

# **In our Words: Sixty years of the National Autistic Society and the story of autism in the UK**

Oral History Interview with Helen Allison School staff. June 2024.

**00:00:00 Jo**

So my name's Jo Neill Smith. I am the Clinical Lead as a speech and language therapist, Principal Speech and Language Therapist, based at Helen Allison School. I worked for the National Autistic Society for a very long time.

**00:00:13 Lisa**

Right. My name's Lisa. I'm the Senior Assistant Head and I run our 14 to 19 department called The Hub. I have been at the Helen Allison School since the year 2000.

**00:00:25 Ian**

My name is Ian Sandford. I am a Senior Support Worker and I've worked for the National Autistic Society for 20 years now.

**00:00:35 Dawn**

And I'm Dawn, and I've worked at the school and down at The Hub, plus our residencies, and I've been here... this is my 19th year.

**00:00:44 Richard**

Hello, my name's Richard. I've been working for Helen Allison (School) for 15 years and I'm a Senior Support.

**00:00:53 Tom Stubbs (Interviewer 1)**

Quite a while, everybody, collectively. So we're gathered together to solve or ponder a, a question, aren't we? And the, the nubbin of the question is?

**00:01:02 John Clark (Interviewer 2)**

How has autistic education provision changed over the years?

**00:01:06 Jo**

How has autistic provision changed over the years? Absolutely massively. When I first came to work at the Helen Allison School, we were in a residential Victorian building and the curriculum was kind of... "it's a great day, let's go to the beach" kind of curriculum. The classes were very small. It was set up really as a family support group almost, and I think at the time in terms of a school role it... there's probably only about 40 children at the house. In fact, we had two houses over at the Overcliffe at Gravesend.

I feel privileged to have worked for the National Autistic Society for such a long time. So '89 I started. Things have changed enormously with the national curriculum, with expectation, with ensuring that autistic people and their families have a voice, that the National Autistic Society now is avidly campaigning, that we, you know, we must... we must use lived experiences. And of course we must, because we're shaping autistic families' and their children's lives for the future. So I think it's changed enormously for the better, I think.

**00:02:16 Lisa**

OK so when I started at the Helen Allison School in the year 2000, I started as a one-to-one support worker. All the classes were taught all day in their own classrooms. There was limited interaction with the other classes. We all taught every subject, whether that was their specialism or not. And there was very little expectation of where our students would progress onto. Exams weren't thought about. There was no expectations that students would get employment or even access mainstream provision. It was very much "you're autistic, so you will be going on to specialist SEN provision for the rest of your life" really.

Now, we have got higher expectations of our students. We have students that have left us, gone off to Cambridge University, employment, apprenticeships, exams AR. Every student at the Hub leaves with some sort of qualification in English, maths, and then obviously we

do other qualifications around the students' interests. So I think our expectations of what a student can achieve is the same for any other young person. The autism is not a barrier for them.

**00:03:37 Richard**

My, my take on it, I come from a, a non-educational background. I come from a, a sporting background where I used to teach sport and I come in, and I was absolutely amazed by the school, the way it worked with the young people and... and the great thing about working here, right, and, you know, I love my job, I've never said I don't, is that you learn a lot from the kids, right? And their actual needs. And you have to think outside the box sometimes to get them to get involved in the subject, you do.

But my, my time here 15 years has flown by, right, and I've never... I've never regretted a day of work, which in very few jobs that I've done that I can say... say that but...the boys like, you know, that they, they learn guitar, they learn drums, they, they do farming, they do cooking, right, you know, they learn a whole like host of activities that, right, you know, a lot of kids outside don't learn and like, you know, that's a great thing we're given, right. You know, I was speaking to one of the boys today, right. And he, he was saying how far he's come to me, right, while I'm at school and that makes a big difference to coming in each day. But... that's my take on it. They've, they've... it's been 15 quick years.

**00:05:03 Tom Stubbs**

And in that time have you... has, has the building changed, has the institute, has the kind of attitudes changed or?

**00:05:10 Richard**

I, I, I used to work at the residential house and like to help cover and, and, and do work and we lost that, and since I helped actually move stuff into The Hub, right, with one, one of my colleagues, we moved all the furniture in. But it's become a little bit more educational, right? But we've, we still focus on preparing for life. But, like, you know, now, with the curriculum that we get given you know, we have to focus sometimes a lot on, on their output which we never used to do, I would say.

