

Autism Act 10 years on: an interview with Tim Nicholls

1. Can you tell us how you first became interested in autism?

- Well, autism's been quite a large part of my life really, my elder brother is autistic and actually he went to a National Autistic Society school a few weeks actually after I was born. So I've kind of grown up around autism and within the National Autistic Society as well. And then about 10 years ago I applied for an internship in the Policy and Campaigns Team of the National Autistic Society. And despite going away for a bit, I couldn't resist it and came back to join the Policy Team, where I think you know, we're just able to do lots of really exciting things and get loads of really important changes for autistic people that then need to be implemented on the ground.

2. Can you tell us about your current work?

So my current role at the National Autistic Society is that I'm Head of Policy and Public Affairs. And basically that means looking at all the things that we think that government, that local authorities, should be doing across health, social care, education, employment, sometimes a little bit of transport, sometimes a little bit of criminal justice thrown in as well. Places where we think that we can make the most difference for autistic people and you know, help create that society that really works for autistic people. So broadly speaking, we're talking about what you know, should we be telling the government it does need to do? Or sometimes, when they're bringing forward legislation, telling them things that we really think it shouldn't be doing as well. And campaigning you know, for autistic people and sometimes alongside other charities to do that.

3. Can you briefly explain what the Autism Act is?

The Autism Act, I mean it's a landmark bill and it remains the only statute on the statute books that is actually about improving the lives of people with a single condition. And I think that's a recognition that autistic people traditionally fell between the gaps of existing services that were often based around learning disability or mental health. What it actually does, it's actually quite a clever act because it doesn't say very much, but it says three really important things.

Firstly, that the government has to create a strategy in England for improving the lives of autistic adults. Secondly, that it has to underpin that with statutory guidance, telling local authorities and health bodies exactly what they should be doing. And thirdly and this is the really nifty bit, it says that they have to keep each of those things under review. So every five years or so, we get the opportunity to go, well this hasn't worked properly, what needs to be

done differently? Or, we've come a long way on this, so how can we go further? Most laws are set in stone, you don't get the opportunity to do that.

So that's why I think The Autism Act is really, really, you know, important and a really important tool for us to be able to use, because we can constantly push the boundaries of change. Doesn't mean that it's always properly implemented and it certainly hasn't been to-date. But we can keep pushing at it and keep trying again and checking what's working.

4. What areas did the autism act succeed in and which areas haven't worked so well?

Well, I think it's important to take stock of where we were 10 years ago, well a bit more than 10 years ago, when the National Autistic Society first launched its I Exist campaign. Where essentially, we were having to convince the government and society at large, that autistic adults existed. I think we're now in no doubt that people know that that is true. And we've seen attitudes and understanding of autism really shift in that time.

We now also, you know, every area has pretty much, has an Autism Lead, so a Lead Commissioner that is designed to improve the service and look at the services for autistic adults in their area. Every area, bar a couple, now has an adult autism diagnostic pathway, where actually fewer than half did, back when we did I Exist.

So we've seen a lot of change in those areas and it's certainly on the agenda, autism is definitely on the agenda in those areas. But, the issue is that progress has been too patchy. Implementation isn't consistent across the country, the reality is there is still a postcode lottery. And sometimes that can be if you live on one side of a street or another, whether you have a good diagnostic waiting time in your area or you know, there's a real whole spectrum approach to who needs social care support, those kinds of things. And that's what we need the new strategy, the revised strategy, to really tackle. Is to set out actions of how are we actually gonna address that postcode lottery and make sure that we're meeting all those basic, you know, rights and duties that exist across the country, not just in the areas that are doing it well?

And to do that, we need to look at the areas that are doing it well and to think about how can, you know, how can that area learn from some of the great stuff that's happening say, in Bristol around diagnosis? Or in Manchester around you know, boroughs thinking together about they can commission across a wider area. But we also need to go to the areas that aren't doing it as well and make sure that they know that stuff, that we're supporting them, that resource is coming in, you know from local money and also from national government, in order to you know, make sure those autism services are really up to scratch.

5. Which areas still need improvement

The areas that still need improving, well diagnosis waiting times are still far too high. At the National Autistic Society, we launched an autism diagnosis crisis campaign, three years ago now, highlighting the autistic adults, who are waiting two years for a diagnosis, children, three and a half years, after asking for help. We wanna see those times come down, so it's great to see the NHS announce that they're gonna be focusing on children's diagnosis waiting times in the long-term plan. I think the strategy review for adults that's coming up, is a perfect opportunity for the government to say yep, we're gonna do that for adults too and really drive down those waiting times.

I think we need to see social care support improve for autistic adults. Too many still tell us that they present to social services and say, I think I might need a care, an assessment of my needs and they're turned away because they don't have a learning disability. Be under no doubt, that is illegal and it shouldn't be happening, but it is and so we need to make sure that is really stamped out.

