

*I don't think it's
bullying - I can't make
them be friends with her.*

*I just don't feel qualified
enough to teach her.
I feel out of control.*

*We can't take
children like her
on the school trip.*

when will ~~they~~ we learn?

Children with autism are being failed by our education system. It's damaging and unfair. But it doesn't have to be this way. Together we have the power to change it.



**Ambitious
about Autism**

About us

Ambitious about Autism is the national charity for children and young people with autism. We provide services, raise awareness and understanding, and campaign for change. Through TreeHouse School and Ambitious College we offer specialist education and support.

Our ambition is to make the ordinary possible for children and young people with autism.

About autism

Autism is a lifelong developmental disability which affects one in 100 people in the UK. It affects the way a person communicates and how they experience the world around them. Some people with autism are able to live independent lives, but others may face additional challenges including learning disabilities.

Early intervention, education and support are critical if children and young people with autism are to lead fulfilling lives, learn, thrive and achieve.

The number of children receiving extra help for autism in schools has seen a 78% rise since 2010. Currently 100,012 children are receiving extra help as a result of their autism. The majority of children with autism (72,540) are educated in mainstream schools and academies.

'when will we learn?' – this report

'when will we learn?' considers the impact of the school system when it fails children and young people with autism and their families, and unveils the scale and severity of this issue. It focuses on the experiences of one family as they desperately try to ensure their son receives the education and support he deserves.

We heard from 745 children and young people with autism, parents and carers in our survey. We collected statistics from Freedom of Information requests, research from other organisations and the Department for Education. Together, they show the damning reality for children and young people with autism at school today and make a compelling case for changes to our education system.

This report is part of the joint 'Every Child' campaign; a partnership between Ambitious about Autism and The National Autistic Society. It was written by Elizabeth Archer, Justin Cooke, Charlotte Lore and Claire Russell, with support from Naomi Lusk and Kate Bowen-Viner.

Thank you to every child, young person, parent, carer and teaching professional who shared their experiences with us. A very special thanks to the Emerson family for sharing their story.

***Some individuals in this report wanted to remain anonymous; their names have been changed to protect their privacy.**

For a detailed breakdown of statistical sources, please visit: ambitiousaboutautism.org.uk/whenwillwelearn-stats

Overview

Ambitious about Autism have been working closely with the government since 2011 to influence the new Children and Families Act and make sure it considered the rights of children and young people with autism. In 2014, we released our *Ruled Out* report; which showed that four out of ten children and young people with autism had been illegally excluded at least once.

Two years after our campaign and the Act becoming law, we are saddened to see that little has changed. Families of children with autism still struggle to get their needs met, and children are still not receiving the education they are entitled to.

Nearly half of the families we surveyed said their child had been illegally sent home from school, or denied a full education.

Children with autism are four times more likely to be permanently excluded from school than any other child.

Nearly three quarters of parents of children with autism say that getting them the right support in school was so stressful it caused them to lose sleep.

80% of children with autism find school so stressful they experience anxiety about attending every day.

58% of those children find this anxiety so debilitating they miss school days as a result.

When will we learn that it doesn't have to be this way? Ambitious about Autism believes children with autism will get a fair deal if:

- ▶ We get it right for children with autism from the start – by making sure their educational needs are assessed after they get a diagnosis.
- ▶ We support schools to do a great job – by making sure everyone who works in schools receives training to support children with autism.
- ▶ We meet the needs of every child with autism – by having the right mix of services and support available.
- ▶ We protect the rights of children with autism – by preventing illegal exclusions and supporting school governors to fulfil their legal responsibilities to children with autism.

Children with autism are being failed by our education system. It's damaging and unfair. But it doesn't have to be this way. Together we have the power to change it.

▶ The statistics are shocking, but hearing the real and lasting impact on individual children and young people and their families is devastating.

Louisa's story

"Hi, my name is Louisa, I'm mum to two children – Fred, my youngest, is autistic. When Fred started at school we discussed with them the possibility that he had autism. Nothing was done, but in Year 2 his teacher told us she felt that he was behind his peers socially and emotionally, and the gap wasn't closing, we had an assessment and were told it was obvious Fred was autistic.

