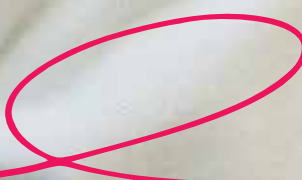


School report 2016

Two years on, how is the new Special Educational Needs and Disability (SEND) system meeting the needs of children and young people on the autism spectrum in England?



Until everyone understands





School report 2016

Two years on, how is the new Special Educational Needs and Disability (SEND) system meeting the needs of children and young people on the autism spectrum in England?

Written by

Catriona Moore

Contents

1	Executive summary	3
2	Introduction	4
3	The first step: assessing children's needs	6
4	Getting the right support in place	12
5	Making sure every school understands autism	17
6	Conclusion	20
7	Summary of recommendations	21

Acknowledgements

Thanks to all the parents and young people on the spectrum who completed the survey to inform this report. Thanks also to The National Autistic Society staff who helped produce this report, including Tim Nicholls, Andrew Cutting, Sarah Lambert, Piers Wright, Olly Parker and Jane Harris.

1 Executive summary

Our charity welcomed the aspirations of the *Children and Families Act 2014* (the 'Act'). Yet two years on from the Act's implementation, too many autistic children and their families are:

- waiting too long and having to fight too hard for the right support to be put in place
- unable to access the range of non-educational support needed at local level to help autistic young people reach their full potential
- unable to access the right help in school because of a lack of understanding and autism expertise across the school system, which in the worst case results in avoidable or unlawful exclusions from school.

So that every child is able to fulfil their potential and contribute their talents and skills to our society and economy, we recommend that:

- 1 The Government must make sure the new system can work effectively, eliminate delays in accessing support and ensure families get help to challenge the system, when needed.
- 2 Central and local government, as well as multi-academy trusts, must work together to make sure the right mix of educational provision and support for autistic children is available locally.
- 3 Training and awareness of autism must be embedded across the education system.

This report is part of the joint *Every Child* campaign, led by The National Autistic Society and Ambitious About Autism.¹



¹ For more information see: www.autism.org.uk/everychild

2 Introduction

More than one in 100 children are on the autism spectrum – an estimated 120,000 school-aged children in England. As one of the most common types of special educational needs (SEN), autism affects children in every school in the country. Over 70 per cent of children on the spectrum attend mainstream schools.²

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life. It is a spectrum condition and affects every child (and adult) differently, although there are some common areas of difficulty.

While it can present some serious challenges, with the right support children and young people can make excellent progress. For some children, this will be a relatively small amount of support, with some straightforward adjustments at school, such as a quiet place to go at break time or time out from a noisy classroom. Those with more complex needs across the spectrum will need higher level and more intensive support. In some cases this may be in an autism-specific special school.

Every young person is different. Each child deserves to have their particular needs understood and met, and to have the opportunity to achieve their potential and develop their unique skills and talents. Every autistic child deserves an education that supports them to reach their potential.



The SEND system in England

Back in 2011, when new legislation on SEND provision in schools was being developed, we published our *Great Expectations* report. This set out what parents and young people wanted from a reformed system. They told us they wanted support to be in place early, and a system that listened to them, was more joined-up between education, health and care and was less adversarial. The Government's reforms were ambitious and promised to reflect these concerns.

Last year, one year on from the introduction of the new system, we asked parents and young people on the autism spectrum what difference the reforms were making.³ We heard that parents were having to fight just as hard for support under the new system as they were under the previous one; that parents whose child had been through an education, health and care (EHC) assessment were often unhappy with the process (although largely satisfied with the contents of their child's final EHC plan); and that parents and young people identified a lack of understanding of autism in schools as a major ongoing obstacle.

A year further on, and two years since the new system was introduced, we have again asked parents and young people about their experiences, to see if the promises of the Act are being fulfilled for autistic children and young people.

We carried out an online survey of 980 parents and carers of children and young people on the autism spectrum in England during June 2016. We also ran a survey of children and young people on the autism spectrum, which was completed by 85 young people under 25. To further inform this report we have used data from phone calls and email queries to The National Autistic Society's School Exclusion Service, which supports parents of children and young people on the autism spectrum who have been, or are at risk of being, excluded from school. The service responded to 601 enquiries last year.

² Department for Education. *Special educational needs in England: January 2016*

³ The National Autistic Society. *School report 2015*

Jody's different experiences with two sons

Jody had very different experiences getting support for her sons Cameron (13) and Harry (11), who are both autistic and struggled in mainstream schools.

Cameron was heavily bullied at school and struggled with depression and anxiety, prompting Jody to home school him while she looked for a placement that met his needs. Under the old SEN system, she faced a long battle and ended up appealing to the SEND Tribunal. This had a huge impact on the whole family's wellbeing.

Although the Tribunal ruled in Jody's favour, the resulting EHC plan stated that Cameron should go to a specialist unit attached to a mainstream school, rather than to a specialist school. Cameron continued to struggle, and the school recently agreed that his complex needs can only be met in autism-specific provision. Jody is now working with the school and council to try to get him the support he needs.

Getting a SEN statement for Harry was much simpler and he's doing well at an autism-specific school. His statement was recently transferred to an EHC plan, under the new system. It took around six months to finalise the plan and Jody was very happy with its contents and how the school implemented it. Harry has continued to flourish.



3 The first step: assessing children's needs

The first step for any child on the autism spectrum in getting the right education is having their needs assessed fully and promptly. Without a full understanding of what a child needs, there is little chance of them getting the support they need and deserve in school. Delays or poor quality assessments mean children missing out on days, weeks and months where they could be gaining new skills and knowledge.

In 2015, 75 per cent of parents who responded to our survey said that it had not been easy to get the educational support their child needs, up from 68 per cent from a survey we carried out in 2011. It could have been argued that this was a sign of a new system and over time this number would decrease. However, a year on, 74 per cent are still telling us they have found it difficult to secure the support their child needs. And many are saying they are having to use the legal system to secure the necessary support for their child.

Delays

“Special educational needs and disabilities will be picked up at the earliest point with support routinely put in place quickly.”⁴

The reforms introduced in 2014 emphasised the importance of needs being “picked up at the earliest point with support routinely put in place quickly”.⁵ However, one of the biggest problems we found was the length of time that many children wait, from the point when concerns are first raised to the point when they begin receiving support that meets their needs.

