



Northern Ireland  
Assembly

Committee for Health

# OFFICIAL REPORT (Hansard)

Briefing from Autism NI

10 June 2021

# NORTHERN IRELAND ASSEMBLY

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**Members present for all or part of the proceedings:**

Mr Colm Gildernew (Chairperson)  
Mrs Pam Cameron (Deputy Chairperson)  
Ms Paula Bradshaw  
Mr Jonathan Buckley  
Mr Gerry Carroll  
Mr Alan Chambers  
Ms Órlaithí Flynn  
Ms Cara Hunter  
Ms Carál Ní Chuilín

**Witnesses:**

Ms Kerry Boyd	Autism NI
Dr Arlene Cassidy	Autism NI
Ms Kelly Maxwell	Autism NI

**The Chairperson (Mr Gildernew):** I now welcome Ms Kerry Boyd, chief executive officer of Autism NI. Kerry, can you hear me OK?

**Ms Kerry Boyd (Autism NI):** Yes, I can. Can you hear me OK?

**The Chairperson (Mr Gildernew):** Yes, I can hear you, Kerry. Thank you. You are very welcome to the Committee this morning. We are also joined by Dr Arlene Cassidy, who is a special adviser. Can you hear me, Dr Cassidy?

**Dr Arlene Cassidy (Autism NI):** Yes. Thanks very much, Colm.

**The Chairperson (Mr Gildernew):** Thank you. And Ms Kelly Maxwell, who is director of family support. Good morning, Kelly. Can you hear us OK?

**Ms Kelly Maxwell (Autism NI):** Good morning. I can hear you.

**The Chairperson (Mr Gildernew):** We are very aware that this is a key session in an area of some considerable concern for the Committee. The Committee has been raising and seeking to address the issues arising from the provision of autism services, or lack thereof, and the pressure that that is putting on individuals, families and health services. We are looking forward to the session in that regard. It is very important to us. You are all very welcome to the Health Committee this morning. Tá fáilte romhaibh uilig go dtí an Coiste Sláinte. Thank you for coming along and giving us your time,

expertise and experience in relation to these matters. I will go back to you, Kerry, to outline how you would like to do the briefing. Following the briefing, maybe we can have a question-and-answer session with you and members.

**Ms Boyd:** I have a 10-minute presentation. Is that OK? It is just a verbal presentation on key issues that affect the autism community. It will not be about Autism NI as a charity, but about the issues that affect adults and families throughout Northern Ireland. Will I just crack on? Is that OK?

**The Chairperson (Mr Gildernew):** Go ahead, Kerry, yes. Thank you.

**Ms Boyd:** Thank you. As a charity that represents autism families and autistic adults across Northern Ireland, we are deeply concerned about the situation for that vulnerable community. As public representatives, you know that many issues are detrimentally affecting the autism community. My biggest concern is that those issues are not being treated with the urgency that is needed. It should also be noted that, because of COVID-19, it has been a particularly difficult time for the community. Some support services were closed completely, and things like autism assessments were also delayed. The unexpected changes that many children and adults went through with the closure of workplaces, schools and social activities have had a detrimental effect on the anxiety and stress levels of those adults and young people, and, obviously, their emotional well-being.

Ten years ago, when the Autism Act (Northern Ireland) 2011 was passed, we knew that there would be an increase in diagnosis levels and prevalence. Inevitably, that is what has happened. The reason we knew that was that, through the likes of Autism NI and other organisations and charities, we have raised awareness of autism with families, the general public and professionals throughout Northern Ireland. That has inevitably led to an increase in diagnosis levels. However, with that huge increase, there has not been the same amount of investment and funding put into it to support those families and children. We led the lobby back in 2011 and for many years. Most of you know that Autism NI led that lobby. Today, the Autism Act is the most comprehensive piece of single-disability legislation globally. However, it has been severely hindered because of the Department of Health's failure to implement the Northern Ireland autism strategy from 2013 to 2020 and the resulting three action plans.

The Autism Act is current and binding. It is the responsibility of the NI Executive to ensure that the autism strategy is fulfilled. However, that has not happened. Only one of the three action plans were ever completed by 2020. It should be noted that there is currently an interim autism strategy, which Minister Swann introduced a couple of months ago, for 2021 to 2022. However, again, that strategy does not have any measurable targets attached to it, nor will it be independently evaluated. Therefore, how can we measure and assess whether things are actually improving for the autism community? The latest prevalence rates from the Department of Health's annual monitoring report show that one in 22 school-age children in Northern Ireland has autism. Autism is the fastest-growing disability in Europe. Although the rest of the UK does not specifically count the number of children coming through, we still know that they have a lower prevalence rate than Northern Ireland. In fact, at present, Hong Kong is stated to have the highest prevalence rates in the world, with one in 27 school-age children being diagnosed with autism. However, as we know, with one in 22 children being diagnosed here, we actually have the highest prevalence rates in the world. Nothing is being done to support that.

