

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

Oral History Interview with Shirelle Stewart. January 2024

00:00:03 Dominic Perry

I am Dominic Perry interviewing Shirelle Stewart for the National autistic societies In our words project. The date is the 31st of January 2024. Please can you confirm your name and how to spell this?

00:00:21 Shirelle Stewart

Shirelle Stewart. That's SHIRELLE STEWART.

00:00:28 Dominic Perry

OK. First question, take us back to the moment your journey with the National Autistic Society began, what inspired or motivated you to get involved with the charity.

00:00:41 Shirelle Stewart

OK, so I joined the charity I think it was in 2008 and I suppose motivation really for getting involved. The job actually itself at that time was as a policy advocacy officer and I had been working in role very similar to that for an environmental organisation before coming to the National Autistic Society, so the role seemed perfect. But it was a personal reason why I wanted to work for the National Autistic Society because my son, who I think was about 3 and a half - four then had been diagnosed with autism.

So I really kind of wanted to work in an area that would benefit him and children and adults like him.

00:01:31 Dominic Perry

When did you start working with the National Autistic Society?

00:01:35 Shirelle Stewart

I started in I think as I think it was 2008 in a policy role and I remember my first job at that time was to produce a report on Autistic adults in Northern Ireland, so it was really the first time that I suppose, a big emphasis was put on autistic adults, up until then I think a lot of the emphasis had been around children. So I produced a report and ran a campaign at that time called *I exist*, which basically was based on the experiences, views of autistic adults in Northern Ireland and really kind of looked at the lack of provision for autistic adults across Northern Ireland.

00:02:27 Dominic Perry

Ok, when you first joined the National Autistic Society, what was the public perspective on autism at the time?

00:02:36 Shirelle Stewart

I don't think there was as much knowledge. I would say there was probably very little knowledge and I would say the majority of people still thought about it in terms of children because most of the portrayals really were those of children and young people, as opposed to adults.

I think that's why the National Autistic Society had decided to do the *I exist* campaign, [this] was to raise the profile of autistic adults across the UK, and obviously we did something very specific in Northern Ireland.

So, I think adults were really unseen, I suppose at the time, hence the name *I exist* because most of the portrayals and most of all of the discussions would have been around the needs or and the diagnosis of children.

And I also think now we talk about understanding of autism as opposed to just awareness. Whereas I suppose back then we were still trying to raise awareness as well as understanding. So, I suppose things have changed, and that people are much more aware that, you know, once you are autistic, you are autistic for life. And I think they're much more aware of that now than what they would have been back in 2008.

00:04:03 Dominic Perry

What do you think of the needs and reasons for the National Autistic Society to have expanded into Northern Ireland?

00:04:09 Shirelle Stewart

Well, I think it was really important that they expanded into Northern Ireland, and especially now, they probably didn't know that at the time, but now we have one of the highest rates of autism in the whole of the UK. So, you know, we're sitting at something like 4.7% of school age children are diagnosed with autism.

Our recent census suggested that there were over 30 odd thousand autistic children and adults in Northern Ireland, so there's a huge demand.

I think also we very much lagged behind the rest of the UK in those days in terms of service provision, there was very little service provision happening across Northern Ireland. There was one organisation, Autism NI, being one of the organisations that were operating here, but there was a real need to expand services and to raise awareness and I suppose to make politicians aware of the needs of autistic children and adults.

00:05:19 Dominic Perry

What challenges were there at this time when you initially came into the organisation?

00:05:26 Shirelle Stewart

Well, I think there is challenges right across the board. So I think that there was, for example, we didn't have very good diagnostic services in place for children, so there was already waiting lists there for, for children who needed to have an assessment and a diagnosis. And the same could have been said for adults. In fact, adults probably, it would have been a worse position because it wasn't widely recognised or people didn't understand.

I suppose adult autism in a way, because they really thought about it as a children's condition, not necessarily as an adult condition. So, there was a lot of lack of public awareness, [and] I think lack of understanding and hence a lack of service provision, and I think that all had to change.

I think as well because there was a lack of understanding there wasn't the right services in place as well to meet the needs. Public places would have been very much inaccessible, public understanding, so for example, if a child, was becoming distressed in the supermarket because of their sensory challenges and difficulties. Then I think parents very much felt that people looked at them and blamed them and thought that their behaviour, the child's behaviour, was naughty as opposed to them being distressed. So, I think there was a lot of judgement early on and a complete lack of understanding and a complete lack of specialist support as well that would either help parents or help children or help autistic adults.

Going in nobody would have thought about making adjustments for children or adults, you know, either in leisure facilities or in employment or that kind of thing. So, I think it was very much a complete lack of understanding. Unless, you know, you yourself had a relative who was autistic.

00:07:46 Dominic Perry

What efforts were put into tackling these problems at the time?