We went to school with the diagnosis to ask what could be done to support Fred. The answer was nothing. We were met with a brick wall because he didn't fit the 'criteria'.

Finally after advice from a specialist teacher the school agreed he needed a statement. But then the local authority refused to assess him because they said the school hadn't been giving him enough support, and they wanted it to be demonstrated that the school was trying to help him before they took any action. He was stuck between the two.

We had to appeal and were going to have to go to a tribunal hearing. The local authority pulled out a week before and agreed to assess him. My husband and I know how to write letters and look for information. We still found everything incredibly daunting and stressful. How other parents deal with all of it without those skills, I don't know."



When will we learn... It shouldn't have to be a battle.

Families tell us that getting their child's needs assessed, and the right support in an environment which meets their needs isn't easy. In fact, **71% of parents we spoke to said they'd lost sleep over it.** 69% of parents said their child had waited more than a year for support after concerns were first raised – and 16% had waited more than three years.



Sue's story*

"When I met the local authority's Education Officer, with my Parent Partnership Officer, she shouted at us that the council didn't have school places for children 'like my son'.

The Parent Partnership Officer said I would have to fight to get him a school place at five. My husband and I were shocked because we thought there was a system and we didn't want to fight.

I tried to get in touch with all the local mainstream schools. Most wouldn't even let me visit. I just wanted, like any other parent, to see what it would be like. The local authority refused to assess him for a statement even though he was considered to be severely disabled. Time was ticking away and we didn't know what to do. Eventually after accessing online support, we got a solicitor and the real fight began. We had to have our son assessed privately and pay fees for a solicitor and barrister.

The tribunal took just an hour to make a decision in our favour. The process took 18 months and cost us £30,000. We had to borrow money and use any savings to pay for it.

What's worse, our son missed out on his first term at school."

Every year over 1,000 parents take legal action against their local education authority to get them to undertake an assessment of their child's needs, or offer the support they believe their child needs to learn.

These cases are becoming increasingly expensive for both sides as parents and local authorities resort to expert advice and lawyers. An overwhelming **85% of cases are won by parents** and anecdotal evidence from parents suggests a high proportion of cases are conceded by local authorities within days of the hearing date.

"IPSEA is very aware that a significant number of cases are withdrawn by local authorities at the last minute. It is often suspected that these late concessions are used as a delaying tactic and possibly a money saving exercise. Either way, it is incredibly frustrating for the parents when this is the case. Late withdrawals do not support the sense that all parties should be working together to find the best outcome for the child in a time efficient and expedient way."

Julie Moktadir | CEO, IPSEA

The cost of tribunals to local authorities has more than doubled since 2010 with them spending just over £3.5 million last year. This is equivalent to 157 extra newly-qualified teachers in the classroom. **Meanwhile, half of the respondents to our survey say that their child's current school placement doesn't meet their needs.**

Our recommendations

- ▶ Pathways are developed between Clinical Commissioning Groups (CCGs) and local authorities to ensure that a diagnosis of autism automatically triggers consideration of whether the statutory test is met for an Education, Health and Care needs assessment to be carried out. This will help ensure that children's educational needs are met promptly after diagnosis.
- ▶ The Tribunal Service to publish statistics on the number of appeals conceded by local authorities within seven days of the hearing date, highlighting local authority areas where there are large numbers of late concessions.
- ▶ The Secretary of State should consider amending the Tribunal rules so that where a local authority concedes late in the appeal process there would be a presumption that the authority should be responsible for all the parent or young person's reasonable costs associated with the appeal, unless the authority can provide a good reason for conceding at that stage.

Our recommendations

- ▶ The recommendations of the forthcoming *Ambitious about Autism* and the National Association of Headteachers (NAHT) *Learning outcomes for children with SEND Report* be put into practice in all teaching schools and teacher training establishments.
- ▶ School leaders should subscribe to the teaching standards and competency framework and provide a whole school culture that welcomes children with autism. This to be supported by school staff being able to access Autism Education Trust (AET) training and resources on autism.