Health inequalities are also arising due to families having to wait in excess of two years to get a diagnosis of autism. Many look to private diagnoses in order to avoid those lengthy waiting lists. In the Belfast Health and Social Care Trust, children are waiting over two years to be assessed, yet families in the Southern Health and Social Care Trust have only to wait up to 13 weeks to have an assessment. I would like to know why that is happening and why there is such disparity between trust areas. Every autism family should have the same level of service available to them and should not have to wait for assessment and support because of where they live. Obviously, that perpetuates a postcode lottery. As of April 2021, waiting lists showed that 180 children waited for less than 13 weeks in the Southern Trust. In the South Eastern Trust, 63 children had a 10-week wait. The Northern Trust had the biggest backlog, however, with over 1,800 children waiting up to 490 days — over a year — for a diagnosis. Similarly, 1,700 children waited for over two years for a diagnosis with the Belfast Trust. In the Western Trust, over 1,000 children waited for up to 720 days — nearly two years.

Autism is categorised as a disability under the Disability Discrimination Act 1995. An autistic child or adult should not be disadvantaged due to their disability, and the huge delays in accessing assessments and early intervention are therefore unacceptable. Is there any other disability for which

it takes two years — nearly over four years, in the case of adults — to get a diagnosis? A private diagnosis costs up to £1,400, and private assessment clinics are on the rise due to the waiting lists. That causes serious health inequalities. Those who can afford a private diagnosis get access to supports more quickly, because access to those vital supports nearly always relies on an autism diagnosis. No family should be at a disadvantage due to their economic status and whether or not they can afford a private diagnosis.

I will give a recent example of a parent who is part of one of Autism NI's support groups. She told us that her daughter, who is now aged seven, was diagnosed with autism at four years of age, and that she had to wait for nearly two years to get that diagnosis. Her son is now three years old and is due to start nursery in September, and she is not prepared to wait two years for a similar diagnosis. She therefore had to borrow money from her friends and family to get a private diagnosis, and obviously she has to pay all that money back. She told me that she felt bad because she is lucky that she has a very supportive family who were able to help her with that financial strain, but she knows — as we do — of so many parents who are in a similar situation but are on those lengthy waiting lists and simply cannot afford a private diagnosis. Ten years ago, the five health and social care trusts did not accept private diagnoses, but they all do today. It should be the NI Executive's responsibility to ensure that the health trusts deliver the assessments within the recommended 13-week period to give all autistic children and adults the right supports as soon as possible. I therefore call for an investigation into the waiting times for assessments. That needs to be carried out urgently.

Another area that deeply concerns me is the disparity in the prevalence rates of each trust area. The latest stats from the Department of Health show that the prevalence of autism in Belfast is three times higher than in the Southern Trust area. In the report, they state that one in 14 children in Belfast is diagnosed with autism compared with one in 48 in the Southern Trust. Can the members of the Health Committee ask the Minister why those disparities happen? We obviously need research into that area.

Over the past 18 months, Autism NI has been working on a private Member's Bill proposed by Pam Cameron MLA, who is also the chair of the all-party group on autism. We have been meeting virtually during the pandemic. Autism NI has provided secretariat for the all-party group. We have worked on that for over a year. The aim of the Bill is to address the lack of accountability, independent scrutiny and transparency that has curtailed key elements of the Autism Act. The consultation process for the private Member's Bill took place in October 2020 and attracted in excess of 1,800 responses. That is the most responses in Northern Ireland history. That shows the need and the concern that families and autistic adults have with the current status here. The Bill will introduce an autism reviewer, which will be independent of the Department of Health and will ensure that the autism strategy is fulfilled properly this time. It will also ensure that measurable targets are set, as well as putting in place a consistent early intervention service, adult services and training. That is to name but a few amendments, all of which will all help to support our autism community. The Bill is at the end of the drafting stage, and we hope that it will reach the Chamber very soon. We also hope that all of you will be able to support it. Autistic children and adults are a vibrant part of our community today, as they will be in the future, and we are all failing them. They are our friends, neighbours, colleagues and family, and they deserve the same rights, support services and opportunities as every other person in Northern Ireland. Change therefore needs to happen, and it needs to happen now.