00:07:51 Shirelle Stewart

Well, at the time as opposed as I mentioned before, one of the first things we very much were concerned about [was] raising it politically. And so one of the first campaigns that we ran was the *I exist* campaign to raise the whole issue of adults who were autistic and we very much worked on that both through the media and through our political representatives and amongst health and social care workers, and we continued really to do that.

So as time progressed as well, you know we also ran campaigns, for example, on mental health in children who were autistic, entitled *You need to know* and that was looking at the lack of understanding actually, amongst mental health practitioners around autism and ensuring that children actually got access to mental health services and that it wasn't just seen as part of their autism.

Unfortunately, we still have a long way to go with regards to that, and I don't think that we have properly tackled that and it is something that obviously the National Autistic Society keeps going back to and trying to improve.

What do we do? We also set up at that time as well, way back, I suppose when we first came here, there was some funding provided by the lottery which ended up providing family support.

So, we had a number of family support workers across Northern Ireland and they were aimed at supporting autistic children and their families and autistic adults in providing what support they needed, and they also ran training for parents and they started up the branch network as well in Northern Ireland. We developed the branch network so that in different parts of Northern Ireland you would also be able to access some peer support as well. And we also had to befriending scheme then as well, that was kind of part of the services that we originally provided.

00:10:08 Dominic Perry

Can you take us back to the early days of the National Autistic Society in Northern Ireland and share any memorable experiences or anecdotes that capture the essence of its founding and early mission?

00:10:17 Shirelle Stewart

As I believe, speaking to Caroline Bogue, who would have been one of our early family support workers, the National Autistic Society first became involved in Northern Ireland through a parent who wanted to set up one of our branches, which turned out to be our branch that we have in Omagh. And I think she lobbied the National Autistic Society to come into Northern Ireland and they, I believe, were one of the first branches that were formed here.

I joined the National Autistic Society I think about really three years before it came into existence in Northern Ireland and it was set up by Regina Cox, who had worked in London and she was... she had worked for the National Autistic Society as a fundraiser but in the London office and had relocated back to Northern Ireland.

So she got the job really of establishing the branch here in Northern Ireland, she really was instrumental in getting her first offices and getting the first amount of funding, really that was here.

And then for starting the kind of branch network and I think our first registered office here I think was 2005 and it was in Botanic Avenue which was a pretty dire office to be fair. We have lovely facilities now because with the new autism centre but back in the day, and it was a very run-down office on the ground floor in Botanic Avenue and I can remember we were very glad when we actually were able to move to our new offices in which we're in a very salubrious as part of Belfast, which we're in Malone on the Malone Road.

Yeah, it was very different... but for me it was a very exciting time because we were new and we were starting to try and expand services. We were really starting to lobby on a political level and it was just really good to see the politicians becoming engaged with autism and becoming involved with the whole area.

But it was also a time where and just like today, it's actually still the same is it is still relatively frustrating because, although we have a lot more awareness and we have understanding the service provision for autistic children and their families and autistic adults is actually quite dire and unfortunately the money has still not been invested into service provision in Northern Ireland that needs to be invested in order to meet the needs. So although we have moved and I suppose progressed it is still frustrating that we still aren't where we really should be, and there's still so much work to be done.

When I first started as well, one of the really lovely things that we did was a photographic exhibition of autistic adults and children. And what happened was part

of that project, the photographic exhibition, and sometimes the autistic person themselves would have taken a photograph of things that they liked, or they would be in the photograph...

So, the photographic exhibition really explained what people really explained what people liked. The first young man was a young man called ... and he took pictures of clocks because he really loved time. And then he also had a photograph of a certain font that he loved on his computer cause he loved how it looked and that was the font that he would have always typed with.

Really, really lovely exhibition because it each came with its own little story. So, one of the first things that we did, we had that exhibition and we held it in Queens Film Theatre, which was really nice. And then actually we moved it and it was displayed up in Stormont as well. So that was just a really, really nice way of raising awareness of autistic children, young people and adults because they got to really say in their own words if they used speech, they described themselves, their passions, what they liked and their interests as well. So it was a, a really, really lovely, lovely thing to do and it was great because I suppose there hadn't been really that much of that kind of exhibition.

Now we have quite a lot of art exhibitions by autistic people or children or whatever, but I suppose at that time that was kind of one of the first. So it was really quite eye opening I think for a lot of people and really helped raise awareness and we got lovely coverage in the media as well from that where they reproduce to the Northern Ireland Pictures and the stories and interviews with some of the people involved. So that was actually a really, really nice thing to do as well.

00:15:50 Dominic Perry

Great. OK. So, what were your first thoughts or goals when you started in your role?

00:15:56 Shirelle Stewart

I suppose my job was basically to raise awareness to raise under... to promote understanding to get better service provision for autistic adults and to make sure that their voice was in built into everything that we did, both from both from a family perspective and also from the autistic persons perspective themselves. So, you know, back in the day as well, we would have for example, taken some people...