▶ One in 100 children have autism. This is approximately one child in every three classrooms. Every teacher will teach a child with autism at some point. Yet nearly nine out of ten Headteachers and school leaders say they don't think Initial Teacher Training prepares them to meet the needs of children with Special Educational Needs and Disabilities (SEND).

We were delighted by the Department for Education's commitment to include information on autism in Initial Teacher Training as two thirds of young people think teachers having a better understanding of autism would improve their time at school and nearly all the parents we talked to said teachers and all other school staff should receive training on autism.

Louisa's story

"Teachers need to get specific autism training. I was flabbergasted when I found out that it doesn't always happen. It's not just autism; teachers need to learn about lots of specific needs. Lots of children with autism will have other needs as well."

It would be good to have specialist SEN placements during teacher training so that teachers can have hands-on experience too, and understand different children. As the saying goes, if you've met one person with autism, you've met one person with autism. I was also shocked by our SENCOs' inexperience. It is a key position and should be filled by experienced staff championing children who are incredibly vulnerable.

You are allowed to be in the job for three years without a qualification which I think is appalling.

It's not just my child who has left the school because their parents did not believe there was enough support for children with Special Educational Needs (SEN)."



Mr Martin* A teacher's story

"In my first year of teaching at the end of one of our lessons, I decided to play a song as a countdown timer whilst we were tidying up. I started to play the music, and one of the children had a complete meltdown.

He was screaming and rolling on the floor, and there was utter chaos. I had no idea that that was how he would react, there was a code against his name in the register to say he had SEN, but it wasn't clear he was autistic.

It was horrible for me because I felt like I'd let him down. It made things worse for him, as it showed his differences from the other children. It was bad for the rest of the class as well. I lost their trust as they had seen me lose control and it made them feel unsafe.

It was in my first year of teaching, and I just had no idea how bad it could be. I knew that I had children with SEND in my classes, but I just thought 'oh, they might find things harder, so I'll differentiate'. I really needed it impressed upon me the severity of SEND for some children so that I could have avoided that kind of situation."



Louisa's story

"The school had threatened us with exclusions or sending Fred home. Whenever they did, I would point out that my son needed support and ask again about a statement or other support. I believe the school knew that they couldn't exclude him if they hadn't been supporting him properly and so they would back down. Once he had his Education, Health and Care Plan he was entitled to 20 hours a week with a support assistant. Often he didn't get it as she was out of the classroom with other children. We later found out she hadn't even seen his plan.

Unfortunately not getting the support he had a right to had real consequences for Fred. His assistant ended up being away from

the classroom during just the sort of turn-taking game which the specialist teacher had previously warned was really stressful for Fred. He was set up to fail in my view.

Fred was so worried that he mistakenly thought his turn was being missed. He reacted by hitting another child. I'm really sad for the child that this happened, and Fred was very distressed that he had done it. Fred was so upset about what he had done that he began crying and shouting and ended up hiding in a corner. Having seen Fred like this before I know how distressing this is to watch. Both Fred and the other child were let down by the school's lack of planning.



Ali's story*

"My daughter was sent home from school early as it was suggested that this would help to make the day easier for her.

This was not a formal arrangement; I received no form of documentation. This arrangement meant that she missed an entire 30 minutes of her education every day. Sadly, she missed story time and saying goodbye to her classmates and teachers. She found this confusing and it did not have a positive impact on her education. It also had a negative impact on me and my family. As I had to go to the school early and also attend regular meetings, I was unable to get a paid job."

On the Friday, Fred was removed from his class. **He was taught in a small back room with his Learning Support Assistant (LSA) for 20 days. He was not allowed to have any contact with his peers either in class, at lunch or at playtime, excluded from attending after school clubs, unable to go on a planned day trip or take part in his class church service.** The school maintained throughout that this was not an exclusion. They continued with their actions despite concerns being raised with them by us, the specialist teacher service, the SEND Advisory Service and the Local Authority. As his parents we were absolutely powerless and no-one seemed able to get him out of that room.