**The Chairperson (Mr Gildernew):** Thank you, Kerry. I absolutely agree with what you said. In relation to no family having to borrow money, this is putting families into debt, or else there are circumstances where families are not able to borrow that money, which therefore puts them at a huge disadvantage, with the inequalities that flow from there. There are two major inequalities here. The first is that financial inequality — the ability or not to go private, and the need for anyone to go private in what is supposed to be a publicly accessible service. The second is the regional disparity and inequality that you have flagged up there. What is your assessment of how that regional disparity has come into being, and how can it be addressed?

**Ms Boyd:** Do you mean the prevalence rates or the waiting times?

**The Chairperson (Mr Gildernew):** The waiting times across the various trusts and the element of a postcode lottery across the trusts. What is your assessment of how that has arisen, and how might it be urgently addressed?

**Ms Boyd:** Obviously, there is a lack of investment. The Autism Act and the resulting autism strategy was brought in ten years ago. The prevalence rates have gone up by 200% or something since then, but the investment has not followed through. I feel that we have asked the Minister of Health a number

of times why there are such disparities between the trusts and why the waiting times are different. That is why I am coming to you today, to say, "Can somebody please investigate this and find out why families in the Belfast Trust have to wait two and a half years when somebody who lives in the Southern Trust can start the assessment process within 13 weeks?" What is the difference that is happening there, and what processes are different? As a charity, we do not know. We are not assessing those children. We are only hearing families come through to our helpline, which receives over 5,000 calls a year. One of the particular issues is the waiting times. Families feel that they cannot wait any longer and that they are being forced to access a private diagnosis. We do not know.

**The Chairperson (Mr Gildernew):** OK. Thank you. The issue about the private referrals is hugely worrying. I have tried on a number of occasions to get information on the level of those referrals, but the figures are not being captured by the trusts or by the Department. That in itself is a concern: if we are not measuring it, how are we going to address it or act upon it? Has there been any discussion or engagement by the Department with you or any other charities or experts to see how that or any other issue can be addressed? Is there any ongoing consultation?

**Ms Boyd:** In relation to waiting times, no. The Department is overwhelmed at the minute. With COVID-19 over the past year, obviously assessments have been delayed and waiting lists are at an all-time high, but that was going on prior to 2020. We know that it has been going on for a number of years. *[Inaudible owing to poor sound quality.]* I cannot understand why — the Department is looking at the figures every year. When the Autism Act was brought in, it made the Department of Health produce an annual monitoring report with all those fantastic statistics that I am just after telling you about. The Department reads that every year, but it does not do anything about it. It sees the prevalence rates and knows the need. What is the point of producing all those stats if the Department is not going to do anything about it?

The figures are there, and the waiting times and the numbers speak for themselves. When we led the lobby ten years ago to get all these statistics and reports, I presumed that the purpose of them was for planning in order to support our autism community. Clearly, it was not. I cannot tell you any more. I think that it is up to you, as public representatives, to do something about this and make that change. We have worked on the private Member's Bill that, as I said, we feel will make the change. It should not have got to the stage of having to introduce a private Member's Bill, but that is the only way, we feel, to ensure that it will happen.

**The Chairperson (Mr Gildernew):** OK. Thank you, Kerry.

**Mrs Cameron:** From the outset, I had better declare an interest as the chair of the all-party group (APG) on autism and the named Member who will table the private Member's Bill on autism, which is, hopefully, very close to introduction in the Assembly. The purpose of that Bill is to strengthen the Autism Act. I thank Kerry, Arlene and Kelly for being here and briefing us on what is a very important subject to all of us, as Committee members.

Kerry, you mentioned that you think that the interim autism strategy is not fit for purpose. Can you explain why? Can you also tell us why you feel that the previous autism strategy failed? Thanks.

**Ms Boyd:** OK. Very bluntly, without getting into every point of the interim autism strategy or the previous strategy, neither of them have measurable targets. If we do not have any measurable targets, how can we assess whether things are being completed or getting any better?

One of the points in the interim autism strategy is:

*"We will deliver focussed training that will enable our workforce to respond to the specific needs of people with autism".*

That is one of the Department's targets, but it is not measurable. How many people will it train? What difference will be made? How will that be assessed? How many adults with autism are in the workplace? We know that only 22% of adults with autism are in the workplace, which is lower than any other group in the disabled community in the UK. Unless we have measurable targets attached to the new longer-term autism strategy that the Department is creating, there will be no point. We will be unable to assess whether it is working.

**Mrs Cameron:** Thank you, Kerry. That is great to hear. I will not hog any more time, because it is important that other members get to ask questions. We have done an awful lot of work together in the

APG. I want to put on record my thanks to all of you for the incredible amount of work that you have put in over the years, particularly over the last year as we have worked together on the private Member's Bill.

