



School report 2021





Contents

3 Executive summary

7 Struggles in getting an EHC plan

- 7 Delays in getting support
- 8 EHC assessments refused
- 8 Having to appeal
- 9 Parents labelled as “problematic”
- 9 Low levels of satisfaction with EHC plans
- 11 Home-schooling but not out of choice
- 11 Recommendations

17 Exclusions and behaviour

- 17 School exclusions: expectations vs reality
- 18 Avoiding exclusions by making changes
- 19 Behaviour management – a different approach?
- 19 Recommendations

25 The impact of coronavirus on education

- 25 Going back to school
- 26 Transitions after the pandemic
- 26 Catching up: with what and how?
- 27 Recommendations

5 Introduction

12 Support and understanding in school

- 12 SEN Support simply isn’t working well enough
- 13 Making learning more accessible: reasonable adjustments
- 14 Building support and understanding in schools
- 15 Teacher training
- 15 The ‘whole school approach’
- 16 Recommendations

20 Having the right support in every area

- 20 Unacceptable levels of unmet need
- 21 Survey of unmet need
- 22 The Local Offer
- 23 An integrated approach
- 24 Recommendations

28 Conclusion

29 Summary of recommendations

34 Endnotes

Executive summary



Survey results

We heard from parents of autistic children about their personal experiences of education and the support they receive. We found:



Around three-quarters (74%) of parents said their child's school place did not fully meet their needs.



Over a quarter (26%) had waited over three years to receive support for their child.



Only one in four parents are satisfied with the special educational needs (SEN) support their child is receiving.



More than four in ten (44%) feel their child's special educational needs are not being met in general.



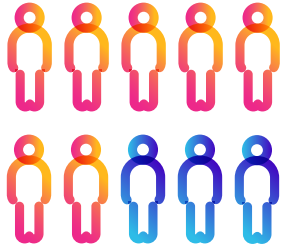
Half were dissatisfied with their child's education, health and care (EHC) needs assessment planning process.



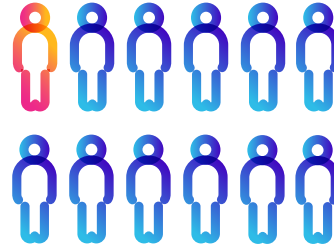
Over a third (37%) didn't know about the SEND Tribunal to appeal their local authority's decision to refuse an education, health and care (EHC) plan assessment for their child.

Survey results

In our autistic children and young people's survey:



Seven in ten said school would be better if more teachers understood autism.



Less than one in 12 (8%) think other pupils and students know enough about autism.



Over half (54%) say they don't have a quiet place to go to at school.



Around half (51%) would like help, in school, to understand how to get on with friends and classmates.



Almost half (48%) said they would like help planning for adult life.



"Everyone should be trained in autism in school, then it would be a lot easier."

Primary school pupil, attending a mainstream school

Introduction



The most recent statistics from the Department for Education show there are 163,041 autistic pupils in schools in England. That is an increase of 8% on 2020. And more than 70% of autistic children and young people are educated in mainstream schools. Autism is the most common type of special educational need (SEN) for children with education, health and care (EHC) plans – with a total of 92,576 pupils.¹

When we last surveyed parents and autistic children about education in 2017, four in ten parents told us their autistic child's school didn't meet their needs. But in our latest survey, this figure has leapt to 74%. That's almost double the number. It seems clear that the coronavirus pandemic has had a profound impact on the lives of autistic children and the support they get. But while many issues may have been exacerbated by the pandemic, they are not new.

In 2017, 55% of parents said their child had waited for more than a year for support to be provided. Now it is similar, at 57%. In 2017, less than half of autistic pupils were happy at school. Again, the figure is very similar now. Despite the promise of reforms in the *Children and Families Act*, our research over the years has shown that for too many autistic children, the system still isn't working. This is not because the reforms were wrong; it is because they have not been fully implemented.

In July, the Government unveiled its long-awaited autism strategy where it committed to tackling many of these education inequalities, with some concrete proposals and funding in its first year. A key element of the strategy is the promise to deliver autism training to education professionals, to help them understand autism in a meaningful way and better support autistic pupils. This is a step in the right direction and an opportunity to make a real difference to the lives of many autistic children and young people, but the strategy needs long-term funding to succeed.

In the coming months, the Government plans to publish a special educational need and disability (SEND) review. This will set out its proposals to improve the SEND system. It is vital that autistic children and their families are at the heart of these changes. Our report's powerful findings set out what we have been told needs to change. Too many parents have to fight **for years**; too many children have to wait **for years** just to get the support to which they are entitled.

That is the problem the Government must solve to truly create an education, health and care system that works for autistic children and young people.

Our survey

We carried out an online survey of 3,470 parents and carers of autistic children and young people in England in summer 2021. We also ran a parallel online survey, which was completed by 605 autistic children and young people. In September, we ran a focus group on our recommendations with autistic people and family members. These findings will be central to our autumn campaigns, where we will continue to fight for better support for autistic children and young people in their educational journey.



Acknowledgements

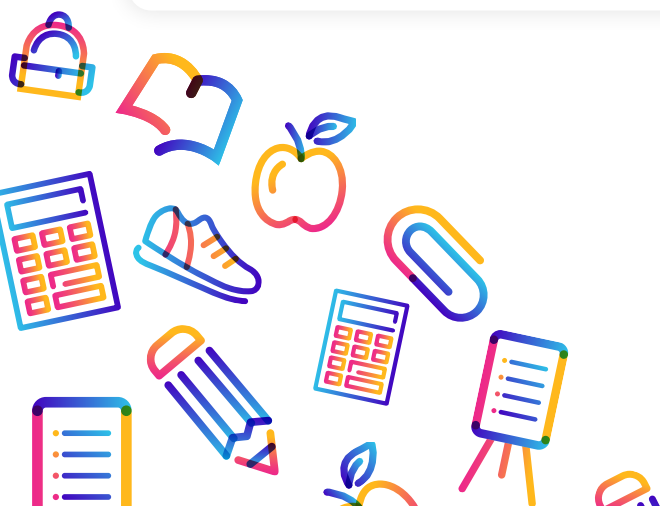
Thanks to all the parents and autistic children and young people who completed the survey to inform this report.