**00:05:46 Dawn**

I worked at the residences. I was there for the students when they woke up in the mornings. I also worked the evenings. We had three houses to begin with, but we've slowly lost them due to students leaving, which was a bit of a shame because it means that our students didn't have the ability to learn life skills because the students, they would make their own beds, they would do their own washing, they would make their own food. So that was a bit of a shame that we lost that, but I worked at the school and then moved down to The Hub. But at The Hub we do do a lot of life skills now.

And a lot of our students are now doing work experience, so they go out to different shops. They actually learn how it is to work, how everybody else has to work. So they work in the shops, they do all the jobs that they need to do. We also have provisions in other schools where our students go to learn mechanics, construction, bike maintenance. We have a student that's doing hair and beauty.

We go to a farm once a week where the students work all day on a farm. So this is... I feel it's really good for independence and for our students to learn that there's more to life than just coming into school. And I think it stands... stands them in good stead for the future, for when they leaved us.

**00:07:10 Ian**

OK, well from my perspective, because I've, I've worked for the National Autistic Society for 20 years and I've worked with both the adults and the children at school. So I've kind of got an awareness of the... those original pupils and I, I would say since those times things have changed a hell of a lot in terms of... we have got a better understanding of autism and I think there's a, there's a much more person-centred approach than there was years ago, which is beneficial to everybody. As a school, I think we've, we always tried to help children in any way we can, whether it's just through, through education or whether it's through life skills. And I, I think there's, there's been greater focus on that over the years moving away from a less understanding time, I think.

**00:08:09 Tom Stubbs**

I mean... because has... because you know, we were talking about the school. But... but there's a flip side is this the society outside. How has that changed?

**00:08:18 Ian**

Society as a whole, I mean, there's been a lot of changes over the last sixty years. I remember reading about how some of the early parents didn't even really consider what was going to happen to their children when they grew up. They didn't realise that autism was going to be a lifelong condition. So obviously nowadays we... there are people who are able to give us a perspective of what their lives are like and it's sort of informed upon our practice as well.

**00:08:50 Jo**

So I think one of the biggest changes in society has been the language, the language of autism, and how people understand what that... what it is and what it means. Years ago, in the '70s, it was very much a deficit model - an impairment of this and impairment of that, the disorder of this disorder of that. And now, thank goodness, it's now a difference.

And actually, that awareness and that understanding has, has actually fed into our children's self-esteem because years ago they'd come to us with, "I'm stupid. I'm sick. I'm this, I'm that (and) the other." And now they just say, "actually I'm different and that's OK". And I think that's really important. That it's far more... it has far more of a, a positivity, it has for... the opportunities are there that that weren't there years ago.

**00:09:40 Richard**

We, we take the children out to parks and things like that, and where in my early years people would sort of like shy away and almost look at them naughty kids, now there's much more understanding from the general public, right. And, you know, a lot of the local people, especially in the shops that we frequent or where we go, they understand and they actually help us, right. And the thing with our kids is that sometimes they might struggle in one area, but they have a interest or a skill in another area which they exceed other people's opinions, and they... people don't realise how good they can be at certain things. Right.

And the highlight this year for me was watching boys in my, my group play in a concert for another disability school, where the whole place went mad because they were singing and dancing to the music that the boys was playing, right. And that exceeds, like, expectations of all the teachers. You know, in a way, it's worth more than a, a GCSE or a O level because that's a life experience that I'll never forget.

**00:10:49 Lisa**

I think that what's really changed over the years that I've been here is how we include the students in talking to them about their autism. Before we very rarely even mentioned the word autism to the students. We include them in any campaigns that are going on in the National Autistic Society in general, so Autism Acceptance Week we make quite a big celebration of that at The Hub. So the students go off into the local community, they've made their own flyers that they've given out to members of the public. They've been able to stand there and explain what their autism means to them and how it can affect them in the community.

We've had one student who was part of the Too Much Information programme in the filming at the shopping centre. He also went on to be an ambassador for the National Autistic Society. So again he's done interviews and promoted autism, saying how it's a difference and how it affects him.

But also the need for the society to accept those differences. So that is one massive change I think that has proved positive not just for the families and the students, but as Ian said, for us in the way that we teach as well.

**00:12:05 Jo**

So I think another thing that's changed drastically over the years is resources. And that relates to making things very accessible for our children and young people, making proper adaptations, recognising how much the sensory differences and the communication differences impacts on their life and impacts on their learning.