What we were doing, ...one of our awareness raising issues, we had a group of autistic people that would have gone up and spoken to one of the Assembly committees. We also, you know, had meetings with ministers.

And really, I suppose my job was initially to make sure that our political representatives were engaged, that we wrote responses to consultations that would influence any kind

of service provision. So yeah, I would have spent an awful lot of my time, really, initially about the assembly when it was functioning.

And in order to try and raise that awareness and understanding and, you know, get an autism strategy, get all of that and to improve. The ultimate aim really is to improve services, provision, support and society so that it was welcoming for autistic people and their families.

00:17:48 Dominic Perry

OK. As the services have evolved in Northern Ireland, could you describe some significant changes you've witnessed in the way support is provided to autistic individuals?

00:17:59 Shirelle Stewart

Yeah. I think as things have... moved on. I suppose we have definitely engaged much more with autistic adults than we would have probably initially. I think initially our branches and that kind of thing would have initially been parents who were involved with autistic children and we still obviously do an awful lot of that work as well but also we would be very much influenced and welcome the participation and I suppose co-production of a lot of the work that we do with autistic adults. So for example, one of the things that that we deliver at the minute is a programme called about skills development for it's called *Skills for life, for young people* and that really was produced in conjunction with some staff at the National Autistic Society who would be parents but also with autistic people themselves. So it was very much a coproduction and it is also co-delivered as well with an autistic adult, so that would be very much as how we see things going forward really that autistic people are at the heart of any kind of service development or anything that we do. So for example, when we were putting together the design for our autism centre in Carryduff autistic people and families and carers were very much consulted from the very beginning about what the design would look like what we needed to provide, what would really benefit autistic adults and autistic children.

So that I suppose that definitely is a really big progression because I don't think that way back when we first started that that engagement would have happened as a matter of course, whereas now I mean that would be kind of our norm.

We're also now, we also see...One of our aims in the Northern Ireland strategy as well as to make sure that autistic people are represented on forums, policy forums and that kind of thing. I know one of our artistic volunteers here sits on the *Belfast Autism Forum* and also on the *Department of Health Autism Panel*. So we are very much pushing that kind of engagement as well.

00:20:26 Dominic Perry

OK, thank you. Can you tell me a bit about the evolution and development of the first branches?

00:20:34 Shirelle Stewart

Yeah. So I think I mentioned that one of the first, the first branches was the Omagh branch and that was kind of a lobby from a parent in that area who basically wanted to see the National Autistic Society come to Northern Ireland. So I think the branch really started off in that way. And then what happened was that we got lottery funding and as part of that lottery funding family support was developed in Northern Ireland and part of the role of those family support workers were to set up branches across Northern Ireland. So I think the next branch after the Omagh branch then was the Ballymena branch. So that would have been one of our oldest branches as well and actually the chairperson there is still the chairperson today which is really, really lovely to see.

Although she started when her child was young and now he's obviously an adult, but she is after a bit of time out over COVID, she's actually coming back in into that role, so that's really good to see. And then we found out that we developed branches really across Northern Ireland. And I suppose as well. Then I joined the National Autistic Society and at that time I set up the Newtownards branch as well, because that was the area that I lived in and really there was no local facilities that my son could attend.

So I set up the Newtownards branch, which is now still going strong, although I'm not involved in it anymore. One of the parents, who is the chair was one of the first parents who came along to the activities that I kind of set up. So that's kind of, I suppose, quite a personal attachment for me because it was just one of those groups.

And they're one of our most successful groups now because they serve over between 250 to 300 families, so they're really, really big group and they have just started to, they've just found their own premises as well. In March this year, they will be doing an official opening of their new premises.

So we've actually seen our branches really evolve. I think the thing about our branches, we're also very involved in setting up activities. So they wanted to run exhibit activities or summer schemes or things where their children could go along and attend and be in a safe environment.

So you found that a lot of the branches in Northern Ireland were very activity led and then we ended up as well with we also have our Dungannon branch, which just before COVID as well had found their own premises and had set up lovely sensory spaces. So you found that our branches have really started to evolve to become much more confident and actually play a really vital role in their local community, because they're

really servicing, you know, the local need and they can make the decisions as to what activities and provisions they provide based on local needs.

So, yeah, you've you have seen obviously branches progress, I suppose COVID was a very difficult time for our branch network as well because it was very difficult to do what they'd normally do, which was normally meeting up for activities and stuff, but quite a lot of our branches, you know, we're very innovative around that time as well and you know, did things online and you know, delivered activities to families and that kind of thing. So yes, we've really seen the development and confidence of a lot of our branches and going forward, that's one area as well that we are looking to expand in, in Northern Ireland into areas where we maybe don't have a branch presence at the minute.

00:24:25 Dominic Perry

How about the development of services within the National Autistic Society Northern Ireland?