**Ms Bradshaw:** Ladies, thank you for coming to the Health Committee. Last night, the Alliance Party's ability group met Deirdre Shakespeare, who, as you will know, is campaigning for the introduction of Harry's law on restraint and seclusion. I do not want you to comment on that specific case, but what is your understanding of how well teachers in mainstream and special schools understand the complex needs of children who are living with autism?

**Ms Boyd:** I do not want to hog the session. I have two other colleagues with me. Kelly, do you want to answer about mandatory teacher training and the obvious need for it? *[Pause.]* Oh, she has disappeared. I do not know what happened. I will answer that.

For the past number of years, Autism NI has been lobbying for the need for mandatory teacher training. School is, obviously, where children with autism spend the vast majority of their days, and anyone who is working with and supporting those children should understand their needs. It seems to be common sense that all teachers should be trained on autism, especially those in mainstream schools — you have to remember that 78% of children with autism are in mainstream education. We know that not all of those teachers are trained in autism. We know that from the parents who have phoned our helpline.

There have been issues with teachers, but the teachers with whom we have spoken really want that training and to understand their children; it is a vocation for them. So many teachers have come to our training sessions on Saturday mornings, in their own time and having paid for it themselves, to gain that training. There is a definite need for better understanding and support. That begins with education.

It is not just about the children and the teacher understanding their autism. Education outcomes are the priority but that understanding starts a culture change in which teachers who better understand children with autism can work better with them. Other children in the class will be watching all of that too and will no longer assume that the autistic child, who the teacher may have had issues with and told off, is being badly behaved because they will understand them better. It starts with the teacher's understanding. We are totally behind that.

There was a debate on this in the Chamber, in February 2020, and Peter Weir, the Minister of Education, said that he was going to implement that mandatory teacher training, but it never happened. That is another part of the reason why the private Member's Bill really needs to go through. Things need to change, and, as you said Paula, the classroom is where that needs to start.

**Ms Bradshaw:** Thank you. My second question is in relation to the support that charities and community-based organisations, such as Sólás in my constituency, provide to individuals and their families and their role and position in society. Will you comment on the difficulties in attracting funding to provide the services in the community and whether you think that part of the issue is that it falls halfway between health and education?

**Ms Boyd:** Kelly, do you want to answer that one?

**Ms Maxwell:** Yes, no problem. Can you hear me OK?

**Ms Boyd:** Yes.

**The Chairperson (Mr Gildernew):** We can hear you, Kelly.

**Ms Maxwell:** Paula, obviously this has been an ongoing issue, and the Autism Act sought to address it. The Autism Act was before its time because it was enacted in 2011, yet it was only in 2016 that the Programme for Government started to look at Departments working collaboratively on the issue. We also have Steven Agnew's Children's Services Co-operation Act, which came into place in 2015, yet we continue to see separate pathways for children, not just in funding but in assessment. So, the child who starts a health assessment with the NHS has to start a separate educational assessment. Sometimes, families are not informed of that, so they spend two years waiting on a health assessment

and think that it will help with support in school but then get the information that they have to start the education process.

As Kerry said, the private Member's Bill is also looking at the need for investment. That need is huge for children and adults. A report by Autistica in 2016 looked at the difference in the life expectancy of autistic individuals and their non-autistic peers: there is a 16-year difference. So, in terms of longevity, health and education, Departments working together is absolutely essential to outcomes for autistic people over their lifetime.

**Ms Bradshaw:** Thank you very much, Kelly. That is very comprehensive. Thank you, ladies.

**Ms Hunter:** I thank the panel — Kerry, Kelly and Arlene — for being here this morning. You can tell that they are tireless advocates for people with autism — children and adults — and their families. We really appreciate the hard work that you do, and it is evident how much you care.

I have a few questions. The social-inclusion-priority section of the document is really important. What kind of training is available for first responders on how to approach people with autism in an emergency and could it be improved?

**Ms Boyd:** Kelly, do you want to answer that?

**Ms Maxwell:** I think that Arlene had her hand up. Did you, Arlene?

**Dr Cassidy:** Yes, I will answer that briefly, but Kelly should major on it. I have a small but, I hope, significant point to make. A cross-departmental working group was set up by the Minister of Justice some years ago to look at what measures need to be put in place to red flag individuals, not just those with autism but those with other social and communication issues. That cross-departmental group also included representatives from the PSNI and the Fire and Rescue Service, and it looked at exactly the point that you mentioned. The report was compiled in, an incredible, 18 months and was submitted to the Minister for action, but nothing ever happened. We wrote to the Minister of Justice at the time to ask what was happening, but no response ever came. I think that we wrote on two occasions. So, work has been done. It is in somebody's archives in the Department of Justice. I think that the working group was led by probation at the time. That is just a point of information before Kelly gives you the meat of this discussion.