And with that has been an investment in clinical support, which I think has been invaluable. Working as a team here is fantastic. We have a fantastic team of speech and language therapists, occupational therapists, psychologists, all of the teaching staff, all of the teaching assistants are one big team, and I think that transdisciplinary approach is fantastic, whereas before it... people were almost doing things in isolation because they weren't quite sure what was the right way and everyone has a shared understanding of how best to support a child or a young person and their family.

**00:13:02 Tom Stubbs**

Because it's... you're, you're, you're... it's a part of... it's a community, isn't it?

**00:13:06 Jo**

Yeah. Definitely.

**00:13:07 Tom Stubbs**

Between, you know, it's... you're not just... you're not just dealing with a child. You're... it's the family and...

**00:13:13 Jo**

Absolutely. And families play a big part, don't they? Yeah, as, as do the children and young people themselves. You know, they, they, they can see what they'd like to do in the in the future. They help plan with their support. They help plan for their and agree their objectives and target setting. As you... as Ian said, it's much more person-centred and, and that's, and that's how it should be.

**00:13:36 Lisa**

I mean, it's also given them the same opportunities as their siblings. Yeah, so quite often, some of their students will say, "so how come my brother can go off to college? How can he do this? Leave home?" Well, we, you know, we give them those same expectations, maybe in a slightly different way where they'd get a bit more support around their autism. But there is no reason why they can't do the same things as their brothers and sisters.

**00:14:03 Jo**

Lots of, lots of our children have said, "I like it here because I can be myself and you understand me and you get it." And I think that's the biggest accolade that we can actually see things from their point of view and hopefully support them in the best way possible.

**00:14:18 Tom Stubbs**

Somebody was mentioning that it's... to get... how, how, how does a parent get a pupil in here?

**00:14:24 Jo**

How long is a piece of string?

**00:14:26 Lisa**

With a big fight.

**00:14:27 Jo**

Yeah, well, sadly, that is the reality that it is a fight. Within the southeast I have to say there has been an awful lot of local provision being set up over the years, whereas years ago when we started over at Gravesend, 50-60 years ago, there wasn't anything for autistic children, and now there is. And that's the fight because we are significantly more expensive. I know think money shouldn't come into it, but that's the reality and we're more expensive because we have very small classes. We have a team of very specialist and experienced professionals.

And we want to give them an enriched curriculum, which of course takes them outside of the classroom and provides them with opportunities to generalise skills out in the community to be as independent as possible. But it is a fight. Yes, it is a fight and some of our parents have had a, you know, had to go to tribunal. Financially it's been a massive impact on them as a family. And hopefully things, things will change, but that's the reality at the moment. It is not easy to get into one of our schools.

**00:15:30 Ian**

A question that I thought would be a good question is what's the same as it was? And I think the main thing is that throughout the history of the school, there have been people (that) are dedicated and passionate to working with our children at the school and, and helping to make their lives as good as we possibly can.

**00:15:51 Jo**

Yes.



**00:15:52 Dawn**

I think that's why a lot of us have been here a long time. There is a lot of staff that have been here over 10 years because you want to help them, the children, you want to help the students, you want them to understand that they can do things. So I think it is a... it is a privilege... to work here, it is.

[general agreement]

**00:16:14 Jo**

But it's wonderful that everyone has the same... the same... mindset that at the end of the day, we're here for the children and their families so that they can be the best they can be.

**00:16:25 Lisa**

I don't think other people actually believe us when we say "I love my job. I love coming to work." There's very few days I've got up and thought "I don't wanna go." Whereas you speak to friends outside of work and it's like, you know, "Ohh I hate work. I can't wait to retire." I'm actually dreading retirement.

**00:16:46 Jo**

You won't go though, will you?

**00:16:48 Lisa**

I probably will stay here forever. [laughter] They will have to drag me out. But I do love my job. And it is the students. That's the reason I love my job.

**00:16:57 Ian**

I agree with what Lisa was just saying. I really enjoy working with our children. I find the job rewarding and every day is different. (It's a) challenge. You never know what it's gonna be and I look forward to it.

**00:17:13 Tom Stubbs**

The challenge of the future that's always quite nice. It's quite nice to think what...