00:24:33 Shirelle Stewart

We have really come a long way, I suppose because I mean to the first. Oh gosh, from its inception, really, we basically had an office and then a lot of our services were community-based services. So things like your family support, we did have, you know, help lines for education and that kind of thing.

We had a befriending service, but everything was, I suppose, very community based and people were out in the community, which was, which was fantastic, but we didn't have any actual buildings. We didn't have, you know what we call a bricks and mortar service and that really all changed in 2019 whenever we opened our first autism Centre in Northern Ireland and Carryduff. And I suppose we're extremely proud of that, because the whole aim behind the Autism Centre was not only to run National Autistic Society services from there, but to provide an example to other organisations, to the statutory sector of what good quality looks like and that's good quality both in terms of what was actually physically in there. So, we have state-of-the-art sensory rooms, we have lovely breakout sessions, we have a gym, we have a lovely outdoor session because a lot of provision in Northern Ireland.

And I think especially day provision, and I think, could have done with having a bit of a facelift in terms of quality and why should autistic adults not have the same kind of quality provision as other adults in Northern Ireland. So it was very much about raising that bar, but also demonstrating what good support looks like. So a lot of the young people that we would support in the day provision would have autism with co-existing learning disability and very complex needs, and their needs couldn't be met in traditional days service.

So what we really did there was, you know we provided a service for people who weren't getting the service and who would have been stuck at home. But we also wanted to demonstrate to people that if you provide the right environment and the right type of support people can get a good service.

But the other thing that we really wanted to do as well was to make sure that the centre wasn't just a kind of, you know, a day service within nothing ever happened in the evenings and weekends. So we now run services every, every evening from Carryduff and we also have services that run at the weekends and those service cater as opposed for everybody across the spectrum and for every age group, so it's called *support for life*. And really that's what we tend to do, which we try to provide a range of supports from children, right the way up to autistic adults and also some parental support. So I suppose that's really how we have changed and developed.

00:27:49 Dominic Perry

So, when you look at where the National Autistic Society Northern Ireland is today, where are we today and where is the charity come from?

00:27:58 Shirelle Stewart

Well, I suppose we have, we have come from... Well, I suppose as well, you know, the National Autistic Society has evolved in terms of how we view autism, about how, about our understanding, we very much as an organisation I think have learned from autistic people who have been able to tell us, you know, things that they need adjustments that they want, what they want to see in society. What kind of supports that they want. So I think that as an organisation, you know, we have learned to change and have been on, I suppose that journey.

I mean, even the way I suppose that we talk about autism. You know way back we would have said, oh, it's a child with autism or the adult has autism, you know, and even the language. Whereas now, you know, autistic people, autistic adults have said, look, we want to be referred to as being autistic, not somebody with autism. It's very much about, you know, understanding that identity as well and making sure, you know, that they have their place in, in society and everything that the National Autistic Society does. It's a work in progress and I think it's ever changing and you know.

As we change society changes as well. So, I think that we've really developed. I think it's also another really exciting time for National Autistic Society in Northern Ireland because and the model that we have in Carryduff is going to be replicated in another part of Northern Ireland. So we have a new Autism Centre and that we hope to open in probably... Spring, early spring, summer 2025 and that's in another part of Northern Ireland and again at the heart of that will be day provision for autistic adults with complex needs. But we will also then consult the local autistic community to find out

what other type of services autistic adults, children and their families will want to run from the centre at evenings and weekends. So I think that we are really continuing to expand the services that we provide.

I think also on a political level and on the influencing level, you know, we also sit on various forums across Northern Ireland such as Belfast Autism Forum, the Northern Trust, Autism Forum the Department of Health Autism panel, you know we're influential in terms of, you know, what issues need to go into these strategies and what needs to change, but also as well, is ensuring that autistic people are also involved in those forums and that their voices really are at the heart of that.

00:31:05 Dominic Perry

Naturally you've kind of answered this next question anyway but we'll ask anyway. How is the charity evolved since its inception in terms of its approach to autism and community engagement?

00:31:16 Shirelle Stewart

I think we're very much part. I think the, the really nice thing about the National Autistic Society is that we were always very embedded in the Community and I think that we, we still are, you know, we we're not just a place where there's a head office and whatever we have always delivered in local communities and alongside local communities.

But I suppose as I said, we have definitely evolved and changed and are continuing to evolve and change as society changes and evolves. I suppose we've also continued to raise awareness as well on other topics such as for example, not even about health and social care services and supports, but things around.

Employment for autistic people. So for example, there's a very, very big employment gap for autistic adults and autistic adults who would very be very well able to hold down employment. So, you know, trying to get organisations to make adjustments to make the workplace, really, I suppose, more opening and inclusive for autistic adults is also a big emphasis and just to ensure that you know the needs and support and the buildings, for example, in our community, is accessible for autistic adults, and I think that is something as well that has really evolved over time.

