

We Need An Education debate

Monday 15 October, 2018

6pm: Introduction

SAM: Welcome everybody and thank you for coming to our event this evening. My name is Sam Ahern, I'm an Ambitious about Autism youth council member, and I'm pleased to be co-presenting tonight's proceedings with my fellow Youth Patron Jack Welch.

JACK: We're very lucky to be in such a magnificent venue tonight and we'd like to thank the Clothworkers' Company for their generosity in enabling us to be here tonight.

Tonight Ambitious about Autism's Youth Council have brought you together to talk about autistic young people's experiences of education.

SAM: Every young person in this country has a fundamental right to an education that meets their needs and enables them to learn, thrive and achieve.

Yet for some unfathomable reason, this basis right remains out of reach for many autistic pupils.

To put this in context, nearly 120,000 pupils in English schools have autism and this number is growing every year. These students should be entitled to extra support at school, but instead we know they are much more at risk of exclusion and find it much harder to cope in that environment.

JACK: Data uncovered by Ambitious about Autism earlier this year revealed that exclusions of autistic pupils have increased by almost 60% in five years.

This points to a worrying trend of more and more autistic young people being denied an education - such a vital part of every young person's life journey.

We want to tell you what it's really like for autistic young people at school.

Each of the speakers you will hear from tonight has had a different journey – at different types of schools and provision. You'll hear about challenges and difficulties - but also about how the right support can lead to real success and achievement at school.

We'll also be sharing some of the findings from our own survey of autistic young people in the country to you an idea of the national situation.

The second part of tonight's event will be focused on how we can go about solving some of the issues facing these young people. We're delighted to be joined by the panel of experts you can see above, which includes our fellow youth patron Georgia Ellin.

SAM: We have a quiet room available to the left of the stage through this door. Any member of our audience is welcome to use this room at any point during tonight's event. When applauding any of our speakers this evening, we'd like to ask you to do this with 'flappause' as XX will now demonstrate. This is so we can make the event a comfortable experience for all.

You should be able to see tonight's agenda and running order on the screen above. We plan to stick to this schedule as closely as well can.

We will be taking a short comfort break between 6.55pm and 7.05pm before we start our panel discussion. This will be another opportunity for you to take a few moments outside this room or use any facilities you would like to.

JACK:

For those of you who use social media, Ambitious about Autism will be tweeting about tonight's event using the hashtag #WeNeedAnEducation

But could we please ask that your phone is switched onto silent mode.

Please feel free to share any thoughts or ideas on anything you hear tonight using this hashtag.

We would now like to introduce our first topic of the evening – the importance of early support.



6.05pm: Early support

SAM: For many autistic pupils, having the right support in place early at school can be crucial to their success.

55% of students with an autism diagnosis also have an Education, Health and Care Plan or EHC.

EHC plans establish a legal requirement on local authorities to provide extra support for these pupils at school. For example providing a dedicated teaching assistant or access to specialist equipment.

However, waiting times for an assessment for these plans are often far too long and many parents and young people also complain about the quality of the support they provide.

JACK: New research by Ambitious about Autism has found that nearly 40% of parents are waiting over 18 months for an assessment for an EHC plan. This is despite statutory guidelines stating it should only take 20 weeks.

Delays like this, and other problems securing the right support at school can have far reaching consequences for autistic pupils.

I'd like to welcome Lucy to the stage, who will be followed by Rayhan. They are going to tell you about some of the problems they experienced as a result of lack of support.



Lucy's story

Hi, my name is Lucy Portway and I'm going to tell you about my experience at high school regarding my autism. When I got diagnosed, I was 15 years old and was in

year 10. I had no idea what support I was able to get, and assumed that my school would suggest some ways in which they could help me. I couldn't be more wrong. When my parents and I told my school about my diagnosis, they simply didn't believe us, and denied me of any support whatsoever. When we finally got through to them that I wasn't lying about my diagnosis, they still didn't offer any support or paid any acknowledgement to this huge change in my life.

I'm not suggesting for one second that I think that anyone with autism should be treated differently because of their diagnosis, because, like everyone in this room, I believe in equality.

However, in my eyes, equality isn't giving everyone the same opportunity, but it is enabling everyone to be able to access the same opportunities, regardless of how much or how little support they need.

What I need out of education, what every child needs out of education, is the support and allyship of teachers and students alike to be able to access the same amount of education and extra-curricular activities as neurotypical students. To have easy access to additional support in the classroom, to be acknowledged and respected by everyone in education, and to be able to feel as though we aren't isolated, different or unsafe.

I remember one time in school, I experienced a major panic attack during my maths lesson as the pressure was building up and I had sensory overload from the glaring screen of the smartboard. For a while, my teacher didn't notice until the students around me started to ask me if I was ok.