Some children were instructed by their parents not to speak to him or sit with him if he returned. Children threw away Christmas cards that our son had written them. Effectively he was victimised.

He's certainly not the only nine year old child who's ever hit anyone, but he was the only child to be taught effectively in a store room, by himself, for a month.

We were trying to challenge what they were doing, but they stopped all meaningful communication with us. All face to face contact ceased. The only thing we got was letters, often on a Saturday, so that we couldn't go in to talk about them. After that we felt like there was no-one we could go to who could tell the school to change.

The local authority's specialist teacher intervened. She hadn't been informed by the school that Fred was also being kept isolated at lunch and break times and she said that she found this shocking. She arranged the first face-to-face meeting that had taken place between everybody involved. This prompted a bit of a gear change, and the school started to put in some support."

It's best for everyone if
he goes home for lunch.

*We can't take children like
you on the school trip.*

Your TA is off sick
so I'll have to get
your Mum to
pick you up early.

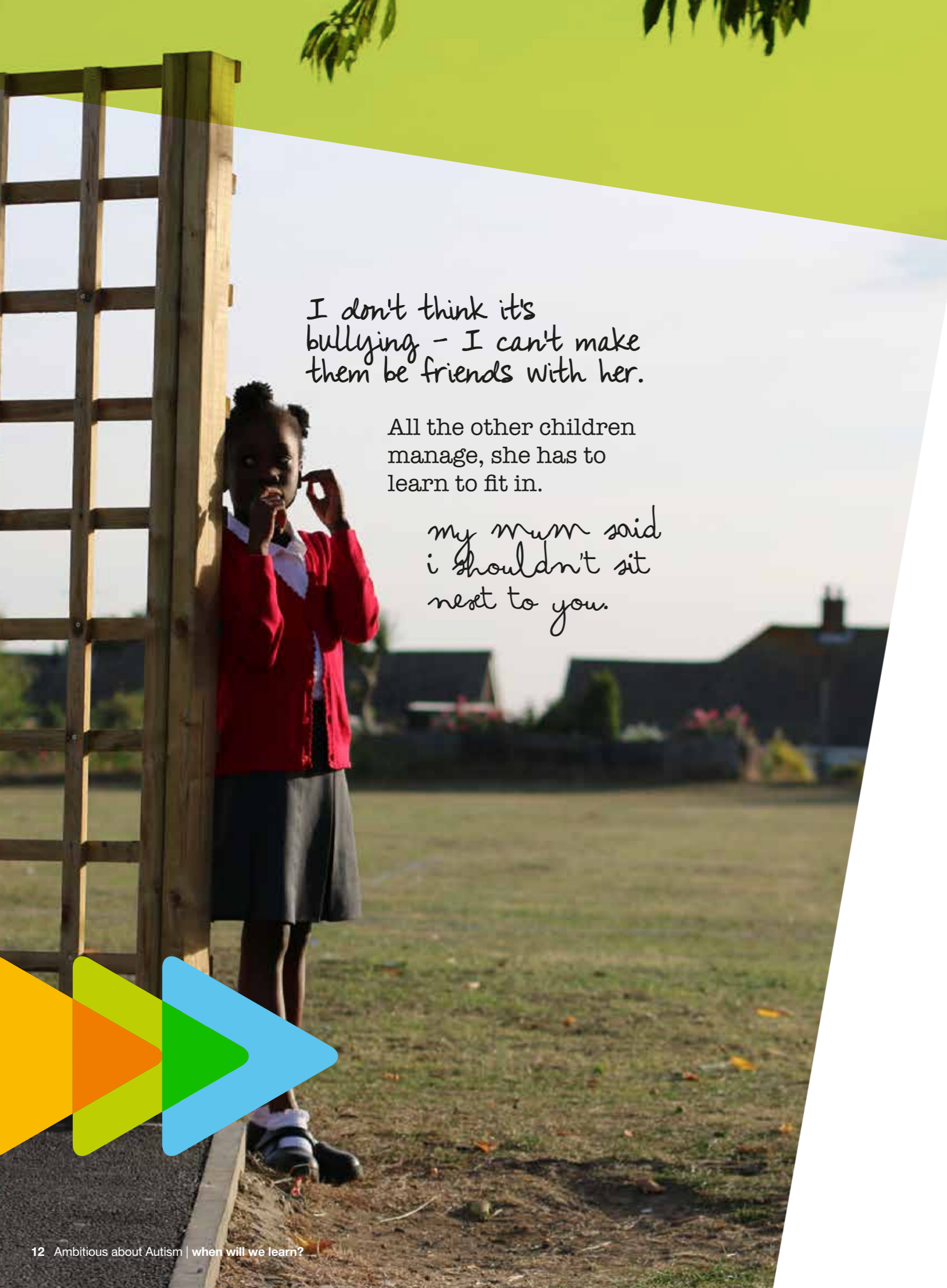
- ▶ Nearly a quarter of respondents to our survey said their child had been formally excluded at some point. Children with autism are **four times** more likely to be permanently excluded from school than any other child.