I also think now, I suppose in Northern Ireland, everybody has heard of autism back in the day not everybody would have heard of autism, but there is still a job to be done in terms of understanding. So you know, there's still a lot of stereotypes out there. There's still a lot of myths. There's still a lot, I suppose, that that kind of needs to be done, although I would say that most people have heard of autism, so we have awareness of autism, but we still have a long way to go in terms of really making sure that people actually understand.

00:33:28 Dominic Perry

That's great. OK.

Throughout the years, what partnerships or collaborations have been most impactful in expanding the reach and effectiveness of the National Autistic society's services?

00:33:41 Shirelle Stewart

Well, I suppose we have had a number of partnerships. I mean one partnership I suppose that was quite effective was we produced a report in 2016 called *Broken promises* and we've produced that in conjunction with Autism Northern Ireland who are have obviously been operating in Northern Ireland for a long time as well, and I think that report was very beneficial in terms of it really looked at the autism strategy 10 years on and how much work we still need it to be done. I suppose it has been pivotal, a pivotal policy report that is being used and repeated over the past number of years, unfortunately as the title suggests, it's basically said promises were broken and all of the things that that initially we were told would happen with the development of an autism strategy hadn't come to provision. So I think that was a really good partnership, another partnership that has been very successful for us is.

We have worked very closely with the Children's Law Centre in terms of judicial reviews, so we have taken a number of judicial reviews. We have supported a number of families through the Children's Law Centre and the Children's Law Centre have helped produce take judicial reviews, which have basically been about trying to get the services that families need and one, way back, it was one in the Western trust that basically really changed and set a precedent for carers rights in Northern Ireland because basically in terms of.

A family at that particular point in time, their rights as carers under the legislation wasn't upheld. We've also had other families who have taken judicial reviews on respite care as well and have won. But again, there is quite a lot of judicial reviews in the pipeline, because the needs of autistic people have not been met and that's through things like education, through health and social care provision, through rights of carers.

So it's still an ongoing issue, and I suppose that also was, has been very, very beneficial and I suppose the other. I mean, there's also the All Party Assembly group on autism that we sit on and that I suppose has been very beneficial in terms of working on the legislation that has come into Northern Ireland. So we had an *Autism Act* back in 2011, which basically was the first *Autism Act* that covered children and autistic adults. And then we had an *Autism Amendment bill* just a couple of years ago. So we've also been involved in that level, and we've worked in partnership, I suppose, with other organisations on Autism Spectrum Disorder forums in, you know particular trust areas, so I think that all of those, well we've worked in conjunction with other organisations, but also with professionals within the statutory sector.

So I think all of those relationships have all been really positive and I suppose the thing to say is that actually working in collaboration with people as opposed is really, really important because the National Autistic Society can't do everything themselves, and that you know, those collaborations really play a really good part in trying to improve things.

00:37:24 Dominic Perry

Were there any challenges the National Autistic Society Northern Ireland faced in raising awareness about autism within communities and how were these addressed overtime?

00:37:33 Shirelle Stewart

Not so much awareness, but I think the problem is tackling stereotypes. I think there was so many, there are so many stereotypes really... You know, and we still see it repeated quite a bit in in places like the media and whatever, you know, we tend to, you know, they're very much whenever we started it was that the Rain Man type Scenario - so every autistic person had, you know, some kind of specialism that they could, they could do, you know that that they were a savant or whatever. And I suppose try and to get people to understand that actually that wasn't necessarily true.

That autistic people are, like all of us, they are very different and they have different personalities. I think a lot of people try to, you know, they think that all autistic people feed into homogeneous type group, you know, whereas like Lorna Wing used to say 'when you've met one autistic person, you've met one autistic person' because like every neurotypical person, they have their own personality and they have their own strengths and weaknesses. And so I think that getting people to understand that, and to understand, you know, that... for another thing, ... it will always be very accepting of people you know, neurotypical, and sometimes, you know, everybody really because everybody's experience is different seeing themselves as an expert because you know, everybody is continually learning, so I'm always really distrustful of anybody who says they're an expert in such and such, because there's always learning to be had.

So I think I think there has always been a challenge around all of those stereotypes, types, all of those myths and I think that's been a really good..., I think also I think some sections, as I said, I mean I've talked before.

Initially, everybody thought of autism and really associated more with something that that children were diagnosed with as opposed to autistic adults. So I think that's been a really, really big challenge is changing that perception. And also I suppose a lot of the work that we've done recently is raising awareness around.

Females who are autistic as well, because I think again, people had a very male version of autism in their mind, so they never really associated it with females. As well, so I think

that's been, you know, quite a big challenge is you know again a stereotype and challenging that kind of stereotype. And I think the other thing is you know, a lot of professionals, if an autistic person is very good in school, very academic, very able to talk articulately.