In an ideal world, the world we are working towards, a teaching assistant would have taken me out of the classroom and calmed me down, maybe even helping me to the point where I could re-enter the classroom and continue with the lesson.

Or perhaps the teacher would have been checking on me throughout the lesson, knowing that I have autism and may be struggling slightly. She could have realised early on that I was struggling, maybe she would have even prevented it from happening.

In reality, I was sent out of the room with a classmate, who had no understanding of

autism or how to help, missing out on her learning too, with the whole class watching me curiously, and told to wait outside the room in a narrow corridor until I calmed down.

Although I struggled in the lesson, I struggle more to understand how this can be right. Teachers have a duty to keep students safe, yet here, I wasn't even sent to the medical room, where the staff might have an idea of how to help.

It was also unfair on the classmate who was sent out with me. If the teacher didn't even know how to help me, how could a student, pulled out of class and told to help me when she didn't understand anything about autism or how to help, possibly support me?

Another time, I was even told by the *head of year* at my school to 'not have panic attacks in front of other students as it was unfair on them to see me like that,' *as if I could control when I had them.*

In conclusion, what I am trying to say is not only that I, and other people with autism, deserve a proper education with proper support for us, but that autism and other learning disabilities should be taught to both teachers and students, in teacher training and in lessons dedicated to helping everyone to acknowledge and understand how they can help and support people. That way, I feel we can truly thrive and get the education we deserve and have been deprived from for so long.

Rayhan's story

Education is important for everyone but unfortunately for those with autism it can be much more challenging.

In primary school I never fitted in and couldn't understand the other kids. I was told I was quiet and shy. I was always behind in class on a very low level - lower than the average. When teachers were talking I was always caught up in my imagination and this meant I ended up getting sent out of class. As a result of this I missed out of work and needed extra support from a teaching assistant who taught me independently during extra hours after class.

Getting the right support in place from an early age is really important. I remember once trying to add complex fractions. I found it very difficult but my teaching assistant kept trying different ways to help me understand them until it worked. I practiced the way she taught me many times. She was really helpful and I think she was the reason I started to enjoy maths and decided to pursue the field of computer science.

I don't think a one style generic education system fits all students. Just because there is a general way of doing things, it doesn't mean it will work for all students. In fact, without making changes, it can destroy the potential of many students with autism.

6.15pm: Having the right mix of schools and support

JACK: Thank you Lucy and Rayhan. We now want to talk about the importance of having the right types of schools to meet the different needs of pupils with autism.

Nearly half of parents who responded to a recent Ambitious about Autism survey said their child's current educational placement was not meeting their needs. That's thousands of autistic children who could be missing out on opportunities to thrive, achieve and just enjoy their childhood.

SAM: It's vital that mainstream schools are able to support inclusion – indeed 70% of all autistic pupils are in mainstream schools. But some autistic children require specialist schools to meet their needs.

Indeed this is the very reason why TreeHouse School at Ambitious about Autism was set up 21 years ago by a group of pioneering parents who demanded better educational opportunities for their children.

Every autistic pupil is different, and will have different individual support needs. The thing we have in common is needing the right provision that's right for us at that time in our lives. We all want an education, and school that's right for us. You're now

going to hear from Grace and Kieran who are going to explain why the right school can make all the difference. Grace will speak first, followed by Kieran.

Grace's story

Hello. I am Grace. I am part of Ambitious about Autism's youth council

I am 21 years old, and I live in central London

When I was 16 my school finished. I then went to the NET - a transition unit, which was part of a college.

I left my friends who I knew for 11 years.

We were meant to be part of the mainstream college but this did not happen.

On the days I went to the mainstream college it felt like being in an airport.

I found the experience disrupting and disabling.

This was because they taught me about time and other things I already knew and when I finished they did not have anything else for me to do.

They did not help me make friendships and was a very small group. They told me off for making my happy noise.

When I was 17 I moved to New York.

I went to a new school, which had a brilliant curriculum.

The curriculum was so different because I learned interesting things in a lot of subjects.

My favourite subject was social studies, which combined history, and geography together in the same lesson. I learnt about Native Americans and crusaders and all sorts of other things.

Another great thing about the school was clubs, which didn't happen at lunchtime or after school but which were part of the school day. You could choose what you wanted to do from a list of options. I chose musical theatre because I love doing that.

What I learnt was a mix of life skills and academic study. For example we did travel training and internships but we also learnt structured writing skills and carried on with subjects like science.

From my experience in New York here are the top 3 things I really recommend for schools all around the world.

1. Councillors – you have timetabled sessions to get to know the councillor really well, and then when you are upset you can choose to go and see them at any time.
2. Writing process – teaching structures in detail about writing and thinking.
3. Acknowledgments - We were given wristbands to celebrate achievements in 4 key areas. **Independence** - doing stuff independently. **Community** - for talking and helping out. **Advocacy** - speaking up for yourself or for another person. **Initiative** - for doing something without being told what to do.