Nearly half (45%) of the families we surveyed said their child had illegally been put on a reduced timetable, sent home early or asked not to come in to school on days when tests or school trips were happening. More than half of these said this had happened this year. These exclusions, if they happen without the school providing the proper paperwork, are illegal.

Not only do children with autism miss out on vital school time because of illegal exclusions, but by going unrecorded or reported the scale of the problem is hidden, making it harder for families to stand up for their children's rights. We know that illegal exclusions are commonplace, with **33% of school leaders confirming that they knew at least one child with autism who had been excluded from their school illegally in the last year.**

Our recommendations

- ▶ All school governors who are likely to hear exclusion appeals to receive training in autism.
- ▶ A clear procedure for anonymously reporting schools breaking exclusions law should be publicised to all parents, with the agencies responsible for holding schools to account reporting annually on the scale of the issue and how they are preventing this illegal activity.



I don't think it's bullying - I can't make them be friends with her.

All the other children manage, she has to learn to fit in.

my mum said i shouldn't sit next to you.

A huge 80% of children with autism find school so stressful that they experience anxiety about attending. **For 58% of those children, this anxiety is so debilitating that they have missed school days.**

Louisa's story

*"Fred was incredibly anxious and didn't feel safe at school, and alarm bells were ringing. As parents you feel like you have to send your child to school, but we felt like we were sending him in to be abused every day. It sounds stupid, but we wanted to be seen to do the 'right thing' so that it couldn't be used against us later. **When I look back I wonder if we should have just refused to send him in.***

*The exclusion was devastating to the whole family. I was quite unwell, and lost one stone with worry. My husband tends to be quite calm, but he wasn't sleeping. None of us were eating or sleeping properly. Fred's behaviour at home got much worse. The family routine which we had spent years honing to meet his needs went out of the window. **We couldn't get him to eat, and he was having night terrors which stopped him sleeping.** He stopped wanting to go out, even to places he usually feels relaxed in, like his grandparents'. During the half term he refused to leave the house. It felt like we'd regressed five years to having a toddler again.*

*Eventually, once the re-integration process had begun he began to refuse to go to school at all. **He was terrified that something would go wrong and that he would be sent back to the room.** It was heart-breaking.*

We felt helpless. I just wanted to get in contact with someone who could help and who could fix things, but there wasn't anyone. In the end we decided to change school.

Starting at a new school was horrendous. Fred was scared and was having anxiety attacks. We had to work with the home support worker to change his routine and learn how to respond to him. With the support of his new school things did improve towards the end of Year 5 and we are incredibly proud of him for trying to overcome his anxiety about school.

*As a result of changing schools, I have had to leave my job. Sometimes I'm in the car until 11am, trying to get Fred to go to school. **He is terrified of getting in trouble because of the experiences at his last school, even though his new school is very understanding.***

I can't look for another job; he has to be the priority. I have to be available. It affects the whole family; we've had to rethink our budget and everything. When I'm at home I'm jumpy. I'm waiting for the phone to ring with another incident. This experience has scarred me.