They think that they don't necessarily need any support or that they, you know, that they can't be autistic and would be the be the other thing because you know they're able to come in and explain how they feel and think and whatever a lot of things I would also say you know.

There used to be very much a stereotype as well around autistic people not being empathetic, and we all know that that is so untrue, and actually they may feel more empathetic than that might be one of the issues that they feel things actually very, very deeply. And that again, can you know, can cause some distress for them. So I think all of all of those are a really, really big issue...

I also think they're one section of our society as well, and those autistic children and adults who have complex and very high support needs. They are not really seen in society and their needs are still not necessarily met because they become very, very isolated, so people as well forget I think, that there are a lot of people there who need really high levels of support and good levels of support.

And that they should be entitled to lead the best possible lives that they can as well. So you know, we're still a long way I think to go and I think those are all things that you know we have tackled through for various campaigns, various awareness, raising through social media through whatever. But I think you know we still have a long way to go. We're not there yet.

00:42:14 Dominic Perry

Can you tell me about your involvement in campaigns in Northern Ireland?

00:42:18 Shirelle Stewart

Yes. So basically in my job, initially before I became director in Northern Ireland, I was employed as the policy and campaigns officer. So really it was about producing reports really and running and devising a campaign and implementing that campaign across Northern Ireland.

So one of the first ones I think I mentioned earlier was when *I exist*, which was a campaign to raise awareness of the needs of autistic adults right across the spectrum. And we launched that up in the Assembly up in, in Stormont and actually we have some lovely photos of a group of autistic adults as well, and we had - I can remember the campaign photo at the time was us dressed in these purple T-shirts and we each had a

letter which spelled out *I Exist* and we had that on the steps of Stormont and we had an event held in the long gallery in order to launch that.

So that was really nice as well because at that time as well, we, not many autistic adults were given a voice to speak out and whatever, so we had a number of autistic adults and speak at that event, which was great. And I would say that it really did spark a lot of interest and people then did start to speak differently, over a period of time because if you run a policy, if you read a report or you run a campaign, it takes a number of years before you finally see kind of a change in attitudes and a change in the dialogue.

But I think now, you know, autistic adults...you can see the change from when we started them, when people really only talked about autistic children to now people talk about autistic children and autistic adults, but it has taken quite a while to get to that progression and so that would have been the first campaign and then one of the other ones that we did was...*You need to know*, and *You need to know* again was a very specific campaign and it was looking at the mental health difficulties of children and young people and who were autistic. And unfortunately the stats are really very high with regards to that and with people who have coexisting mental health conditions and that's really because we've never had the right support for autistic people.

It's not that, you know, you will automatically get mental, you will have mental health problems if you're an autistic, but you are coping with an awful lot more in society.

So that campaign really looked at all of the potential reasons why autistic children and adults or autistic children and young people may have mental health problems, so it was looking at, you know, things like bullying within the school environment, adjustments not being met, the right support service is not being there.

And actually the right mental health support and provision not being there and a lack of training, I think amongst mental health practitioners in the area of autism.

So I think that was really very important and we took that again we launched that up in Stormont and we had meetings with the ministers and we presented to various committees on that, and we had various promises about the improvement in mental health services for autistic people, but we still have real challenges with the provision of child and adolescent mental health (CAMHS) services, children and adolescent, mental health services for children. There just isn't enough. People are waiting really, really long periods of time in order to get the right support, and I still think that we still need a lot more training of mental health professionals so that they can deliver the right types of intervention if an autistic person also has a mental health difficulty.

So that was one of our campaigns and then another one that we did, which was really in response to changes in proposed Specialist Educational Needs (SEN) legislation. And that was *A star for autism*. So that was really looking, it was in response to an education proposal consultation that was called *make every school a good school* and our campaign was entitled *A star for autism: Make every school good school* and it was

really trying to highlight the challenges that autistic pupils faced within the school environment.

And that and it looked at all kinds of challenges and it was very much based on interviews with children, young people and their families and what they felt was happening in the school environment. So it was with young people, you know, not getting the right support in the classroom.

It was about a lack of understanding teachers and how they understood, autistic pupils in a lot of the times as well, you know, there still was that 'Oh, it's not autism, they're just badly behaved'. And there was a lot of that kind of attitude I think very much in the education system. So it was really about challenging that, suggesting ways with all of our campaigns we've always tried to suggest ways to improve things not just saying 'Oh, this isn't working'. It's about OK what do we need to do to improve, Improve that environment?

And they kind of feed into one another because the *You need to know* campaign emphasised that actually, education had a fundamental impact on children and young people's mental health. So, you know, we need to start really early about getting the right supports in place. So that was just another campaign really that that again was to raise awareness and as a result of the campaigns, I mean we have seen so many different initiatives you know across education, across mental health, across adult service provision but as I said, although we have, I think, completed really good campaigns and reports and jobs that are very much influenced decisions, we still have a lot of work to do.