It was a place where we had graduation, prom, ring day and spirit week. Just like any other kid.

There was so much to celebrate.

Good Evening.

My name's Kieran and I get to be one of Ambitious' Youth Council members. I wanted to tell you all tonight about the impact you could make for the education of young people with autism.

I had to be taken out of the school I was in about halfway through year seven due to getting inadequate support for the difficulties that autistic people face in secondary

education such as bullying, sensory needs or even knowing what to do or where to go, and that's all on top of having no 1:1 support.

Once I got out of there, I heard that The Rise was going to be opened soon and that it was a special needs school which would give me help. I would have chosen this over being chucked into a behaviour referral unit when, rather than being "problematic", just wasn't being supported properly.

I am so glad I managed to go through the rest of my secondary education there.

What the right support looked like to me was that I could always have the choice to work 1:1 outside the class, a supportive network of teachers and TAs that I still like to keep in touch with, and a consistent routine throughout the week that breaks up lessons to stop them becoming tedious.

Not too long ago from now, I got my GCSE results. I am so proud of them and I credit it directly to the school's endless assistance for the last 4 years. An A in English. A 5 in Maths. The Nobel Peace Prize. Maybe the last one is an exaggeration.

If not for the opportunity to join The Rise, I fear I would have ended up like the growing number of children that just vanish from the radar of councils and schools because they have given up hope in getting the right education for their children and instead have chosen to be home schooled. I want the number of people who have given up lowering to zero.

With your help, we can secure a future where we can give children and young people that have autism the education they both need and deserve. Because like everybody else in the world, **WE NEED AN EDUCATION**

Thank you very much for your time tonight and I hope I opened your mind to the struggles we face.

6.30pm: Feeling safe and happy at school

SAM: Thank you Grace and Kieran.

Classroom learning is only one part of young people's education. School should also be a place to make new friends, try new things and grow in confidence.

Sadly, for far too many autistic young people, this isn't the case, and school can actually feel like an unwelcoming and hostile place.

JACK: Our survey of young autistic people's experiences of school highlighted a very worrying picture. Over 75% of young people said they had experienced bullying and only half of young people said they felt safe at school.

83% also said they experienced anxiety about attending school.

Autistic young people often feel different to other pupils and this feeling of being an 'outsider' can have a profound impact.

Shane experienced this feeling at school and he is now going to share his thoughts with you.

Shane's story

Hello Everyone,

My name is Shane- Shane Gunesh and I'm 17 years old.

Being autistic hasn't been easy for me. I have always found it very challenging to talk to people and make friends.

I find it difficult to process the language and most of the time I don't really know what to say to people.

At school I was always the shy little boy who spent most of the time with adults. Children didn't want to play with me. I didn't know how to play with them.

I have often seen in some of my reports that I am contented to stay on my own. The truth is that I don't really know how to start a conversation. This is too scary for me. I am scared that I will say the wrong thing and people will laugh at me.

As I am growing up, I am finding it a bit easier to respond to people. Since I've joined Ambitious about Autism I have had the chance to express my views. I don't always say things that make much sense. But everyone listens to me and this makes me feel good about myself.

I am autistic and this is who I am. Thanks to Ambitious about Autism, I'm here today talking in front of an audience. I enjoy doing it.

I have set up some challenges for myself this year. I want to travel independently on the bus to some places and find my way back home.

It is going to be very challenging because I always get very confused when there are too many diversions or changes.

Because of my autism, there are many things that I can't do or understand. I am a slow learner but I know that:

"If I believe I can, then I will"

6.40pm: Exclusions

JACK: As we said at the beginning, exclusions of autistic pupils are increasing, by 60% in the last five years. As a result we know that many, many autistic pupils are currently missing from our education system when they should be learning.

What is more worrying is that this could be affecting even more young people than we know about – due to unlawful exclusions.

This involves young people being told not to come in for trips or being taught in isolation from their peers, without a formal record being given to parents.

SAM: Over half of the families surveyed by Ambitious about Autism said their child had unlawfully sent home from school or denied an education.

The impact of exclusions cannot be underestimated – but it is not only young people’s academic progress that can be damaged. The feeling of isolation and rejection that exclusions can cause can have terrible consequences.

In this video, Olivia is going to tell you about the impact that several different kinds of exclusions had on her.

Olivia’s story (video link)

Olivia is 17 and from Stockport - she has a severe anxiety disorder as well as autism (as well as an auto immune condition). Due to her anxiety she has found it very difficult to cope at school in the past and has been to nine different schools. She has been variously excluded, off-rolled, self-excluded and even told to take a year off her EHC plan due to lack of local provision for her.

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6.50pm: A way forward

Jack W: Hello, I’m Jack and this is Georgia and we’re going to share with you some thoughts on how we can move forward and create an education system that better supports the needs of autistic young people.