Sixty nine per cent of respondents to the survey said their child had waited more than a year after first raising concerns, and 16 per cent had waited more than three years – a similar proportion to previous years, and an indication that the system is still not prioritising early identification and early intervention.

In part, this is due to the challenges of ensuring early identification and then diagnosis of autism. Lack of understanding of the condition across the health and early years system means that individual professionals may not be identifying autism. In addition, long waiting times for diagnosis (a recent study showed on average children wait 3.6 years for a diagnosis after concerns are first raised with a professional⁶) suggest that commissioners are not ensuring sufficient capacity for diagnosis.

There is also a need for a clearer join-up between health and education, so the needs identified when a child is diagnosed are passed on to local authorities to inform the help the child gets in school.

Recommendation: Clinical Commissioning Groups (CCGs) should ensure they are following National Institute for Health and Care Excellence (NICE) Guidelines⁷ on identifying and diagnosing autism in children and young people, and that they are commissioning sufficient capacity in their autism diagnosis services.

Recommendation: CCGs should ensure that children diagnosed with autism are flagged to local authorities so they can be identified in the education system and the right support put in place at an early stage.

The transfer to an EHC plan

As well as the issue of early identification, delays in getting support are also due to difficulties in implementing the new system.

As a result of the Act, statements of SEN have been replaced by EHC plans, which aim to bring together a child's health and care needs with their educational support. This change was a particularly welcome part of the reforms and should mean that support between different services is more joined-up.

⁴ Department for Education and Department of Health. (2015). *Special Educational Needs and Disability Code of Practice: 0-25 years* – from the Foreword

⁵ Ibid

⁶ Crane et al. (2015). *Autism*. City University London and Goldsmiths: London / Jones et al. (2014). *Journal of Autism and Developmental Disorders*. City University London and Goldsmiths: London (available at: <http://www.autismdiagnosis.info>)

⁷ National Institute for Health and Care Excellence. NICE Guidelines [CG128] *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*

The legislation is clear that children who have SEN statements should be assessed for transfer to an EHC plan by April 2018.

Of the 201 parents of autistic children and young people who responded to the survey who still have a statement of SEN, over half have been informed about when their child's EHC transfer review will take place – **but 44 per cent have not yet received this information.**

Some parents have been told very little by their local authority about the process of transferring from a statement to an EHC plan, what this means for their child, and their right to be informed and consulted. One parent told us:

“We went for our child’s annual review to find it was the draft EHC plan and we had not been informed of any of the process.”

It is not always made clear to parents that their child is entitled to a full reassessment of their education, health and care needs as part of the transfer review. But the law is clear: “Realising the benefits of the new EHC plans for children and young people who already have statements of SEN or young people who receive support as a result of a Learning Difficulty Assessment (LDA) will require their transfer to the new system to be more than simply a re-badging of their existing statement or LDA.”

One parent told us:

“The reports from professionals used for [my child’s] EHC plan were the ones used for the original statement six years ago. Despite requests, I have not been able to have a reassessment.”

Another issue raised by parents is the question of who writes EHC plans. The *Children and Families Act 2014* makes local authorities responsible for producing EHC plans, but in practice many authorities have delegated this responsibility to schools.

While this may work well in terms of ensuring that a child's plan is written by someone who has a good knowledge of the individual child, it can also mean that the plan is heavily slanted towards education rather than health and social care. This goes against the ambitions of the reforms. It can also have other implications. One parent told us:

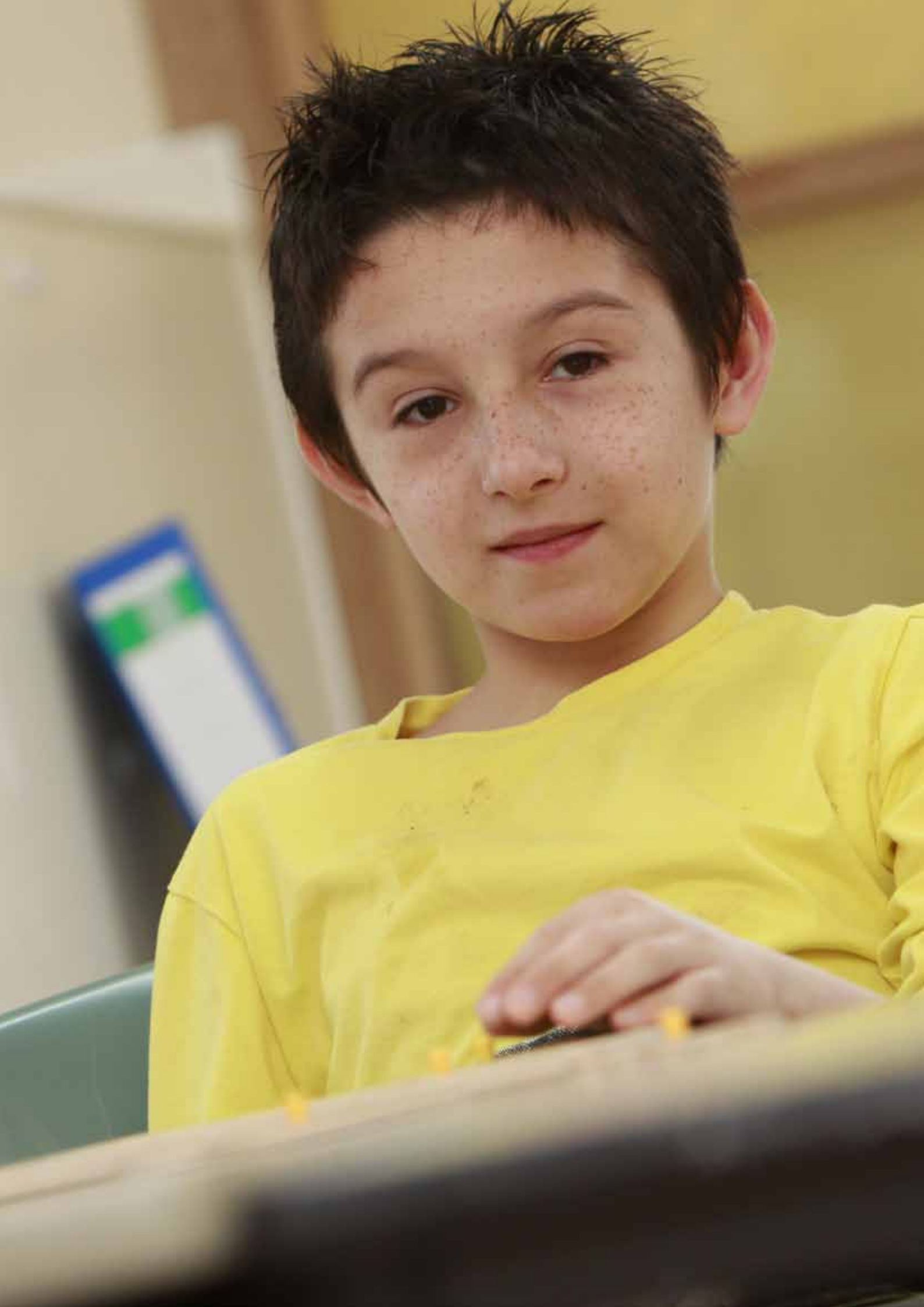
“Our council SEN team did not write EHC plans but have given this job to special educational needs co-ordinators (SENCOs). This is not in my child’s interest as the SENCO wants to add things that the school is okay providing and not things my child needs.”