00:48:55 Dominic Perry

Can you share a Particular moment or event that stands out as a pivotal moment between the National Autistic Society and the Northern Ireland Government or policymakers?

00:49:07 Shirelle Stewart

I suppose that we have, we've had quite a number because we have had meetings obviously with ministers and we've presented at committees. I think as well as, I suppose one of the things, I suppose that, and we have appeared on various media programmes you know, with Government officials and whatever. I suppose one thing I suppose that I do remember was actually during COVID and at that time it was coming up to autism awareness week.

When COVID first hit, autistic people were really highly impacted because and some autistic people actually kind of quite liked to COVID because there was no societal demands upon them. But there were other people as well who found it actually really, really difficult. So say, for example, children who were in the special school. well, all of a

sudden, schools stopped, respite stopped. Everything really stopped for them, and they weren't really able to understand. You know, they couldn't go to their favourite places. They couldn't go to parks. They couldn't get outside. So that was really difficult.

And I suppose during that time we did a lot to change things. But the first minister at that time actually gave an address during one of the COVID briefings where she particularly addressed autistic people and children and just said that she understood the particular challenges that, that they were faced and she referenced as I suppose us, the National Autistic Society and I suppose myself. So that kind of stood in my mind because it was... As I said during a COVID briefing and I think that it probably regardless of what your political opinions are, I think it was it was good for Government to acknowledge that this was particularly challenging for a certain section of society as well.

But we've had, you know so many, you know, we've had a number of excellent engagements, I suppose politically with ministers and with committees. One of the most powerful, I suppose as well was again during COVID when we were presenting on children who had very complex and high support needs and the impact that COVID had upon them and that was just very powerful testimonies, I suppose, most of the things that stand out in my mind are the testimonies of autistic people or parents and carers themselves, because really, you know, they're speaking their truth. They're telling people what is happening to them and to be honest, they tend to be the most powerful things that you can hear and I think they stick in my mind probably much more than, you know, other as I said, political events. Because we have had political meetings, we've had changes in legislation, we have had all of those kind of things. But I think it's the actual real-life experiences of autistic people and their families and careers that stick in your mind.

00:52:37 Dominic Perry

In your interactions with policy makers or advocacy efforts, can you recall a specific instance where the National Autistic Society in Northern Ireland successfully influenced positive changes for autistic individuals?

00:52:54 Shirelle Stewart

Well, I suppose one instance... there's as again, there's a number, you know, we have brought about as oppose changes by supporting families as I said through judicial review where you know changes have had to be made, during COVID as well we very much strongly lobbied because there was a policy whereby children who had the most complex children were still meant to be allowed to go to school, to attend school, and this was a, you know, Government policy.

Unfortunately, in reality, that didn't happen. So those most complex children and young people were not allowed into school because they were basically saying, well, their needs are too great and, you know, we can't. So we ended up taking judicial review at that period and time.

As well, no, we didn't, we didn't get right to the judicial review because we managed to persuade the education authority and the Department of Education that they had to implement the policy properly and those people who those children and young people who had the most complex needs were then allowed in to school, which was, I suppose, a real achievement because they were also suffering. You know, and could not do online learning. You know, a lot of these children and young people had no speech, you know, you couldn't be teaching somebody online. They weren't getting any of their therapeutic intervention so we did manage to reverse that practise, which really stands out for us.

And we have also, I can remember going back as well and it's probably one of the campaigns that we didn't really talk about, but we also did the United Kingdom wide campaign called *Don't write me off* which looked was when employment and support allowance (ESA) the benefit first came into took place and at that time we had really successfully changed...

It was a United Kingdom wide campaign, but Northern Ireland actually and although it is benefits as a restricted matter, what happened in Northern Ireland is that we were able to change how it was implemented operationally. So for us, we actually ended up having, I suppose, more changes than perhaps the rest of the United Kingdom because we managed to work with the department around things like - nobody would lose their sanctions because they would or nobody would be sanctioned or lose their benefit, because if they were autistic or whatever, they would be given a number of different letters and opportunities in order to sign up. We also ended up doing training with all of the telephone operators who were doing that, the employment and support allowance (ESA) migration over as well.

So we had lots of safeguards that were actually put in place to ensure that autistic people wouldn't unduly suffer by this new benefit coming into place and then moving over onto this new benefit. So I suppose that also was, but I think as well I'm finding that kind of quite difficult to think of just particular things that have to go back as I've been here too long. Actually my memory. You know you can't remember every single kind of policy change, but there's the ones that I kind of remember.

00:56:37 Dominic Perry

Yeah, that's good. Looking back over the past decade, what personal observations or experiences stand out to you as defining moments in the growth and development of the National Autistic Society Northern Ireland?