Thanks also to National Autistic Society staff Thomas Brayford who wrote the report, and those who helped in its production including Tim Nicholls, Andrew Cutting, Denise May, Ian Dale and Samuel Cropton.

Thank you to our longstanding partner Clifford Chance whose kind support helped us to deliver this project.



**C L I F F O R D
C H A N C E**



Struggles in getting an EHC plan



Delays in getting support

Once again parents told us it is taking far too long to get support, with long waits being the norm for the vast majority. Worryingly, more than one in four said it took **more than three years** to get the right support in place. Moreover, nearly a third of parents said that the first time they asked for an EHC plan, they were refused. Too often parents feel that lack of services and budget is behind this refusal. This is not how the system should work.

“Most difficult experience of my life.”

Parent, on getting an EHC plan

From making a request for an EHC assessment to receiving the completed plan, the process should take no longer than 20 weeks. A council must decide whether or not to proceed with an EHC needs assessment, and inform the child’s parent or the young person within a maximum of six weeks of receiving the request. And if a local authority decides not to issue a plan after carrying out an assessment, it should tell parents or the young person within 16 weeks. These statutory deadlines are clearly not being met.

One parent expressed dismay at how their child’s school was only now “pushing for an EHC plan **after three years of asking**”,

Parents continue to describe their situations using the language of the battlefield. They have to “fight” and it’s a “battle” to get the right support for their child.

having been passed from pillar to post and constantly “**being told**” what is best for their child. This leaves parents feeling helpless and disenfranchised, as well as increasing distrust in the council and sometimes even in education professionals. Parents who responded to our survey expressed their frustration at the delays in support and funding, as well as the spiralling waiting lists.

The system can be hard to navigate for everyone, but we also heard about the lack of reasonable adjustments made to support parents who have English as a second language or are autistic themselves. Without these, they can face additional barriers because of the opaque and confusing system.

Councils, schools, health and other services currently lack the staff and funding to meet demand. The Government must use the SEND Review to get to grips with EHC plan delays, by making sure every part of the system has the investment it needs to support autistic children.

EHC assessments refused

The support an autistic child receives should be based on that child's needs and to identify those needs, an assessment should be carried out. The SEND Code of Practice clearly states that, "a local authority must conduct an assessment of education, health and care needs when it considers that it may be necessary for special educational provision to be made for the child or the young person".² Most children who have a diagnosis of autism will meet this threshold.

However, our survey found that it is not uncommon for an autistic child to be refused an EHC assessment. In our survey, nearly three in ten stated they'd had an assessment refused, at least once. And for one in ten, an assessment had not been carried out at all.

This suggests that, too often, the law, as set out in the SEND Code of Practice, is not being followed. This results in further delays to young people getting the right support and in parents having to engage in lengthy (and costly) appeals processes.

Having to appeal

Autistic children represent the largest group of children whose parents are left with no other choice but to go to a SEND Tribunal. The Government's own figures show that the number of legal appeals continues to rise - with a 6% increase in 2020.³ Of those cases being heard by a tribunal, 95% are resolved in favour of the parents.⁴

Of those who had been refused an assessment, two in five parents appealed to the SEND Tribunal - with the local authority conceding before the hearing in most cases. One in four appeals made because the parents didn't agree with the support provision that was included in an EHC plan

**"We were completely in the dark
It's been a very steep learning
curve – support required to get
an assessment is absolutely not
available to all children in need
of one."**

Parent

were won outright. A system that relies on this situation for autistic children to get the right support cannot be labelled as anything other than "broken".

Challenging a decision can be a daunting prospect and even though the success rates are high, the process puts an enormous strain on families. Although the expanded powers of the Tribunal to consider claims across health and care as well as education have been made permanent, the Tribunal remains unable to make binding recommendations across them all equally. This leaves health and care as the "poor relations" in families' fights to get the right support. Appeals are also costly to both councils and parents, pushing many families to financial breaking point. Fixing the issues in the system would drive down the number of claims that need to be brought to the Tribunal and make sure that autistic children get the right support sooner.

Worryingly, in our survey, more than one in three said they did not appeal because they did not know about the SEND Tribunal. Councils should make sure that parents have clear information about what to do if they are not happy with their child's support, yet this does not always happen. From the responses, it would appear that parents face a vast minefield, and getting an EHC plan very much depends on a parent's familiarity with the SEND and legal systems. One parent described being "exhausted by the system".

Parents labelled as “problematic”

Parents often face long and arduous battles to get the right support for their children. Only around one in two parents said the type of education their child currently receives is their preferred type. What’s more, only around one in eight parents believe their child’s special educational needs are being fully met at school and an even lower proportion of parents feel their child’s special educational needs are met across all services. In the process of advocating for their children, some parents feel that they are seen as “problematic”.

“I wasn’t believed and the school put it down to poor parenting.”

Parent

“I’m disabled myself and with bad health and an awful memory. I was made to feel that I was making a fuss when he wasn’t as bad as I made him out to be.”

Parent

Parents are often misunderstood and simply want to see their children reach their full potential. Above all, they want to see that their child is included and accepted. Guidance and training for all school staff and council staff working with autistic children would help to tackle any existing misunderstandings. Ultimately the people making decisions about children’s support, education providers and parents should work together to create support that aims high for autistic children because “high aspirations are crucial to success”.⁵ The relationship between all three is extremely important, and the value and experience of parents must not be overlooked.