The 2018 deadline the Department for Education has set for statements to be transferred to EHC plans is getting closer. However, the most recent statistics show that, a third of the way through the implementation timetable, **only 18 per cent of statements had transferred to EHC plans.**⁸ This suggests that areas are struggling to go through the transfer process in a timely manner.

Rushing the plans could lead to poor support and, ultimately, worse progress in getting autistic children the support they need. The Government has already recognised some of the challenges local authorities are facing by in January 2016 announcing a continuation and expansion of transitional funding, to help local authorities implement the reforms. Monitoring the use of this funding and making sure local areas have the resources they need to implement the new system is essential.

Recommendation: The Department for Education should report on how local authorities are using the transitional funding they have been allocated to help with the transfer, and use these reports to determine any additional resources needed to implement the reforms within the timeframe. If local authorities cannot implement the reforms by 2018 without compromising the help that children receive, implementation should be delayed.

⁸ Department for Education/Office of National Statistics. *Statements of SEN and EHC Plans*. England: 2016



Missed deadlines, delayed support

Jane* has two children on the autism spectrum, Anna* (15) and James* (13). They are both academically bright, but they have high anxiety and experience sensory difficulties, which makes it hard to be in noisy or busy environments.

It took 30 weeks to finalise an EHC plan for Anna and 28 weeks for James, both outside the 20-week timeframe. Jane had to employ solicitors to negotiate with her local authority. She was pleased with the content of Anna's plan but disappointed that it took so long to find her a place at the named autism-specific school and that her daughter has to travel for around three hours to get there each day.

Jane was very dissatisfied with James's EHC plan. She successfully appealed to the SEND Tribunal against the decision to send him back to the mainstream school where he struggled.

*names have been changed

The wait for an EHC plan to be finalised

The statistics on EHC transfer from the Department for Education cited above, plus parents' accounts of their own experiences, suggest that getting to the point where a child or young person's EHC plan can be finalised and signed is often not straightforward.

Only six out of ten EHC plans were issued within the 20-week time limit specified by the Department for Education (with considerable variation between different authorities).

It is very important to get every child's plan right, ensuring that it accurately records all necessary information about the child's needs and support. However, parents told us that taking too long over this process can be frustrating and counterproductive. This applies whether it is new provision or a transfer from a SEN statement.

One parent reported that it took 48 weeks, over twice the Department for Education time limit, for their child's EHC plan to be finalised. Others said:

“Children shouldn't have to wait months or longer to have the necessary support in place to assist with learning. Autistic children often fall behind educationally while this long process takes place.”

“I've had to make a lot of changes to the draft EHC plan, both to ensure it describes my son properly and to make it compliant with statutory guidance. The process has taken so long that my son's needs and desired outcomes have changed considerably since we started.”

“We got there in the end and are happy with the final EHC plan but the process was very stressful and deadlines kept changing. We think the County Council couldn't cope with the workload and their own and statutory deadlines.”

Recommendation: The Department for Education should evaluate and publish how well each local authority is processing EHC needs assessments and share examples of good practice in implementation.

A less confrontational system

The Act was intended to promote collaboration and joint working around the needs of the child, and reduce conflict between parents and local authorities. To do this, Section 19 of the Act puts participation in decision-making at the heart of the reformed system.

The SEND Code of Practice spells out that: “It is in a child’s best interests for a positive dialogue between parents, teachers and others to be maintained, to work through points of difference and establish what action is to be taken.”⁹

Nonetheless, some families continue to believe, based on their experience, that the SEND system is skewed against them, with local authorities engaging lawyers to fight against them. Several parents who responded to the survey highlighted the recent publicity around law firm Baker Small’s series of comments on Twitter about winning cases against parents of children with disabilities.¹⁰ Parents saw the comments by the law firm – which was acting on behalf of a number of local authorities – as an indication of what they were up against as they tried to have their child’s needs understood and taken seriously.

For parents of children on the autism spectrum, the right to appeal to the SEND Tribunal against a local authority’s final decision is a crucial last resort. If the ‘dialogue’ described in the SEND Code of Practice fails, the law is there to help their child receive the educational support they are entitled to.

However, the large number of appeals to the SEND Tribunal suggests that parents have to use this ‘last resort’ too often. Autism is the most common type of SEN identified in SEND Tribunal cases. In 2014-15 autism-related appeals made up 35 per cent of Tribunal appeals.¹¹

Figures from the Ministry of Justice show the Tribunal **only decided about a quarter of cases – the remainder were subsequently withdrawn or conceded by local authorities**. Of the appeals that proceeded to a decision, **86 per cent found in favour of the parent – a three per cent increase on last year**.¹²

The fact that local authorities conceded or parents won so many cases suggests that too many wrong decisions are being made. This demonstrates the importance of the Tribunal, but it is also important to remember not all parents have the knowledge, energy or resources to put up the necessary fight.

Of the parents who responded to our survey, **17 per cent had appealed to the SEND Tribunal**. The main reasons for doing so were the local authority’s refusal to issue a statement or EHC plan for their child, or to change the school named in the child’s statement or EHC plan.