Stories like Olivia’s will be shared by many autistic young people and their families. Stories of wasted potential, of stress and anxiety, of exclusion rather than inclusion.

Of course, at times school can be a difficult place for lots of young people - not just those with autism. But being autistic can add a new range of complication.

Social situations with peers are harder to read, busy corridors at break times and lunchtimes can feel totally overwhelming, and that’s before someone has even reached their lesson, where sometimes instructions from teachers can be difficult to carry out in the classroom.

On the screen is just one insight from our survey that sums up what a lot of autistic young people are feeling about school:

‘School is hard. It’s hard being different. It’s hard not being understood’

Georgia: Looking at the findings from our survey of autistic young people was like plugging into the mainframe of awful. What particularly stood out for me was the fact that over three quarters of young people said they had experienced bullying.

When giving more details about their experiences, young people told us that autism seemed to make them a particular target for bullying behaviour. For example, some young people – including myself - have experienced situations where bullies deliberately provoke them into having meltdowns.

In these horrible situations, it's crucial that teachers understand what has triggered autistic students' behaviour and deal directly with those who are responsible, rather than expecting the autistic student to in some way change their behaviour.

Unfortunately bullies continue to exist, but the right support and understanding from school staff in these situations can make a huge difference to how autistic pupils are able to recover and move forward.

Another issue that came through from our survey was the number of autistic young people who don't have, or are currently waiting for an EHC plan. This is something I have personal experience of.

I was first diagnosed aged 9, but my parents had to fight hard for it, constantly coming up against the attitude of "She's getting really good grades, so what's the problem?" (Everything else was the problem...) That same attitude meant I ultimately never got a statement of educational needs (as it was called back then) – I remember feeling like it was just me not fitting in anywhere, being autistic enough to be mocked and judged for it but not autistic enough to get any support, but this project shows it's actually a common experience. And it has long-term consequences – when university and living away from home brought its own set of challenges, and I found that I did need a bit more support, I no longer had any proof of my diagnosis in the first place. I was diagnosed aged 9, and I had to be diagnosed *again* aged 22. I can't fault the brilliant team in London that assessed me, but I came scarily close to having a huge part of my identity denied from me because a decade before someone thought I was "too clever for a statement".

Every autistic person is different and has different needs. Academic ability shouldn't be the only factor in determining whether someone gets extra support at school (and beyond!). It's crucial that educators base their decisions on a fully rounded understanding of the different types of support pupils might need.

Jack W: This is something I empathise with as someone who was also bullied constantly for a year and a half after starting Secondary School. While my family were waiting for a diagnosis I was put into groups with other students with similar Educational Needs because of being suspected to be Autistic. Though some people I met would become long-term friends there were a number of people here who would bully me and this escalated to most of my Tutor Group doing this. Again, because I got good grades and could express my problems, the attempted interventions to stop this were purely verbal to the people bullying me and just made me more of an example. Eventually I got the EHCP which helped me have independent time socially and with staff who I interacted better with, which is what I needed, but at the cost of hearing voices for five years and several years of psychotic traits afterward. If there had been more action plans that were preemptive and more flexibility, this could have been avoided.

Some of the problems we've discussed require changes to how education law is enforced - tackling growing school exclusions being one example we're highly aware of. These are issues I'm sure our panel will be exploring in the second half of this event.

However, the young people we surveyed also had a great selection of simple, practical ideas about what would help them feel happier and more supported at school, and we'd like to end this part of the evening by sharing some of these with you.

The first was having access to sensory toys, a quiet space and visual aids such as visual timetable whilst in the classroom. These are very small adaptations that can really help to reduce anxiety and help autistic pupils to regulate their emotions.

Another common theme from our survey was a desire to have more structure to breaks and lunchtimes. This could include being able to go front of the lunch queue to avoid big crowds, or having somewhere safe to go during free time. Again, these

are simple changes that can make autistic young people feel a lot safer and calm at school.

Finally, many young people told us that more support and understanding from teachers would make a huge difference to their day. This includes teachers listening to their needs and checking their understanding of tasks so that they are fully able to participate and feel included.

We know there are many wonderful teachers that do this every day, but the more we increase understanding and awareness of autism throughout our education system, the more we can make this a reality for all pupils.

Thank you for listening to our ideas.

SAM: Thank you Jack and Georgia and thank you all for listening to our presentation tonight.

JACK: I'm sure many of you who have done public speaking before are aware how exciting but also how daunting it can be. We're very proud to have spoken out tonight and hopefully shown you all the talent and potential that autistic young people have to offer.

We will now be taking a 10 minute comfort break before we move on to the next part of our event, so that everybody has a chance to take a few moments if they need to.

So this is goodbye from me and Sam and thank you for listening.