Low levels of satisfaction with EHC plans

Just half of the parents responding to our survey were satisfied with the EHC assessment and planning process for their child. They felt that their views, concerns and preferences were not fully considered and reflected in their child’s final EHC plan. Families should be allowed and encouraged to play an active part in the educational decision-making for their children. Being left out of the process results in parents feeling unhappy and disempowered.

Regrettably, the frustration of parents being excluded from the process is a reoccurring theme. In 2017, the All Party Parliamentary Group on Autism (APPGA) found that only just over half of parents felt fully involved in the EHC process,⁶ despite the requirement in the *Children and Families Act 2014* to involve parents.⁷

Survey results

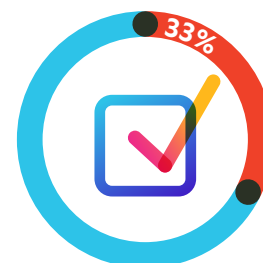
Only a minority of parents are very satisfied with any element of their child's EHC plan.



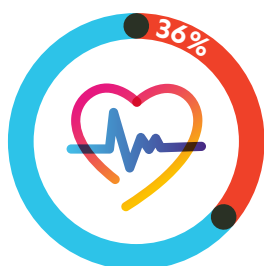
Only **38%** were happy with the education provision.



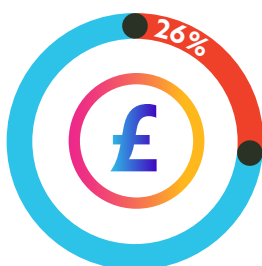
Only **30%** were happy with the description of their child and their needs.



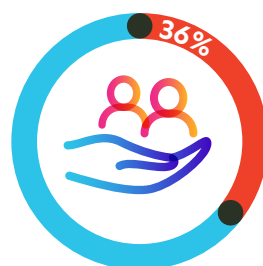
Only **33%** were happy with the outcomes set out for their child.



Only **36%** were happy with the health provision.



Only **26%** were happy with the personal budget.



Only **36%** were happy with the social care provision.

Not only are parents critical of the process, but some were frustrated with the language and the lack of accessibility in the layout of EHCPs which impacted on the parents' and children's understanding of them.

The quality of EHC plans has to improve. This should start with including parents and autistic children more, but it also relies on a solid understanding of autism and having the right services in each area.

Home-schooling but not out of choice

Of the children in our survey who were being home-educated, nearly seven in ten were being home-schooled because parents felt their child's educational needs were not being met at school.

If parents decide to educate their child at home, this should be a positive choice based on how the child's needs can be best met. Schools should not be putting pressure on parents to remove their child, nor should it be the only available course of action for

families who see their child struggling at school.

During the pandemic, many children were educated from home. While for some this reduced their anxiety about going to school, our *Left stranded* report found that seven in ten parents said that their child struggled to do online work and around half said their educational progress had suffered.

Following the pandemic, some parents might decide to educate their autistic children at home, but this is no replacement for making sure that schools work better for autistic children.

Recommendations

In the upcoming SEND Review, the Government must:



- restate its commitment to statutory deadlines for EHC assessments being met and provide sufficient funding and support for local authorities to meet them
- introduce a presumption by local authorities that a child with an autism diagnosis may need an EHC needs assessment, and this should be carried out when it is requested
- equalise the powers of the SEND Tribunal across education, health and social care, so that disabled children don't have unequal abilities to challenge decisions, depending on their type of needs
- ban the practice of local authorities defending appeals to the SEND Tribunal, only to concede shortly before the hearing. This is a wasteful, costly approach and erodes trust
- ensure that clearer instructions are given to councils that parents should not have to wait for a diagnosis to start an EHC plan
- work with the National Autistic Society Education Rights Helpline and other helplines to gather insight on system performance and make sure that parents are correctly guided through the EHC assessment process
- create a programme to take direct action to support commissioners and improve practices in areas that are consistently identified in CQC/Ofsted joint area inspections as having lengthy delays and high numbers of Tribunal appeals
- increase the participation of autistic children and their parents in decision making, giving them more choice and control over their education preferences.

Support and understanding in school



SEN Support simply isn't working well enough

SEN Support is a staged approach to identifying needs and providing support which will involve the education provider, parents or guardians, children and young people. It is a level of support beneath an education, health and care plan, where a child's needs can be met by a school without extra resource. For many autistic children in mainstream schools, SEN Support should in theory meet their needs, but we heard from parents that:

- The majority feel there is an inadequate quality of support.
- Most believe there are insufficient professional resources or intervention.

In order for autistic children to thrive and succeed, the right services and support must be available in their local area. Yet there are huge gaps across all types of support between what is needed and what is received. 74% of parents said their SEN Support does not fully meet their needs.

One parent described the support offered by the school as "sporadic" and told us there didn't seem to be "enough staff qualified to deliver the specialist support required". Another commented that individual support was "limited and not

"Lack of SEN Support at mainstream school meant I had to apply for an EHC plan. He is now thriving in a special school."

Parent

really tailored to autism and its many faces". In another case, a parent described a lack of autism understanding from a primary SEN coordinator who had spent two years telling them that their child "was rude and lacked respect as he wouldn't look at people when they spoke to him and he would not always answer them straightaway".

Schools need to be more aware of a young person's needs after they leave school. As well as input with academic skills, it is clear young people want their school to equip them with the tools for adult life and build life skills. Planning for adult life and help finding work placements in settings where people understand autism both ranked highly. One student stated that "one-to-one support sessions with a member [of staff] to explain social cues, emotions or just other classmates" would be of enormous help to them. Providing this support gives autistic children and young people the essential life skills they require to succeed in an educational setting.