The system does not allow parents to appeal to a single body against all aspects of a child’s EHC plan. Although the EHC plan brings together education, health and care needs, the only provision within it that can be appealed at the SEND Tribunal is the education section. Parents dissatisfied with the health or social care aspects of their child’s EHC plan can use the usual NHS complaints process or their local council’s complaints process to challenge this. Only a very small minority of parents who responded to our survey had done this. It is unclear whether this is due to lack of awareness of the process or if there have been other challenges in accessing the complaints process.

As a result of campaigning from organisations including our charity, since April 2015 the SEND Tribunal has been running a pilot in 13 local authority areas allowing the Tribunal to make non-binding recommendations on health and social care needs and provision specified in EHC plans.¹³ At the time of writing this report, an interim report on the outcomes of the pilot was anticipated but had not been published. However, we continue to believe that a single point of appeal on all aspects of an EHC plan is needed, with a Tribunal being able to rule equally on all education, health and care provision matters to make sure the system is integrated.

Recommendation: The Government should reconsider its position on the SEND Tribunal and work to introduce a single point of appeal for education, health and care, using the findings of its pilot to inform how this would work.

⁹ Department for Education and Department of Health. (2015). *Special Educational Needs and Disability Code of Practice: 0-25 years* – from para 1.7

¹⁰ *The Guardian*. (14 June 2016). ‘Fury as law firm boasts of ‘great win’ over parents of vulnerable children’

¹¹ Ministry of Justice. (July to September 2015). *Tribunals and Gender Recognition Certificate Statistics Quarterly*

¹² Ibid

¹³ Explanatory memorandum to the Special Educational Needs and Disability (First-Tier Tribunal Recommendation Power) (Pilot) Regulations 2015

Advice and independent support for parents

Parents are entitled to support from an Independent Supporter in their local area to help guide them through the EHC assessment or transfer process. The Government has commissioned the Council for Disabled Children to recruit Independent Supporters and provide this service across England.

This service was well received in our survey. Of the parents who responded to the survey who received help from Independent Supporters, around two thirds said it was helpful. More needs to be done to make sure parents are aware of the service and how it can help, as **fewer than half of those who had gone through the process were offered this support.**

Recommendation: The Government should work with the Council for Disabled Children to make sure that all parents going through the EHC assessment process are aware of the help they can get through Independent Supporters and determine if the service needs to be expanded.

Advice services

For parents of children on the autism spectrum our charity runs the Education Rights Service. Our Education Advice Line can help when you want general information about your child's educational rights and entitlements or advice on specific topics such as getting extra help in school, assessments, education plans, reviews or school transport. Our Tribunal Support Line can help you consider your options if you have a right of appeal against a decision about your child's educational needs. Last year we responded to 2,351 enquiries to the Education Advice Line and Tribunal Support Line in England.

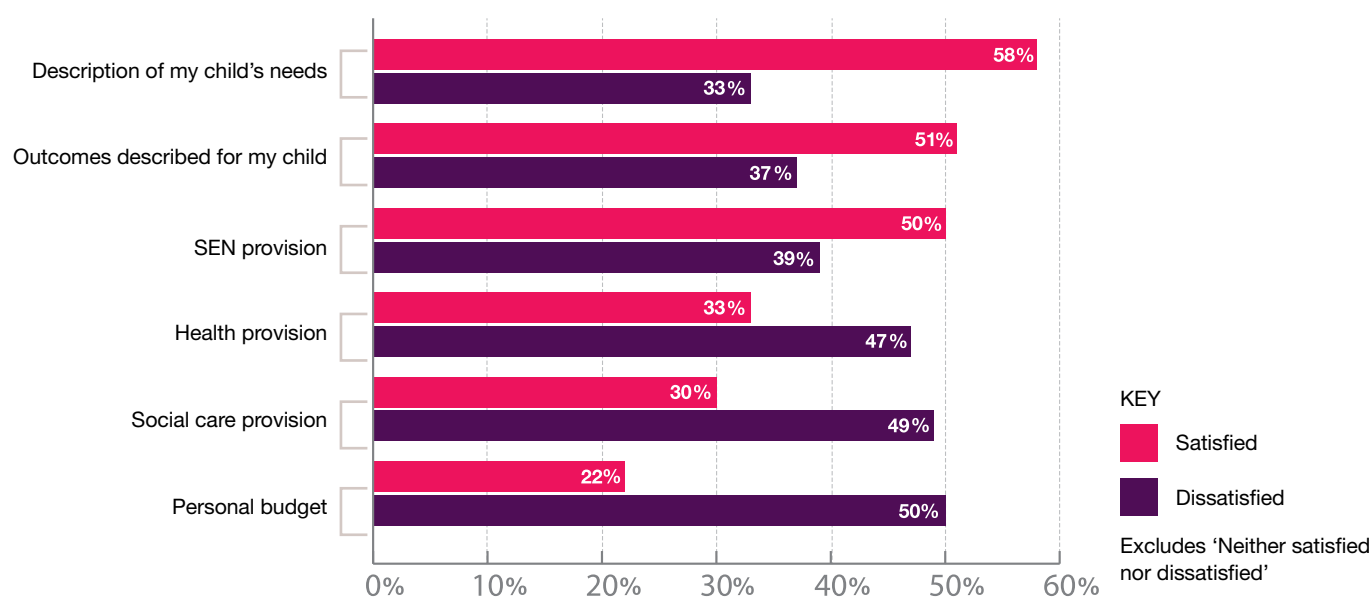


4 Getting the right support in place

Once needs are identified across education, health and care, it is vital that the individual child is able to access the right help. Many parents report that after having to fight for an EHC plan, they are relatively satisfied with the final plan. Overall satisfaction with the education that autistic children receive is mixed and a significant minority are unhappy with their child's school placement, wanting instead a place in a school with more autism expertise.

There are also significant challenges with getting the right help outside education. For many, the help they need is with social and communication skills and to interact with others. These skills help all of us learn and cope with day to day life, but these types of needs are often overlooked, in commissioning and on an individual basis.

Parents' satisfaction with elements of their child's final EHC plan



Although it can be difficult and time-consuming to finalise and agree an EHC plan, parents are on balance more satisfied than not with the way the plan describes their child's needs and anticipated outcomes.

It is clear, however, that parents have more confidence in the educational provision in their child's plan than in the health or social care provision, suggesting there is still some way to go to secure the cultural change needed so that services across education, health and social care are working together systematically to meet the needs of children and young people in a co-ordinated way.

