providers and more placements for trainee teachers in special school settings
- › scholarships for teachers and support staff
- › local 'clusters' of schools that share good practice and expertise
- › SEN to be a feature of school leadership qualifications.

We welcome these proposals, but more needs to be done to address such a fundamental issue. In this section we have set out some excellent and innovative practice in developing autism expertise in schools.

### To build such expertise across the country:

- › SEN scholarships for teachers should include specific scholarships on autism. There should be incentives for teachers, and teaching assistants, to take these scholarships up and share their knowledge
- › local authorities should work with schools and other services, such as health services, to make sure that all schools in their area can access specialist support for pupils with SEN.

We also want SEN training not to be just for staff at the school, but for those who oversee the running of the school, too:

- › training for Chairs of governing bodies must include a focus on SEN.





## Conclusion

**The Government's reforms** will shape the future of a generation of children with autism. The opportunity to fundamentally change the system for children with SEN and disabilities does not come round often. We have to take this chance to secure the right support for every child, to stop parents having to fight every step of the way – to create a system which works for everyone.

**Children expect an education that sets them up for life.** Without the right support from school, the educational progress, social skills, self-esteem and health of children with autism can all suffer. With support, they can achieve their full potential throughout childhood, paving the way for a happy, fulfilled life as an adult.

**Parents expect a system that works with, not against, them.** Parents will always want what's right for their children. But too many parents of children with autism have had to battle to get the support their child needs. Too many more are still fighting. A real voice for parents must be at the heart of these reforms.

**We expect the Government to listen, and to act.** In this report the NAS presents the real views and experiences of children with autism, parents and professionals as they try to get the support that is their right. We know what needs to change.

We have **Great Expectations** for children with autism, for their families and for these reforms.

**Let's work together. Let's get it right.**

# Methodology

The research for this report was carried out between October 2010 and April 2011. There were two main stages of work, described below.

## 1. Qualitative discussion

Discussion groups focused on the issues involved with the education of young people with autism, specifically within the context of proposed changes to the special education needs system in England. These discussions are referred to throughout the report as 'focus groups'.

### A: Discussion with parents

Participants were recruited through local NAS branches across England, resulting in five group discussions. The sample represented families with children across the autism spectrum, including those with autism and learning disabilities, high-functioning autism or Asperger syndrome. Transcripts were coded and analysed.

### B: Discussion with young people

The NAS invited a group of seven young people aged between 13 and 20 to take part in a discussion of their experiences in the school system. This group of young people regularly takes part in NAS activities as part of our Young Campaigners Group. This sample represents the higher-functioning end of the autism spectrum; all have had experience of the child mental health system.

### C: Discussion with professionals

Discussion groups were also held with professionals working with children and young people with autism in NAS schools. Three groups were held, one with the principals of the five NAS schools in England, one with six deputy head teachers, and one with 15 educational psychologists or behaviour coordinators. These discussions took place within scheduled meetings of these groups.

## 2. Quantitative survey

### A: Survey of NAS members who are parents of young people with autism

The NAS designed a survey, which elicited largely quantitative responses and offered the opportunity for lengthier qualitative responses to selected questions. The aim was to find out more about the experiences of parents and carers who are members of the NAS relating to their children's education.

**Sample:** 9,188 NAS members were invited by email to complete the survey online. A link to the survey was also included in the April e-newsletter to NAS members in England and the April newsletter to NAS branches.

**Analysis:** A total of 897 parents and carers of young people with autism completed the survey by the deadline, representing a response rate of 9.8%; only responses from parents of those under the age of 19 who are NAS members were analysed, leaving a sample size of 739.

### B: Survey of young people with autism

The young people's survey was advertised on the front page of the NAS website, inviting any young person with autism aged under 19 to take part. A link was also provided from the parents' survey. 307 people began the survey and 295 responses fitted the overall criteria specified.

**Analysis:** There were no incentives for respondents to complete the survey. The introduction to each survey explained the purpose of the research and set out confidentiality procedures. Numeric responses were anonymised and analysed using a software package to produce aggregated tabulated results. Qualitative open-ended responses were also anonymised and coded for analysis.





# Great Expectations

**The Government's reforms will shape the future of a generation of children with autism.**

**Children** expect an education that sets them up for life.

**Parents** expect a system that works with, not against, them.

**We** expect the Government to listen and to act.

**Let's work together. Let's get it right.**

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

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

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

***Together, we are going to change this.***

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