“My child’s secondary school experience was awful. The school just tried to make her leave their establishment as this seemed the easiest option for them.”

Parent

Making learning more accessible: reasonable adjustments

Generally, we found there was greater dissatisfaction than satisfaction concerning school staff and their knowledge of how to understand and support autistic children and young people. The exceptions to this were SEN co-ordinators (although almost four in ten still expressed dissatisfaction) and primary class teachers.

A considerable number of parents thought that important adjustments or adaptations had not been made to facilitate their child’s learning. We asked parents to what extent a variety of reasonable adjustments had been made, such as a quiet room or the way tasks are explained. Across every type of adjustment, the most common answer was that it had not been made at all.

Where adjustments had been made, they were usually around homework, exams and the teaching approach. However, parents felt that more could be done to create a better learning environment, autism-friendly teaching materials and more flexibility with breaks.

We also asked autistic children and young people about the support they can access and availability of reasonable adjustments. Just half (53%) of the autistic children and young people who responded said they have someone they can go to if there is a problem. A similar number (48%) have a quiet space to go to or have extra time to do their work. Yet there is a clear demand for these adjustments. More than half (54%) of autistic children and young people expressed a strong desire to use quiet spaces more often, particularly during break times when they felt they needed a safe space.

Reasonable adjustments are vital to children’s learning. Without them, autistic children risk their potential being stifled.



“Fortunately, my child’s school is very supportive. They have created their own independent support plan to follow her through her primary years. She takes part in smaller group activities to build on her weaker points such as fine motor [skills]. They try to be very aware of changes they make to the class routine which can cause her upset.”

Parent

Building support and understanding in schools

Awareness of autism has increased hugely in recent years, with research from the National Autistic Society in 2016 showing that 99% of people had heard of autism. But it also uncovered that autistic people and their families didn't feel that this awareness led to enough understanding.⁸ This issue of not enough understanding pervades schools too.

In our survey, more than half (54%) of the autistic children and young people who responded told us that having teachers who don't understand them is the worst thing about school. The biggest thing that would make school better is having a teacher who understands autism. Seven in ten autistic children responding said this, which is consistent with our previous education research in 2017. This is an entrenched issue that autistic children and young people face.

Teachers need to understand what autism is, how it can affect children in schools, and what strategies and approaches are most effective in engaging autistic children at school. This will enable autistic children to succeed and achieve their potential. Without this essential teacher understanding, autistic pupils can feel adrift in classrooms that seem unpredictable and chaotic, and can become confused by lessons and tasks that lack meaning to them.

Worryingly, just a quarter of the autistic children we surveyed felt happy (26%) or included (24%) at school.

Better understanding can also prevent autistic children becoming overwhelmed and distressed. A lot of the distressed behaviour (often categorised as "behaviour that challenges") can be attributed to the stress and anxiety they experience in poorly adapted environments.⁹ Too often, autistic children then end up facing consequences or sanctions because of this - even though the root cause may have been a poor understanding of, and failure to meet, their needs.

"Mainstream schools are often horrible places that are extremely busy and totally exam-based, so many... young people can't manage in them at all."

Young person



Teacher training

We welcome the inclusion of teacher training in the recent autism strategy, through the Autism Education Trust (AET) in 2021-22. However, we are concerned that without a long-term goal – and funding – to train all teachers, the strategy will not deliver the progress it needs to.

For new teachers specifically, autism must be reinstated in the Initial Teacher Training (ITT) core content framework. We were very pleased to see autism specifically referenced in the 2016 ITT core content framework, but extremely concerned to see SEND and autism removed again in the version published in November 2019.

The previous core content framework was very clear, and was widely welcomed as an important shift in helping autistic children get the education they need and are entitled to. We believe its removal was a backwards step that must be addressed, especially following the inclusion of autistic children for the first time in the national autism strategy.

Without the appropriate training for teachers, England's 160,000 autistic children are twice as likely to be excluded, and many are pushed towards more intensive support by not having their needs met earlier. A generation of autistic children are being held back from reaching their potential.

The 'whole school approach'

Autistic children's experiences are shaped by more than just their teachers. We firmly believe that a 'whole school approach' is needed to build capacity of school leaders, teachers and education support staff to create autism-friendly cultures, implement evidence-based strategies, and improve outcomes for autistic students. High

quality autism training is the key to future implementation of the autism strategy, but we have a long way to go before that training has reached all school staff – though the AET has already trained over 200,000 education professionals.

It's important to look further than staff too, considering that only one in 12 autistic children in our survey felt that other students at their school knew enough about autism. Other children's understanding will be vital to young autistic people making friends, working with their peers and feeling accepted and supported. Much more needs to be done on improving autism understanding in schools – and throughout the whole school.

"Everyone should be trained in autism in school, then it would be a lot easier."

Primary school pupil, attending a mainstream school

Promoting autism understanding will support greater inclusion and acceptance. Only a minority of children asked felt safe, happy, included and properly supported in school. It comes as little surprise, therefore, that recent studies¹⁰ on school attendance suggest a high rate of school absence for autistic students.

"People not being nice to me" featured highly in our young person's survey. We are hopeful that the Government's new anti-bullying programme, outlined in the autism strategy, will make schools more welcoming and understanding and improve autistic children's experiences of education as well as their ability to succeed. But to end bullying once and for all, improving autism understanding will be key.

Recommendations

In the upcoming SEND Review, the Government must:

- invest in SEN Support, to make sure that more autistic children are supported better when they don't have an EHC plan
- commit to creating clear guidance and models of SEN Support for schools to use
- create and fund mandatory autism training for all education staff and governors so that they are fully able to support autistic pupils and students. The Autism Education Trust is well placed to roll this out
- set out a clear plan to reinstate autism and SEND more broadly in the Initial Teacher Training (ITT) framework
- stipulate that curricula and lessons are planned with the autistic child in mind, so that teaching and learning activities are accessible to all pupils
- set out plans to improve sharing good autism practice, including resources produced by the Autism Education Trust.