In addition, parents of older children had much less confidence in the system. Sixty eight per cent of parents of 16-19 year-olds said their child's EHC plan is not clear about who will be providing support with preparing for adulthood and how this support will be provided. Extending SEND support up to the age of 25 was a key part of the reforms. The potential of this change is yet to be fully realised for autistic young people.

The right school?

We asked parents whether their child is in their preferred educational setting. **Sixty one per cent of parents said their child was in their preferred type of school.**

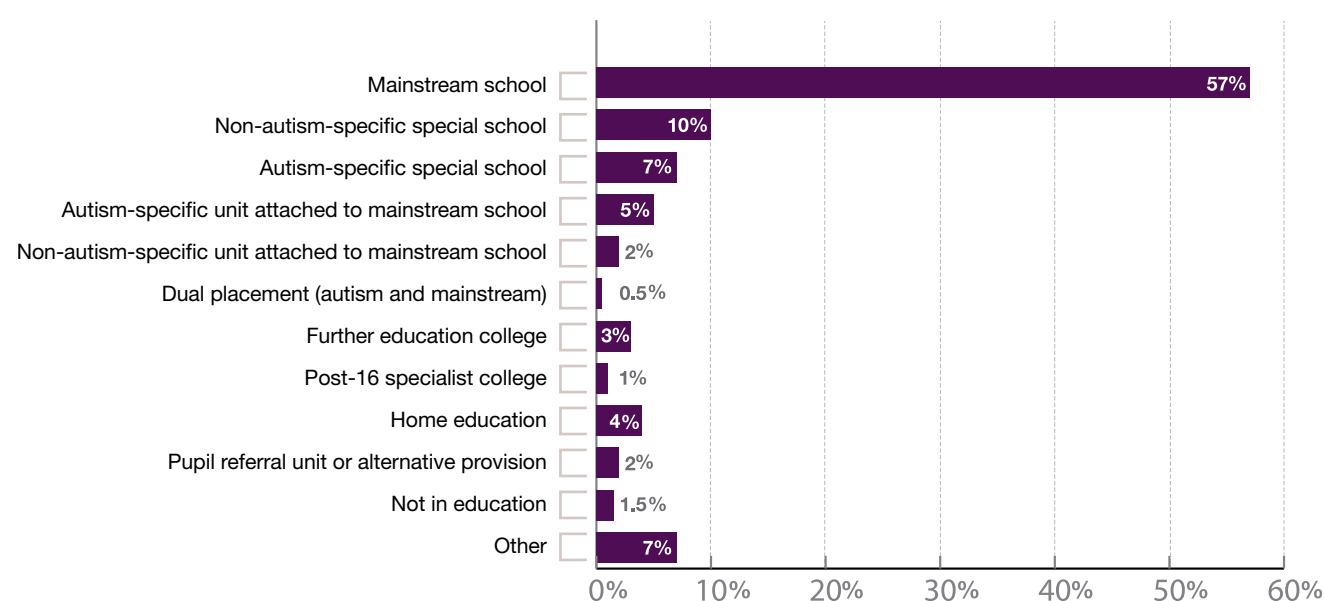
A significant minority – a quarter of respondents – said they would prefer a different type of education for their child. Of these, the main preference was for their child to attend an autism-specific special school (42 per cent), followed by an autism-specific unit attached to a mainstream school (24 per cent).

Parents who are less satisfied with their child's current school place express a clear wish for their child to be educated in a place where autism is a specialism and is well understood, demonstrating the importance of greater autism understanding and expertise throughout the system. This is considered in more detail in section five of this report.



Where children and young people on the autism spectrum are educated

Parents who responded to the survey said their children are in the following settings:¹⁴



¹⁴ The percentage of children in mainstream schools is lower in this survey than in national statistics: Department for Education/National Statistics. (January 2014). *Special Educational Needs in England*

Finding the right school for Joshua

Joshua (14) has a diagnosis of Asperger syndrome and is flourishing at school, preparing to take his GCSEs a year early.

But 18 months ago things were very different. Joshua was desperate to learn but was struggling with mental health problems and was unable to go to school. He found it difficult to cope with the school's size and constant social pressures and his anxiety grew. His mum Pippa says that his mainstream school was very understanding and put support in place but just couldn't meet his increasingly complex needs.

Joshua spent about six months out of school, a difficult time for the whole family in which he became suicidal and self-harmed. They researched other schools but struggled to find one that could meet Joshua's needs and stretch him academically – until they found The National Autistic Society's Thames Valley School.

Joshua felt that the smaller class sizes, specially designed classrooms with relaxed lighting and displays and flexible approach to the curriculum, would reduce his anxiety and help him learn. The family are taking everything one step at a time but are excited for the future – Joshua recently took a school assembly and aspires to be a Formula 1 commentator.

Charlie's transfer to an EHC plan

Charlie (14) has always been in mainstream school and, after progressing well, is about to start his GCSEs.

Charlie was diagnosed early, at the age of two, and had a statement in place by the time he started school. This has meant that teachers can immediately give him the support he needs, including one-to-one help from a teaching assistant who helps him structure his thoughts, take notes and get things down on paper. His parents, Tom and Beth, feel really lucky that the school have such a good understanding of autism and are so willing to make reasonable adjustments.

However, Tom and Beth are worried about the ongoing transfer of Charlie's statement to an EHC plan and how this will affect their son. They're supportive of the new system but are concerned that the review could see how well Charlie is doing and recommend a reduction in support. This would be a disaster and put at risk Charlie's progress so far.



When asked whether they are satisfied, overall, with the support their child receives at school for their autism, respondents were fairly evenly divided. **Forty two per cent of parents were either 'quite' or 'very' satisfied, while 40 per cent were 'quite' or 'very' dissatisfied.**

Some parents expressed satisfaction with their child's school placement and the support they receive, while emphasising how hard-won this is:

"I had to fight every step of the way to get her a suitable placement."