I don't trust schools any more, which is awful."

Here's some of the things young people told us about what school was like for them:

The school sees me as a problem because I need extra help sometimes. They don't understand and are not helpful. I feel isolated at times.

I just hate school.

In all honesty I'd never EVER consider going back to school ever in my life. CRUEL

It's the worst thing ever. I like learning but one can't when too stressed. It sucks.

I never got the support I needed from my school and it got so bad I had to leave that school.

i don't like school.

It was shit being bullied by teachers as well. The support staff didn't even know I was autistic.

Extremely stressful; teachers need to be taught about mental health. Education has definitely been the worst years for me.

I want to understand more what the teachers want from me, but they don't understand me.

I feel like the education system has left me struggling to carry on and deal with my anxiety and depression.

I have experienced teachers with very limited understanding of autism and as a result I feel I have been treated unfairly.

School made me very ill and I can't go there at all.

No child should ever find school so challenging that it causes them anxiety and fear. Teachers who are trained to meet their needs, who have been properly resourced and supported to make reasonable adjustments can be the difference between a successful school life and the heartbreaking examples above. It's not inevitable.

We're determined to make school better for children with autism; better schools mean brighter futures.

Show your support by asking your MP to sign our pledge.

I _____ support Ambitious about Autism in their aim to make the ordinary possible for children and young people with autism. I believe that all children deserve access to an education that helps them make the best of themselves and their futures. Which is why I support the **'when will we learn?'** campaign, and pledge that for the wellbeing of the children and young people with autism across the UK, I will do everything in my power to ensure:

- ▶ **We get it right for children with autism from the start –** by making sure their educational needs are assessed after they get a diagnosis.
- ▶ **We meet the needs of every child with autism –** by having the right mix of services and support available.
- ▶ **We support schools to do a great job –** by making sure everyone who works in schools receives training to support children with autism.
- ▶ **We protect the rights of children with autism –** by preventing illegal exclusions & supporting school governors to fulfil their legal responsibilities to children with autism.

Signature _____



Having read the stories in this report, I am shocked and appalled young people with autism could be let down in this way. Every child deserves access to a good quality education, and children with autism are no exception. Many show great interest in learning, and have great skills to offer the world which education is instrumental to developing – but they need to be supported properly through this.

As people on the autism spectrum ourselves, Ambitious about Autism's Youth Council know first-hand how important support in education is. For myself though I faced difficulties, I was encouraged to learn and this helped instill the drive to succeed and contribute I have today. **Children with autism should be encouraged, included and supported – this benefits everyone.**

On behalf of Ambitious about Autism's Youth Council I support the recommendations in this report. Awareness of autism and other special educational needs among teachers is vital if we want to provide young people with autism a strong start in life, rather than repeating the examples of poor practice we see here. It is only then that young people with autism can feel truly understood, avoid being excluded and stigmatised because of who they are; and grow up happy, confident, and able to both enjoy and make the most of their education, and to use the skills it grants to benefit society.

**Jonathan Andrews | Chair
Ambitious about Autism, Youth Council**



A special thanks to Gaby, Joe, Christopher, Harley and Elliot for taking part in our photo shoot.

Thousands of people right now are supporting our campaigns for children with autism. Join **Team Ambitious** and together we can make a difference.

We never use government funding for our campaign work. We rely on the support of people like you. If you would like to support or invest in our campaigns to make the ordinary possible for children and young people with autism, please visit: ambitiousaboutautism.org.uk/our-campaigns.





**Ambitious
about Autism**



The National
Autistic Society

Every Child

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

Children with autism are more likely than other children to be excluded from school, to be bullied and to leave school with no plans for adult life or 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. Ambitious about Autism and The National Autistic Society'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 children with autism'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.ambitiousaboutautism.org.uk/every-child or autism.org.uk/everychild for more information.



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