Local authorities should:

- consider working strategically across all schools in their area to make sure all staff receive autism training. The Autism Education Trust has experience doing this.

Schools should:

- recognise the importance of a whole school approach to autism understanding
- support staff and governors to co-produce inclusion policies for their schools together with autistic children, their families and education staff. These policies would set out a governance plan, as well as the ongoing professional support available in relation to autism.



Exclusions and behaviour



Autistic children in England, according to recent figures from the Department for Education, are already twice as likely to be excluded from school either for a fixed period or permanently as pupils with no special educational needs. This has huge ramifications for autistic children and their families. The child may be cut-off from their friendship circles and may well feel apprehensive about returning to an educational setting.

School exclusions: expectations vs reality

In the Government's autism strategy, there were some encouraging signs regarding its approach to school exclusions. The Government expressed a wish to see "fewer autistic children who are permanently excluded or suspended from school" as well as enabling "autistic children and young people to access the right support, within and outside of school". In addition, it will help "to prevent avoidable admissions [to mental health hospitals] by increasing respite support

and providing help for autistic children and young people in schools to prevent suspensions or permanent exclusions."¹¹

But the current situation is very different. More than one in ten parents responding to our survey said that their child had been suspended in the last two years. And of considerable concern is that more than one in five parents said that their child had been **informally excluded** at least once in the past two years. Informal exclusions include children being sent home and asked not to come in. They are illegal and should not be happening. Yet they clearly are, and due to their informal nature, they are not officially recorded.

Government figures show that the most common reason for formally excluding autistic children from school is "persistent disruptive behaviour" (22% of fixed-term exclusions). But "disruptive behaviour" is often an indicator that an autistic child's need for support at school is not being met and they have become completely overwhelmed, which could have been avoided.



More than one in five parents said their child had been informally excluded at least once in the past two years.

The impact of exclusions on autistic pupils and their families is severe. One primary age pupil attending a mainstream school told us, "Being excluded from school due to meltdowns or needs not being met hurt me a lot". Any type of exclusion could result in a child feeling frustrated, lost and confused, without their normal routine of going to school, and even scared and uncertain.

“Autism is not a behaviour – it is a way of thinking and understanding the world, which results in behaviour. Always try to understand why the person may have responded in the way they did, by working backwards to find out the root cause. There will always be one, and it will always make sense - in their world.”¹²

Sarah Hendrickx, autistic adult and autism specialist

Avoiding exclusions by making changes

Parents have told us that schools will often argue that their child’s behaviour is a choice, while as parents they recognise their child is overwhelmed by the social and sensory demands of school.

Due to their social communication difficulties, autistic pupils may not be able to voice their difficulties, but changes in behaviour can indicate they are under emotional stress. We have seen in our surveys that schools all too often punish pupils for this behaviour rather than address the main causes. In such instances, a cycle of distressed behaviour and exclusion can begin and will continue, until either the individual’s needs are met, they are moved to another school, or are permanently excluded.

A common reasonable adjustment for a school to make, for an autistic pupil, is to allow them access to a quiet room where they can self-regulate: a place they can escape to if they feel overwhelmed in the classroom. As an example, some schools will provide an autistic pupil with an ‘exit pass’ so that they can leave the classroom and access this room but too often this is not available.

Schools have a legal duty to make reasonable adjustments to the school environment and to their policies - in line with the *Equality Act 2010* and the important ruling on school exclusions by the Upper Tribunal in 2018. It ruled that disabled children, including autistic children, should not be excluded for behaviour related to their autism if schools have not made reasonable adjustments to support the child and meet their needs.

We know from enquiries to our Education Rights Helpline that schools remain unclear about the implications of the ruling and what is required of them. We are still waiting for guidance from DfE to schools on the implications of the Upper Tribunal ruling. While many parents of children on the autism spectrum are aware of the ruling, it seems that schools are not similarly aware.

The Autism Education Trust has worked with local areas to make an impact on understanding and exclusions. Working with just one council since 2015, it helped decrease the number of exclusions from mainstream settings by 80%. This is not only much better for individual autistic children who are better supported and happier at school, it has also led to significant savings to the council as they did not have to rely on alternative and more intensive support.

Behaviour management - a different approach?

In February, the Department for Education unveiled a new three-year programme to improve pupil behaviour. The programme matches schools with exemplary behaviour practices, called lead schools, with partner schools who want and need to improve pupil behaviour. However, our research suggests that there is a considerable worry about pursuing an approach that focuses too rigidly on managing behaviour and that autistic children could be punished for behaviour that is related to autism.

The Government has acknowledged the need for schools to be supportive, not punitive – but we need to see this happening in practice in every school. It will need to be underpinned by a good understanding of how autism can affect a child's behaviour in the school environment, and what schools can do to make a difference. As previously mentioned, there needs to be a strong emphasis on making reasonable adjustments. Implementing rigid behaviour policies, without considering additional needs and disabilities, could be discriminatory and unlawful.

Recommendations



Through its upcoming SEND Review, the Government must:

- tackle the unacceptable practice of informal exclusion once and for all, setting out plans to identify where this is happening and taking action to instil better understanding and support in schools
- set a clear commitment that all work on behaviour in the Department for Education better reflects the needs of autistic children and other children with SEND. Its recent Behaviour Hubs Programme work must embed reasonable adjustments and autism understanding better
- set a clear target for reducing the number of exclusions of autistic children. The work of the Autism Education Trust demonstrates that better autism understanding can lead to fewer exclusions
- make sure that all schools receive guidance on the implications of the ruling by the Upper Tribunal in 2018 on school exclusions and what it means for them.