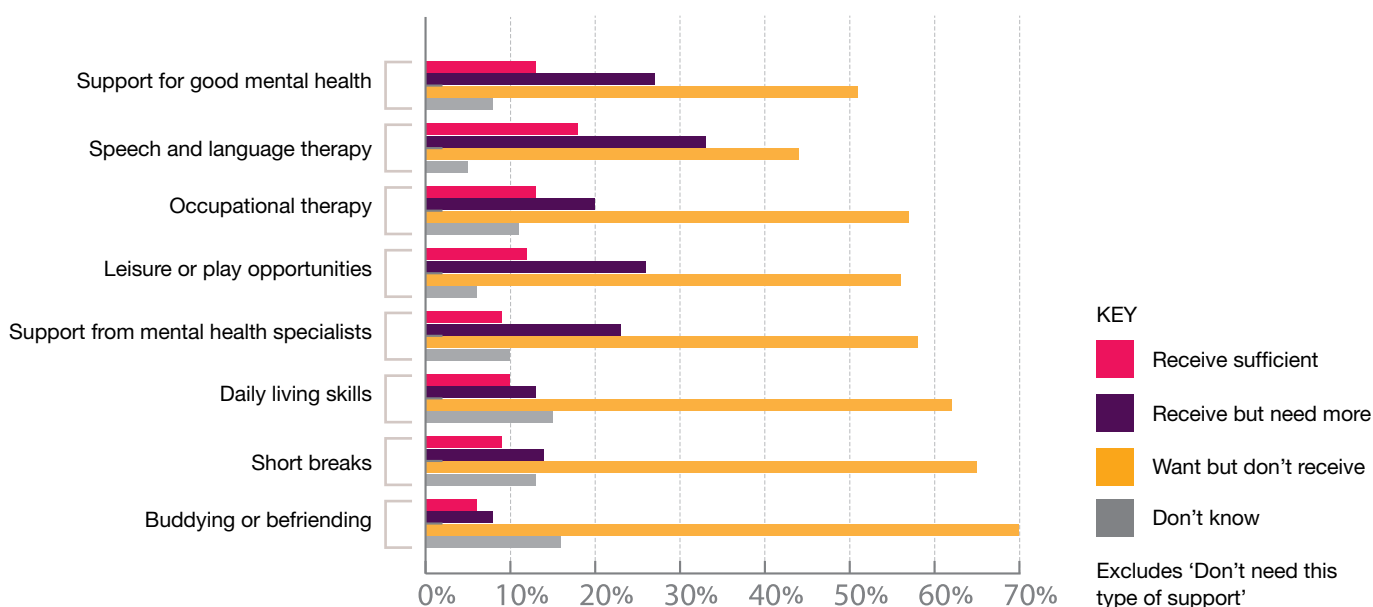
"I am happy with the education – but the fighting it takes to ensure your child gets what they are entitled to is a scandal. The system has a fundamental conflict of interest at its heart. How can you have a local authority who acts as assessor of need, decision-maker, funder and provider?"

The survey found that **four per cent of children are home educated**, representing 38 children. **Fourteen children (1.5 per cent) are not currently in education at all.**

We asked parents who educate their children at home whether this was their first choice. Only six parents said they home educate by choice. The remainder said their child is home educated because their needs cannot be met at school, or their child's school placement had broken down and they had been unable to find an alternative.

Recommendation: The Department for Education should work with local authorities and multi-academy trusts to develop a clear service model, which sets out the right 'mix' of different types of provision to meet the needs of children across the spectrum.

Types of support children on the spectrum need



The range of support autistic children may need is often not purely educational. They may need help with socialising or in developing the daily living skills other children develop without any specific help as they grow up.

Our survey showed a demand for a range of support services that currently far outstrips supply, leaving many families unable to access the support their child needs. The most wanted and least received type of support is 'buddying or befriending'. This reflects the concern many parents express that their child will be isolated from their peers as they get older and move into adulthood.

The local offer: information and access to services

A central component of the reformed SEND system is the local offer – information published online by local authorities about all the education, health and care services for children with SEND in their area. Local authorities are specifically required to include provision that will help young people prepare for adulthood.¹⁵

The SEND Code of Practice is clear that the local offer has two key purposes: to provide clear, comprehensive, up-to-date information about what is available and how to access it, and to make service provision more responsive to local needs and aspirations.

We asked parents about the local offer:

- > Fifty two per cent of parents said they had looked at the local offer in their area, while 42 per cent had not.
- > Forty four per cent of parents who had looked at it said that it was 'very easy' or 'quite easy' to find information about support for children and young people on the autism spectrum, while 55 per cent said it was 'quite difficult' or 'very difficult'.

However, **only 28 per cent of parents said they had been able to access services for their child as a result of the local offer, while 72 per cent had not.**

Simply knowing about the existence of services is not in itself enough to ensure that children and young people on the autism spectrum can access the support they need.

One parent commented:

“It’s just a list of random things that may or may not actually be happening and may or may not be available to your actual child.”

Recommendation: The Department for Education should develop a guide to showcase good practice in commissioning local support that children on the autism spectrum need.

Recommendation: Local authorities should use autism-specific data collected from the School Census and other sources to inform their planning and ensure that a wide range of appropriate educational options is available for children on the autism spectrum, as well as other necessary services such as after-school provision and holiday activities.

Recommendation: In line with the *Autism Act* statutory guidance, local authorities should seek input from local autism partnership boards in the development of their local offer.



¹⁵ Children and Families Act 2014, Section 30

5 Making sure every school understands autism

The SEND reforms are not being implemented in a vacuum: the extent to which autism is understood is vital and determines whether children and young people on the autism spectrum will thrive and make progress or struggle and fail.

Fifty eight per cent of parents said schools' knowledge of autism is the single most important factor in meeting their child's needs. Parents who responded to the survey believe that, within schools, classroom assistants and SENCOs are most likely to understand how to support children and young people on the autism spectrum, while school governors are the least likely.

When asked what would improve their experience of school, two thirds of children and young people themselves said "if more teachers understood autism". Other factors that would improve their experience are people being less noisy in class (around four in ten), other pupils understanding autism (around a third) and other school staff understanding autism (a quarter).

Six in ten children and young people who responded to the survey said the worst thing about school, from their perspective, is teachers who do not understand autism. This was followed by not having friends, exams and tests, and not knowing what happens next in the school day.

The recent announcement that autism will be included in the new Initial Teacher Training framework is therefore a very welcome development and will help make sure every new teacher has a basic understanding of autism.¹⁶

It will also be important that every teaching professional, and the schools they work in, has the training and resources to meet the needs of autistic children and young people. It is important that the lived experience of parents and autistic young people informs this training.

In addition, we know that not all teachers are going to become experts in autism and may need extra help from those with more knowledge. It is important that this is made available to them throughout their careers.