00:56:49 Shirelle Stewart

I suppose from my own personal perspective, one of the biggest things that that I think has been the establishment of the autism centre here in Carryduff and the new autism Centre that is coming on board because I think it just has cemented our standing in Northern Ireland and I think it has also raised our I suppose our profile and our reputation in terms of what I always believed that we always did do, and we always delivered, but sometimes outside people don't necessarily see that and that is about a quality service and that's about the quality of how we support people. You know the type of environment that we want people to have. You know, we want them to have, we want everybody regardless of your ability to have a really good environment. You deserve a good environment, you know to attend, to do activities in, and to continue that process of learning because I think, you know, like one of our campaigns as well, like around employment and stuff is things like *Don't write me off*, but I think a lot of the time people have written off autistic people and what they can do. So I think those are obviously really important developments, but I also think I suppose whenever I first came into post...we were starting from scratch now, then we had no National Autistic Society Northern Ireland had no political profile and they wouldn't have worked up at the assembly. They wouldn't have had that engagement with politicians.

So I suppose now, you know, we would be very well known up at Stormont. As I said, we sit on particular panels, you know, we have good relationships with most with all the political parties. I think that was demonstrated as well because when we were trying to get planning permission for the new service in Randallstown, all the political parties in Northern Ireland supported us and it's not often that everybody agrees on one thing that they all provided support so that we could get planning permission. So I think I think, yeah, we've definitely raised the political profile and also I think the awareness and I think we, from my perspective, I think that we led the way on autistic adults because I think that we were one of the first organisations really talking about autistic adults.

Most other organisations way back, you know, when we first started really focused attention on children and parents. But I think we were one of the first to really start, you know, campaigning and trying to promote understanding and raising awareness of autistic adults. So those are kind of the I suppose some of the key things in in my mind.

And also our branch network, can't forget about our branch network as our branch network. You know they're like the lungs, I suppose, of the National Autistic Society as well because they're in each and every community. You know, we're still not massive in Northern Ireland, we're still a relatively small organisation, but that gives us outreach you know and enables us to meet the needs of everyone. So all of those people as well involved in running our branches are all volunteers.

So they're all giving up their free time, and sometimes, you know, they have, they have their own jobs, they have their own family responsibilities in terms of, you know, their obviously raising an autistic child or they have someone in their family who they maybe are a carer for. So they do a really, really amazing job I think as well giving up their own

time. And as I said, providing that really pivotal support to other families in the community as well.

01:01:09 Dominic Perry

OK. As we conclude this incredible journey through the history and evolution of the National Autistic Society in Northern Ireland, looking ahead to the next 60 years, what would you like the charity to go on to do and achieve?

01:01:23 Shirelle Stewart

60 years I'll be gone [Laughs], 60 years is a long time. I think, I think. I think the thoughts of...

Well, I hope, and I mean really if you are... all charities are working to do themselves out of a job. I mean, I would hope in 60 years that we wouldn't still be fighting for services for autistic people and their families and carers.

I would hope that autistic people are living the best life that they can with equal access to whatever it is that they need to, that be through support, should that be through employment, should that be just, you know, being accepted within their society and having the right adjustments made. I mean, basically that's what you want to see and that's where we're I think that that's your end goal is really trying to see yourself out of a job in terms of, you know, we shouldn't have to be, you know, constantly campaigning to improve services.

They should be at that level where they're meeting the needs of autistic people through education, through employment, through societal, through, you know, support. We may still have a role in terms of, you know, there are still going to be young people or and adults who need 24-seven kind of care and support and hopefully we will be there, but I would hope that in the next 60 years that we would be at a much better place in terms of autistic people's inclusion and acceptance in society and that it's not seen as something that we have to keep talking about that it just actually is there.

01:03:12 Dominic Perry

Great. And lastly, how do you envision society evolving to better embrace and support autistic individuals moving forward?

01:03:21 Shirelle Stewart

Well, I think I mean it, it sort of ties in a wee bit with what I say, I mean basically, you know, autistic people should be involved as decision makers. They should be involved

and all of these kind of strategies and forums and everything, not just even ones related to autism because there is loads of policies that are being made that will impact on autistic peoples lives that are not necessarily just related to autism.

So I think that you, we need to see, you know, autistic people as politicians, we need to see autistic people, you know, become prominent heads of companies. We need to save them, you know, as incorporated, I suppose, into every echelon of our society. And you know, I think that's when we will get really positive change because I think that also really tackles a lot of the stereotypes that people have around autism. If they see autistic people being very visible doing you know, jobs that they're well capable of doing and, you know, influencing, but I think it, yeah, I think that, you know, autistic people's voices really need to be at the heart of everything I suppose that we that we do, and I suppose the rights of carers as well, because there is a lot of families out there who, you know, have to provide a support to suppose for autistic people 24-seven.

So you know, you need to create that support as well, so that they're able to provide support as well. But I think the more autistic people we have involved in civic life, I suppose if you if you would call it that, then I think the better, things will be.