Having the right support in every area



Autistic children and young people can be supported effectively by having people around them who understand autism. This understanding enables effective approaches to support needs and the creation of an individual learner profile of the child's strengths and difficulties. Getting to know the individual is the key to achieving the best learner outcomes. One service that helps one child may not necessarily be suitable for another. What is most important is that every area has the range of support, in sufficient quantities to meet the needs of local children. But this isn't the reality.

Unacceptable levels of unmet need









As previously mentioned, there are critical issues around the timeliness and quality of EHC plans, as well as the provision at the SEN Support level in schools. Both of these are exacerbated by a fundamental lack of having the right services locally to support autistic children.

In our survey, this was particularly stark in relation to support outside of school. Our research uncovered shocking levels of unmet need: the support people need but don't get. Of those whose children need the support, more than four in five parents said they don't receive any short breaks (84%), buddying/befriending (86%) or leisure/play opportunities (81%).

Similarly, over two-thirds (69%) told us they want mental health support for their child, but **don't receive any**. And a majority want speech and language therapy, but get none. Only a small minority reported getting enough support in any category.



Survey of unmet need

	Receive sufficient	Receive but need more	Want but don't receive
 Buddying/ befriending	5%	9%	86%
 Short breaks outside the home	6%	11%	84%
 Other	7%	10%	83%
 Leisure/play opportunities outside school	7%	13%	81%
 Help with daily living skills	11%	14%	76%
 Occupational therapy	11%	18%	71%
 Mental health support	8%	23%	69%
 Speech and language therapy	19%	28%	54%

In school, social skills training, physical therapy, and sensory integration therapy all featured heavily in additional services which parents stated they would like to see. In theory, many of these services could be offered by schools. In reality, however, there does not seem to be enough staff qualified to deliver the specialist support. And even where there is, there are long delays responding to the needs of autistic learners.

In one particular case, involving a parent of a secondary school age child, services were offered but commitments were not kept. The parent told us that her son, “was offered a mentoring programme but it never happened despite numerous calls and emails to the professionals involved.” These services aren’t “nice to haves”. They are pivotal to autistic young people’s progress and their wellbeing. Without them, autistic children are being held back.

“Services are only reactive to a certain situation or issue, no proactive support is provided.”

Parent

In the example quoted above, the school had assessed that there was an issue with handwriting and a laptop was provided on the recommendation of an occupational therapist “after two and a half years of assessing my child’s difficulties and still trying to force handwriting interventions upon him”. Surely, this assistive technology needed to be there from the beginning. Conducting a thorough needs analysis is essential to putting autistic learners onto the right learning path.

Services need to be consistent across the board and the support autistic children and young people receive needs to be the same high standard whether in or outside of the classroom.

The Local Offer

The Local Offer provides information and advice about services that autistic children, young people and their families can expect from local agencies. It should also provide details of any eligibility criteria which apply so parents know if they can use each service.

In our survey, more parents found it difficult than easy to find information in their area’s Local Offer about support available for autistic children and young people. Parents experienced problems accessing the right services either because they were overwhelmed by the amount of information available, or in other cases they were let down by long waits, poor signposting and the lack of availability. One parent of a primary school age child in Staffordshire was dismayed at not being able to access “practical help” such as “holiday clubs, after school care, details of schools that are particularly good with SEN”.

Of those that were able to access their area’s local offer, less than one in four said they were then able to get those services for their child. The Local Offer and children’s individual EHC plans should be used as a commissioning tool to help local authorities identify where the gaps are, and as a starting point to develop and deliver the services children need.



An integrated approach

Only around half of parents who responded to our survey say their child is in their preferred type of education. Of those who are not, an autism-specific school run by our charity is their preferred option. This is followed by autism-specific units attached to mainstream schools and autism-specific special schools run by other organisations.

Our Cullum Centres are specialist autism centres in mainstream schools. From our own experience of running these centres, parents attributed their child's success to the staff's autism-specific knowledge and open communication. The mainstream setting combined with the support of the Cullum Centres allows the pupil to thrive. As one parent of a Year 7 pupil put it, "Because it's mixed with the mainstream ... it's not just a special school in itself, he has that opportunity to interact with other people and see how they behave and he will as he's growing up, which I think is really positive."

A parent of a Year 11 pupil described how well their child had been supported on his educational journey. "M has been given so many opportunities that I never thought would be available to him for example [Duke of Edinburgh], school productions and a mainstream school experience. His school experience has had an impact on the quality of life for the whole family. I have recommended Cullum Centres to other parents who are looking at KS3-4 provision for their own children and will continue to do so."

Other autistic children may need specialist education at an autism-specific school, but places at these schools are limited and children often end up having to travel long distances to get to them. This can put a huge strain on a young autistic person, especially if lengthy journeys are disrupted by unexpected changes like heavy traffic.

Every area needs to have the right number of the right kinds of school place to meet the needs of its local autistic children. Councils should use the data they have about autistic children to make sure they are creating enough of the right school places. But we know that councils also need support to do this better, meaning the Government has an important role in creating clearer commissioning guidance.



Recommendations

Through its upcoming SEND Review, the Government must:

- ask the Department for Education to develop an autism good practice guide, so that there is more consistency across schools in their support for autistic children
- create a commissioning model for autism so that local authorities and schools understand not just what they should do, but how to do it
- set out clear expectations for areas' local offers to make sure that there is consistency of provision and quality across local authorities.

Councils should:

- collect data on the number of children and young people in their area who are on the autism spectrum, and on the profile of their needs, and use this data to plan and commission the school places and other services they will need
- improve their information for parents and families, including the local offer.