We asked young people how happy, safe and included they feel at school or college. Responses to the survey indicated that **only half are happy, one young person in seven does not feel safe and about a third do not feel included.** This further demonstrates the importance of professionals being trained, but also highlights the importance of raising awareness of autism among other pupils.

Recommendation: Multi-academy trusts and local authorities should ensure the schools they are responsible for have access to autism expertise, perhaps through an autism advisory service, to help every school provide the right support for autistic children in their care.

Recommendation: Schools should make use of training offered by the Autism Education Trust to ensure teaching and non-teaching staff are equipped to support autistic children throughout the school.

Recommendation: Teachers should make the most of information and free resources that are available on how to support children and young people on the autism spectrum as effectively as possible and how to raise awareness of the condition, for example by signing up to our charity's *MyWorld* initiative (www.autism.org.uk/myworld) or by signing up their school to participate in Schools' Autism Awareness Week.¹⁷

¹⁶ Munday, S. (July 2016). *A Framework of Core Content for Initial Teacher Training*

¹⁷ www.autism.org.uk/get-involved/world-autism-awareness-week/schools-autism-awareness-week.aspx



Adjustments made by schools and colleges to meet young people's needs

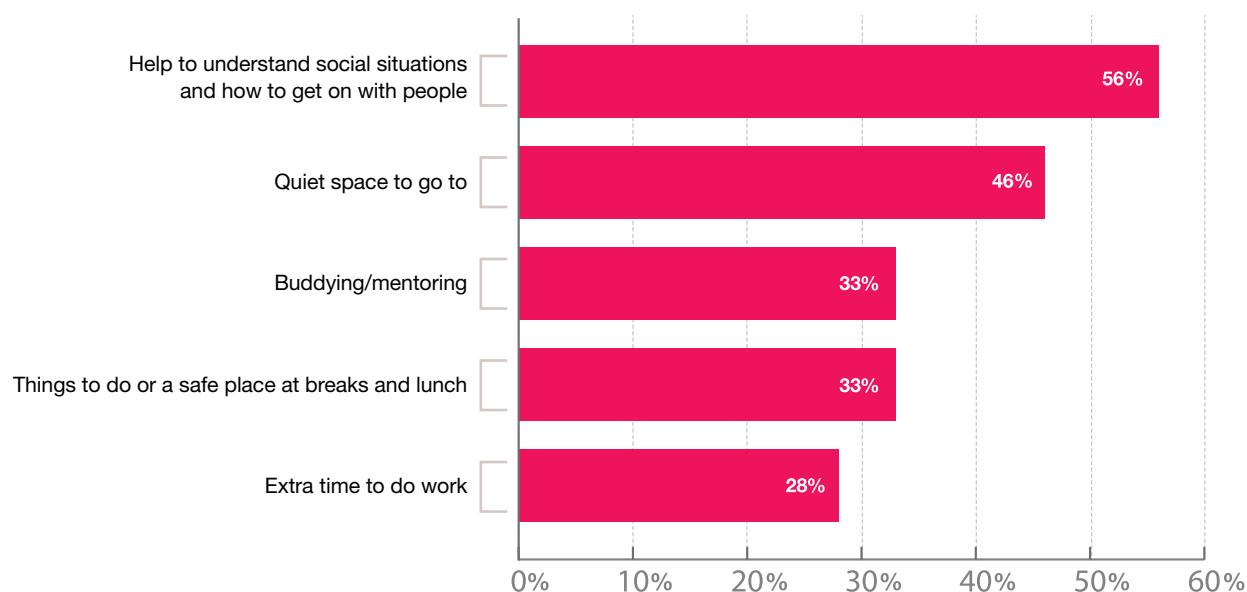
Our survey asked parents and young people on the autism spectrum what type of adjustments schools and colleges have made to meet their needs. The *Equality Act 2010* is clear that schools have a duty to make reasonable adjustments for individual disabled children, including those with SEND, to prevent them being put at a disadvantage in relation to their peers.

However, we found a variable picture in terms of how much schools and colleges are making adjustments for individual children on the autism spectrum. Most parents said that their child needs adjustments of some sort, including teaching materials, teaching approaches and the classroom environment.

We also asked young people what help they would like at school that they do not currently get.



What help would young people like at school that they do not get?



Tackling school exclusions

A lack of understanding by schools of the needs of autistic pupils, and a failure to make reasonable adjustments to meet these needs, can result in schools resorting to exclusion more often than is necessary.

In our survey, one in 20 pupils whose parents responded have been permanently excluded from school and nearly one in five have received at least one fixed-term exclusion. National figures from the Department for Education show that pupils on the autism spectrum are four times more likely to receive a fixed-term exclusion than pupils without SEN (3,030 pupils on the autism spectrum were given at least one fixed-term exclusion in 2013-14).¹⁸

The most common reason for exclusions given to our charity's School Exclusion Service is physical assault against an adult or another pupil. While there may be different underlying reasons for this, for many children on the spectrum, behaviour that is difficult to manage may be caused by a build-up of anxiety that occurs as a direct consequence of their autism. For instance, some children and young people on the autism spectrum are so sensitive to light or sound that an overhead light or humming computer can be physically painful and make it almost impossible to follow a lesson. For others, a small change to the day's schedule, like the school bus turning up late or a sudden change to the seating plan, can feel like the end of the world. If these needs aren't recognised and met, a child can become overwhelmed and 'melt down' which leads to difficult behaviour that may be misinterpreted as naughty.

Alarmingly, our survey found that one third of children and young people have been informally excluded on at least one occasion. And 12 per cent of enquiries to the School Exclusion Service last year were about informal exclusions.

'Informal exclusions' have no basis in law. They should not happen. What the term means in practice is that parents are asked to remove their child from school, either as a one-off occurrence or on a regular basis, without any formal records that this is happening.

The result of these informal exclusions is that the child has gaps in their education and parents lose their right to appeal, quite apart from having to be constantly available to collect their child from school. This requires a parent to either have an extremely sympathetic employer; to be self-employed, but able to endure loss of earnings or rearrange their workload; to be unemployed; or to have a partner or close family member who can share childcare.

"My son is excluded daily from school 12-3pm."


"The school would call on a regular basis to ask that my child be taken home, as he was disrupting the class."

"It has often felt like it was easier for the school to call us away from work to collect him rather than giving him the time and space he needed to calm down after a problem. It feels like he has often spent more time at home than in school over the last few years."

"Not all staff understand the issues or behaviours that are autism-related and blame bad behaviour."