I think the area where we can see some real improvement is that following our campaigning and an inquiry from the all-party parliamentary group last year, children are gonna be included in the strategy for the first time ever, which is a really big step for us. That means that while we're seeing diagnosis waiting times probably grow faster for children than they do for adults and they're now longer, we've got, we might be able to have, if it's done properly, something that really drives down those waiting times.

And also, something that can really tackle understanding in schools and make sure all teachers understand autism, all school staff understand autism. That head teachers do, you know, there the ones that hand out sanctions, they're the ones that exclude pupils and they need to understand it too. How can we improve pathways to autism diagnosis and suitable post-diagnostic support?

6. Do you think the duties of the Autism Act and Think Autism are wide enough?

The duties in The Autism Act and the statutory guidance, they attach to health and care, 'cause that's the way the statute was written, it's the property of the Department for Health. And the staff that fall under that will be people who work in the NHS and people who work in social care. So in reality it is limited at the moment to those people, but we know that, you know, autistic people don't only encounter health and care services, they need support in education, they may need support to get out and about on transport, by way of you know, better understanding.

Or they may run into problems with the law, they may you know, be talking to a police officer, either having just you know, been a victim of crime, or perhaps a perpetrator. But either way, it's equally important that that police officer understands that they're autistic and is able to communicate with them in a way and approach that situation in a way that means that things don't escalate, that things don't go wrong, that that autistic person is supported through the criminal justice system.

So I think yeah, we've got a system that is based around health and care and those duties are really important to make sure are properly implemented. But we do need to be thinking much broader as well, about making sure that all people who work for public bodies are sufficiently trained in autism. There's no reason why an autistic person should walk into a job centre and not expect exactly the same level of understanding of their needs as any other disabled person or any other person would expect. But at the moment, in reality, too few staff who work in those services do understand autism. And that means that people will be put off going to get support and when they do try they will feel badly supported. And so there's a lot that we still need to do across the entirety of government to make sure that happens.

7. Have we seen progress in every part of the country or every part of Government?

We've seen progress in some parts of government and we've seen progress in some parts of the country, I think it would be foolish to claim otherwise. I think the only bit where we have seen fairly universal improvement, is actually in the awareness of autism, I'm not even gonna say understanding there, definitely I mean awareness. We're in a very different place than we were 10 years ago and I think we at the National Autistic Society are often approached by government departments that we haven't previously had much to do with, in order to, with them saying, look we're planning on doing this, will this work for autistic people? And that's a great thing, that shows that a cross-government strategy has in some ways worked at raising the profile of autism and the needs of autistic people.

But no, you know, understanding and policy change hasn't happened universally across government. And actually, I'd like to see government departments who aren't the Department of Health, so Department for Education, Ministry of Justice, Home Office, Department for Transport, lots of other government departments, really taking ownership of the autism strategy. Signing up to actions within it, that will really drive forward the autism strategy and making sure that they deliver on those. Because otherwise, we won't see that filter down to a local level either.

And then in areas where good stuff has happened, I want, you know, government to be playing its role in saying yeah, this is what's worked well over here, how can we make it work well over there? And it might need each area's gonna need a different level of support to make that happen. It

might just be telling them and getting them to go and meet that service and learn from what they've done. Or it might mean, you know, real expert advice on how to set up a service and extra funding and all of those kinds of things. And that's a role that really only government can play, so that's what we need to see from them.

8. How can we make sure that the next 10 years of the Autism Act create a fairer society for autistic people?

I think this is the moment when we set out what's gonna happen for the next 10 years in autism. So it's a really important moment and really important that we get it right. I think if we were to look back at the 2014 refresh of the strategy, I think we would look at it now and say, these principles are great, but the actions, so what government has set up to do, do they really get us to those outcomes of what we want to see? Possibly not. So, you know, it doesn't sound like the most interesting thing in the world, but what I want to see in the next strategy is a really like a strategic document that says, these are the steps we are going to take, this is how we're gonna know we get there.

To be ambitious with those, but also to be realistic as well. And to make sure that we're not making, or government isn't making bold promises that then can't be fulfilled. And really thinking about what are the things that would really implement the strategy in that area? So focusing on making sure that every autistic adult can access a diagnosis and then when they do, that there's actually post-diagnostic support in place, in their area. That there's clear pathways to better information, that you know, that they're signposted to a care assessment because they may well have needs. That stuff isn't happening at the moment and it's really achievable, but we want to see actions, like really setting out clear actions about how that's gonna happen. And that's how you start off the next 10 years, but have a big, bold vision as well about how we're gonna truly create a society that works for autistic people.