The impact of coronavirus on education



Our 2020 *Left stranded* report highlighted the impact the coronavirus pandemic has had on the education of autistic children.

- Seven in ten family members said their autistic child was anxious at the loss of routine and 65% said they could not do online work.
- Children relied heavily upon their parents to provide most of their support, often while parents were juggling other work commitments.
- Better and more inclusive planning is required for online, offline and blended learning approaches to make reasonable adjustments for autistic children and young people.

As discussed in chapter one, while some autistic children may have experienced an immediate reduction in anxiety due to not needing to attend school, many parents have told us that the impact on learning and accessing the curriculum has been profound. Parents often have not been able to provide all the support at home that their child needs. In our *Left stranded* report, a parent of an autistic adult despaired that coronavirus led to a reduction in support and services.

The lack of availability resulted in the family “going round in circles”. They were not alone: many parents wrote that being unable to be at school and the lack of a routine impacted their autistic child hugely.

Going back to school

Since the end of lockdown and the return to school, one in six parents have either had to withdraw their child from school, their child has been excluded or is at risk of being excluded. This was why we called upon schools to make sure that every autistic child had a personalised transition plan, created with the autistic child, parent and teaching staff, to aid their return to school. Such a plan might have included visits prior to school starting, more autism awareness among staff, safe spaces, accessible information and videos showing changes to layouts or school rules as well as a main contact for parents. Crucially, such a plan requires an element of flexibility to be updated whenever and wherever necessary.

This echoes the suggestion from one parent, who stated that the return to school might have been much happier if the school had “managed changes in routines, involving the parents and child in decisions being taken

and being open to the need to adapt, then reviewed and amended the plan if needed but with all involved.”

Parents' experiences of lockdown and their child's return to school should be used in reflective practice to strengthen current and future provisions. Opinion was split on how well schools had kept parents informed about changes at school and made exemptions to coronavirus policies like masks. While there were pockets of good practice, this wasn't consistent. But the impact of the pandemic on home life was clear: seven in ten parents felt exhausted from the extra responsibilities during the pandemic and, 59% said they felt more isolated. Families might need more support now than they did before the pandemic, from both schools and councils.

Transitions after the pandemic

Many autistic children and young people particularly find the change of starting or moving to a new school difficult. These transitions would have been difficult under normal circumstances but have been exacerbated by lockdown. This situation is recounted by one parent whose child was moving from primary to secondary school. That said, three in four parents or carers are happy that their child is back at school in either a full-time or part-time capacity.

“He has not been allowed to step foot in the school, he hasn't met a teacher and he has no idea what he's walking into in September. And it's not okay.”

Parent whose child was moving from primary to secondary school



Routine is particularly important for autistic children and young people. The routine of school gives a degree of structure to their lives, which enables them to learn what to expect and when to expect it.

Catching up: with what and how?

In June 2021, DfE published a report which found that the lockdown had led to a widening of the disadvantage gap chiefly in the primary years, where those most affected included SEND pupils.¹³ The Government had, in the previous year, announced a catch-up premium to support children and young people to catch up on missed learning caused by coronavirus.

44% of parents surveyed said their autistic child has fallen behind with work and 47% believe their children are more anxious about attending school than before. We naturally welcome this extra learning support but also believe that many autistic children's needs will have changed since the lockdown, and therefore in addition to regular catch-up tuition, an autistic child may require greater mental health and wellbeing provision. Support for autistic children and young people to catch up also needs to be long-term, considering the huge emotional impact the pandemic has had on autistic children.

In our survey, parents called for a “greater understanding of mental health issues and autism” and “having the correctly trained staff to intervene before incidents escalate”. The loss of services and support during the pandemic, fears about increased infection rates, and disruption of daily routines have adversely affected the wellbeing of autistic children and their families. It is critical that mental health services remain accessible during and after the pandemic, particularly for parents raising autistic children.¹⁴

Not all experiences, during lockdown, were bad ones. Almost one in two did not feel as rushed to do things. A high number of parents also felt that lockdown gave them an opportunity to explore different approaches to learning and they also

noticed a positive change in their child's mental health. There is a lot from each child's individual experiences during lockdown that schools and councils could learn, to better support them after the pandemic.

Recommendations

In the upcoming Spending Review, the Government must:

- listen to autistic children and their families about the challenges during the pandemic, acknowledge where this exacerbated deeply entrenched issues in the SEND system and tackle them. It should include a clear long-term plan of how to improve support for this generation of autistic children
- support autistic children and other children with SEND through targeted funding and resources as they adjust to being back at school
- acknowledge that this is a long-term issue and the consequences of the pandemic will last beyond this year. Support must be provided on a long-term basis, with more focus on social and emotional support, not just academic support
- top up funding for local authorities so they can make sure that any additional assessments of need and support can be put in place
- be clear with parents, teachers and schools what will happen over the winter and in the next year in terms of pandemic response, so families and autistic children know what support they can expect.

Local authorities must:

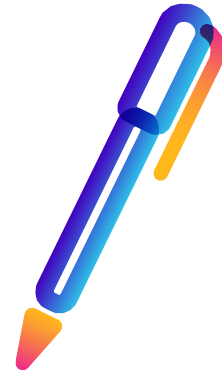
- make sure that assessments are carried out where children's needs may have changed during the pandemic. This shouldn't be left for annual reviews.

Schools should:

- build in time in returning to school life for autistic children to reflect on lockdown and think about what they want to achieve now they are back at school
- work with local authorities to review educational and safeguarding needs post-lockdown.
- review of what went well/what could have been better during lockdown education and develop contingency plans for future lockdowns.



Conclusion



“Any positive changes would be welcome, especially to ensure children do not slip through the cracks.”