¹⁸ Department for Education. (January 2016). *SEN absences and exclusions: additional analysis*



A number of parents commented that, once they became aware that informal exclusions were unlawful and raised this with their child's school, the practice stopped.

While headteachers may believe that an exclusion – whether formal or informal – is the solution to maintain the safety and wellbeing of other pupils, it is important that staff are aware that behaviour that appears disruptive and uncooperative can be an indication of unmet needs in autistic children. In such cases, exclusion is unlikely to improve their behaviour and can disrupt their academic progress.

From discussions with parents on the exclusions helpline, we know it can also reinforce feelings of isolation and a sense that they do not belong. Ultimately, it can result in them becoming disengaged from learning.

Knowledge of autism and empathy for the individual pupil are key. An autistic pupil's experience of school can be transformed by tailored reasonable adjustments by trained teaching staff, working collaboratively with parents, colleagues and autism specialists.

Recommendation: Schools should make reasonable adjustments to the school environment, including behaviour policies, to meet the needs of autistic children and young people. This should improve their experience of school, avoid placing them at a disadvantage, and reduce the number of avoidable exclusions.

6 Conclusion

“Our reforms are as much about a change in culture as a change in law.”¹⁹

This is how the children's minister described the SEND reforms just before they were introduced two years ago. The experience since the new system was introduced shows that it actually takes longer to bring about genuine cultural change in the way things are done at local level than it does to change the law nationally.

The SEND system the *Children and Families Act 2014* introduced prioritises collaboration around the individual child, joint working, early identification of needs, planning ahead, inclusiveness and openness. Yet the experience of parents of autistic children is that they have to advocate as hard as they did before on behalf of their children.

As one parent who responded to our survey said: “Unless I fight to ensure his needs are met, they will not be.” Parents' experience is that they are frequently engaged in tiring and demoralising struggles with their local authority to get access to the support their child needs, and with their child's school to have their autism understood.

If children and young people on the autism spectrum are to receive the educational support they need – and to which they are entitled – to enable them to achieve their potential and enjoy their lives, the SEND system needs to work for them in the way it was intended. Parents and young people need to be full participants in decision-making; local authorities need to respond more quickly to requests for assessment and support; education, health and social care need to work together with the child at the centre; and everyone needs to think ahead and plan ahead to support young people to live the lives they want as they move towards adulthood.

¹⁹ Edward Timpson MP, 29 April 2013, Pears Annual Lecture

7 Summary of recommendations

To help support implementation of the new SEND system:

- CCGs should ensure they are following NICE Guidelines on identifying and diagnosing autism in children and young people and that they are commissioning sufficient capacity in their autism diagnosis services.
- CCGs should ensure children diagnosed with autism are flagged to local authorities so they can be identified in the education system and the right support put in place at an early stage.
- The Department for Education should report on how local authorities are using the transitional funding they have been allocated to help with the transfer to EHC plans and use these reports to determine any additional resources needed to implement the reforms within the timeframe. If local authorities cannot implement the reforms by 2018 without compromising the help that children receive, implementation should be delayed.
- The Department for Education should evaluate and publish how well each local authority is processing EHC needs assessments and share examples of good practice in implementation.
- The Government should reconsider its position on the SEND Tribunal and work to introduce a single point of appeal for education, health and care, using the findings of its pilot to inform how this would work.
- The Department for Education should work with the Council for Disabled Children to make sure that all parents going through the EHC assessment process are aware of the help they can get through Independent Supporters and determine if the service needs expanding.



To ensure that the right 'mix' of school provision and wider support is available to autistic children and young people:

- The Department for Education should work with local authorities and multi-academy trusts to develop a clear service model, which sets out the right 'mix' of different types of provision to meet the needs of children across the spectrum.
- Local authorities should use autism-specific data collected from the School Census and other sources to inform their planning and ensure that a wide range of appropriate educational options is available for children on the autism spectrum, as well as other necessary services such as after-school provision and holiday activities.
- The Department for Education should develop a guide to showcase good practice in commissioning local support that children on the autism spectrum need.
- In line with the *Autism Act* statutory guidance, local authorities should seek input from local autism partnership boards in the development of their local offer.

To help ensure there is expertise in autism across the system:

- Multi-academy trusts and local authorities should ensure that schools they are responsible for have access to autism expertise, perhaps through an autism advisory service, to help every school provide the right support for autistic children in their care.
- Teachers should make the most of information and free resources that are available on how to support children and young people on the autism spectrum as effectively as possible and how to raise awareness of the condition, for example by signing up to our charity's *MyWorld* initiative (www.autism.org.uk/myworld) or through signing up their school to participate in Schools' Autism Awareness Week.²⁰
- Schools should make use of training offered by the Autism Education Trust to ensure that teaching and non-teaching staff are equipped to support autistic children throughout the school.
- Schools should make reasonable adjustments to the school environment, including behaviour policies, to meet the needs of children and young people on the autism spectrum. This should improve their experience of school, avoid placing them at a disadvantage, and reduce the number of avoidable exclusions.



²⁰ www.autism.org.uk/get-involved/world-autism-awareness-week/schools-autism-awareness-week.aspx

Every Child

Every Child with autism deserves an education that supports them to reach their potential.

Autistic children are more likely than other children to be excluded from school, to be bullied and to leave school with no plans for adult life and getting a job. Their parents tell us that securing the right school placement can be stressful enough to lead to family breakdowns.

This is not acceptable, nor is it inevitable. The National Autistic Society and Ambitious about Autism's *Every Child* campaign is working to get the right educational support so Every Child and young person with autism can reach their potential. Ambitious about Autism and The National Autistic Society believe that four things need to happen for Every Child with autism to succeed in education.

Every Child and young person with autism must have:

- > their needs assessed fully and promptly
- > access to school and college places that meet their needs.

Every teaching professional and the schools they work in must have:

- > the training and resources to meet autistic children's needs
- > the tools to prepare Every Child with autism for their lives after school.

Together we are determined to make sure Every Child with autism gets the right educational support.

Visit www.autism.org.uk/everychild or www.ambitiousaboutautism.org.uk/everychild for more information.

The National Autistic Society

393 City Road
London EC1V 1NG

Switchboard: 020 7833 2299

Autism Helpline: 0808 800 4104

Minicom: 0845 070 4003

Email: nas@nas.org.uk

Website: www.autism.org.uk