**00:17:19 Richard**

The challenge of the, the future is that right? We're getting so caught up with technology. The, the technology is gonna help these guys tremendously, right? Because, you know, now handwriting isn't as necessary as and communication is a lot easier from the, the technology and, you know, if I need anything done on technology, I'll see one of the kids and they will sort me out and teach me. You know, technology is improving, it's, it's getting quicker, right. And it'll, it'll get quicker for these guys and improve for these guys.

Right. And they'll, they'll, they'll latch on to it really quick as a tool that they can use, right. And you know, when they find something that's really useful to them, they master it really quickly. I think they're quicker than, you know, stereotypical children, right. You know, they, they will, they will use it and, and find the way to use it correctly and, and well. So I think it technology is going to be a big help for them.

**00:18:15 Tom Stubbs**

Any thoughts on the future, Lisa?

**00:18:17 Lisa**

Like what Richard was saying with technology, I think even with that it's another opportunity for our students, for the future. I've had students that actually have left us gone off to college, then university and, and now he actually works from home. He's got his own studio at home and I know we sort of like push for our students to integrate with society, but actually he's got a very successful business sat at home in his workshop doing animation, doing websites for people, that sort of thing. But he's happy, he's making money, he's independent, and that is his future. And that's so... you know, there are the exceptions where it's not always integrating with society in the way that we see as the norm. It could be at home working from home, which is actually quite common for, you know, people without autism nowadays due to COVID.

**00:19:16 Jo**

Absolutely. Yes, I absolutely agree with you. I think you know, looking back on it, perhaps we were... we weren't, as I suppose mindful of the difference in our autistic population and we wanted them to be sociable, be communicative, be chatty, be like us when actually... in actual fact, why, why should we be saying those things?

Actually I think what's, what is, has changed enormously is acceptance and it is actually OK to say "I'm not really a sociable person, but I'll do this instead." And I think as you said, Richard, IT will be a absolute draw in the future. And I think also some of our young people because they have been stereotyped as "oh, you're only gonna be good at maths or science or factual things," they haven't been given the opportunity. We have fantastic creative young people here that have won awards for art that have won awards for their... for stop motion videoing and animation. So yeah, I think the creative side of things is also being recognised now in both our girls and boys, and that's, that's a big change.

**00:20:24 Ian**

One challenges I would say as well we... is the financial challenges ahead. I mean we, we are not such a profitable country as we once were and I think that the, the money in education is not... there's not so much as there once was. And so, you know, there's sort... there's a sort of the danger of, of things... sort of services not being able to offer as many services as, as we have been as well.

So... You know it's, it's sort of the, the, the worry and the sort of the danger of things slipping backwards somewhat as well.

**00:21:02 Tom Stubbs**

Do you have anything to add?

**00:21:02 Dawn**

No. But I do think like... like Ian was saying, the money is a, is a thing and local authorities are gonna start tightening their belts, which means that they're not going to be able to provide the funding for students to come to schools like ours. So I do think in the future that there may be not so many schools... specialist schools for autism around, which would be a, a huge shame because I do think the students and the young people that come to us,

they get such a lot from being here. So it would be a shame if we did lose schools in the future.

**00:21:39 Lisa**

When I first started there was obviously students that had mental health difficulties, but because of their autism it was just looked upon as part of their autism. So it was very rare that they would get that additional support from CAMHS or any, any other sort of services. Now we, we do recognise and we actually support students in getting the right support they need around their mental health. And it has increased a lot over the last few years, especially with more girls being in the school, which I mean we've had, we've got more girls now than we've ever had and they're, they're just so different to having boys with autism. Their mental health needs... they need a lot of support around their mental health. I mean, we do have a clinical psychologist who his workload... if he could be here all day for 24 hours a day, seven days a week, he still wouldn't be able to see everybody he needed to see. But also within our staff team, we now have mental health advisors for the students and for the staff, which is a really positive move.

**00:22:52 Jo**

I think in terms of mental health, what wasn't being recognised years ago, which is now absolutely commonplace, and it wasn't the go-to, is how much anxiety affects and impacts on our children and young people. I think possibly years ago it was almost dismissed as "oh they're being inflexible." Or they... "oh, it's just because they don't like change." And actually anxiety is one of the biggest causes of, of, of our children's well-being in terms of how it impacts on them. Having said that, our attendance at school is actually fantastic. So it's because we understand their anxieties and we put support mechanisms in place to, to help them best in the best way we can.

**00:23:37 Tom Stubbs**

Thank you very much...

[General thanks]