Parent

After long campaigning for an autism strategy in England that included children and young people, it was a relief to finally see it published. Real change for autistic children and young people, however, is very much dependent on long-term funding of the strategy and the Government’s upcoming SEND Review.

In this report, we’ve set out the actions that our research shows the Government must take to transform the lives of autistic children. It must tackle the delays in getting support and improve the support that is on offer. It must involve autistic children and their parents better in the decisions that are being made about them, ending the “fights” and “battles”. It must tackle the unacceptable postcode lottery that means getting support depends too often

on where you live, not what your needs are. And, vitally, it must underpin this with a whole school approach to improving autism understanding.

Only then will the Government create an education, health and care system that really works for autistic children. Alongside autistic children and their parents, we have high expectations of the Government’s SEND Review. It’s vital these expectations are met.



Summary of recommendations



Addressing struggles getting an EHC plan

In the upcoming SEND Review, the Government must:

- restate its commitment to statutory deadlines for EHC assessments being met and provide sufficient funding and support for local authorities to meet them
- introduce a presumption by local authorities that a child with an autism diagnosis may need an EHC needs assessment, and this should be carried out when it is requested
- equalise the powers of the SEND Tribunal across education, health and social care, so that disabled children don't have unequal abilities to challenge decisions, depending on their type of needs
- ban the practice of local authorities defending appeals to the SEND Tribunal, only to concede shortly before the hearing. This is a wasteful, costly approach and erodes trust
- ensure that clearer instructions are given to councils that parents should not have to wait for a diagnosis to start an EHC plan
- work with the National Autistic Society Education Rights Helpline and other helplines to gather insight on system performance and make sure that parents are correctly guided through the EHC assessment process
- create a programme to take direct action to support commissioners and improve practices in areas that are consistently identified in CQC/Ofsted joint area inspections as having lengthy delays and high numbers of tribunal appeals
- increase the participation of autistic children and their parents in decision making, giving them more choice and control over their education preferences.



Increasing support and understanding in school

Through its upcoming SEND Review, the Government must:

- invest in SEN Support, to make sure that more autistic children are supported better when they don't have an EHC plan.
- commit to creating clear guidance and models of SEN Support for schools to use
- create and fund mandatory autism training for all education staff and governors so that they are fully able to support autistic pupils and students. The Autism Education Trust is well placed to roll this out
- set out a clear plan to reinstate autism and SEND more broadly in the Initial Teacher Training (ITT) framework
- stipulate that curricula and lessons are planned with the autistic child in mind, so that teaching and learning activities are accessible to all pupils
- set out plans to improve sharing good autism practice, including resources produced by the Autism Education Trust.

Local authorities must:

- consider working strategically across all schools in their area to make sure all staff receive autism training. The Autism Education Trust has experience doing this.

Schools should:

- recognise the importance of a whole school approach to autism understanding.
- support staff and governors to co-produce inclusion policies for their schools together with autistic children, their families and education staff. These policies would set out a governance plan, as well as the ongoing professional support available in relation to autism.



Tackling exclusions and behaviour

Through its upcoming SEND Review, the Government must:

- tackle the unacceptable practice of informal exclusion once and for all, setting out plans to identify where this is happening and taking action to instil better understanding and support in schools
- set a clear commitment that all work on behaviour in the Department for Education better reflects the needs of autistic children and other children with SEND. Its recent Behaviour Hubs Programme work must embed reasonable adjustments and autism understanding better
- set a clear target for reducing the number of exclusions of autistic children. The work of the Autism Education Trust demonstrates that better autism understanding can lead to fewer exclusions
- make sure that all schools receive guidance on the implications of the ruling by the Upper Tribunal in 2018 on school exclusions and what it means for them.



Having the right support in every area

Through its upcoming SEND Review, the Government must:

- ask the Department for Education to develop an autism good practice guide, so that there is more consistency across schools in their support for autistic children
- create a commissioning model for autism so that local authorities and schools understand not just what they should do, but how to do it
- set out clear expectations for areas' local offers to make sure that there is consistency of provision and quality across local authorities.

Councils should:

- collect data on the number of children and young people in their area who are on the autism spectrum, and on the profile of their needs, and use this data to plan and commission the school places and other services they will need
- improve their information for parents and families, including the local offer.



Addressing the impact of COVID on education

In the upcoming Spending Review, the Government must:

- listen to autistic children and their families about the challenges during the pandemic, acknowledge where this exacerbated deeply entrenched issues in the SEND system and tackle them. It should include a clear long-term plan of how to improve support for this generation of autistic children
- support autistic children and other children with SEND through targeted funding and resources as they adjust to being back at school
- acknowledge that this is a long-term issue and the consequences of the pandemic will last beyond this year. Support must be provided on a long-term basis and more focus needs to be on social and emotional support, not just academic support
- top up funding for local authorities so they can make sure that any additional assessments of need and support can be put in place
- be clear with parents, teachers and schools what will happen over the winter and in the next year in terms of pandemic response, so families and autistic children know what support they can expect.

Local authorities must:

- make sure that assessments are carried out where children's needs may have changed during the pandemic. This shouldn't be left for annual reviews.

Schools should:

- build in time in returning to school life for autistic children to reflect on lockdown and think about what they want to achieve now they are back at school
- work with local authorities to review educational and safeguarding needs post-lockdown.
- review what went well/what could have been better during lockdown education and develop contingency plans for future lockdowns.



Endnotes



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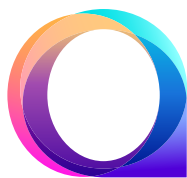
About the National Autistic Society

The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people.

We transform lives by providing support, guidance and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work.

We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

We have come a long way but it is not good enough. There is still so much to do to increase opportunities, reduce social isolation and build a brighter future for people on the spectrum. With your help, we can make it happen.



**National
Autistic
Society**

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