**Ms Maxwell:** Autistic individuals and their families call our helpline. As Kerry said, we take over 5,500 calls per year. We hear from autistic individuals who will describe environments and experiences not taking account of their differences. About 10 years ago, before I commenced working for Autism NI, the organisation had an initiative where there was training for the PSNI, the Fire Brigade, the Ambulance Service, to name a few, and we developed an awareness card off the back of that initiative. The awareness card was reviewed recently by autistic adults in the organisation. People can carry that to assist them when they are out and about and are feeling overwhelmed. However, I do not know of any initiative where there is mandatory training for front-line staff in the NHS. That would need to be explored by the Committee, but autistic people would articulate that it is very much needed.

Sometimes, autistic people are described as not engaging with services or being hard to reach. Autistic people and their families regularly tell us that those services seldom hear their voice. They will discuss their needs and their sensory difficulties, and they will clearly articulate what they feel they can partake in, but, for some reason, on occasion, that is not heard.

**Ms Hunter:** Thank you, Kelly and Órlaithí. That is really important to note. Hopefully, we as a Committee can chase that up with the Department of Justice, so thank you for highlighting that.

I must declare an interest here as I have a family member who is currently on a waiting list for an autism assessment, so I know, at first hand, the stress, uncertainty and frustration that that can cause.

For those struggling with an autism diagnosis later in life, what support mechanisms are in place for things like housing, for example? How do you feel that that can be improved?

**Ms Maxwell:** There is no collaborative multi-agency approach to an adult getting a diagnosis and receiving follow-up support. There are some initiatives, for example, the Belfast Trust has a Belfast adult autism service, and the Northern Trust has a northern adult autism service, but there is no

consistency throughout the trusts. It also relies on the autistic individual going to a central location. That, in itself, may be a barrier for some of our individuals. That consistency and provision of pathways of support needs to be looked at.

With regard to the adult pathway, there are three programmes of care: learning disability, physical disability, and mental health. We find that when children who have been receiving support transition to the adult world, they often fall between those gaps because they do not quite fit mental health, they do not fit learning disability and there is a lack of support.

**Ms Hunter:** That answer is spot on. I am sure there is no member on this Committee who has not had someone come to their office and voiced their frustrations about the gap in services.

The priority in the strategy is about the availability of more short-break services. We know that those are of great benefit to individuals and their families. Will you provide more information on those? Also, what can we as elected representatives and Health Committee members do to express support for the families and siblings of those with autism?

**The Chairperson (Mr Gildernew):** Before you come in, Arlene, can I ask everyone who is not contributing to make sure that they are on mute. Perhaps broadcasting can put people on mute? There is background noise coming through that is quite distracting. Is it, maybe, coming through your microphones, Arlene or Kerry? I think that everyone else is on mute.

**Dr Cassidy:** No.

**The Chairperson (Mr Gildernew):** OK, so we will give it a try, Arlene. It seems to have reduced now.

**Dr Cassidy:** Could I defer to Kerry and Kelly on this one? Someone has just knocked at my door.

**The Chairperson (Mr Gildernew):** Certainly, Arlene. That is a frequent hazard with these Zoom meetings, so we understand.

**Ms Boyd:** Kelly, I am sure, will be able to give you more insight into this from the calls that we got through the helpline. I did an interview on Radio Ulster last week about this. Respite care is extremely important for so many families and young people. Especially over the past year, so many services have been closed. Therefore, it has not been as available as it was before for those families. Even some of the day centres that so many adults with autism were attending have been shut completely. Some are back up and running, but the adults are only there, maybe, one day per week instead of three. All those changes in routines are very disruptive, not only for that adult but the entire family that has to deal with that. It can come out in behaviours and frustrations with those adults.

Respite care for the mental health of families and parents is extremely important. Even before the pandemic, there were not enough respite services in Northern Ireland. Kelly will be able to tell you about some of the waiting lists for some of the respite care. It is unacceptable. You are right, Cara: it is one of those issues that needs to be addressed. If a parent or carer is not in the right place and is having mental health issues, they need that bit of respite for themselves as well as for the child.

Kelly, do you want to talk about the waiting times in the trusts to access that?

**Ms Maxwell:** There is an autism pathway called the Six Steps. Step six, when you get your assessment and diagnosis, lays out the types of support that are available. There should be a child-and-family planning meeting that would look at the services that you just listed, whether that is respite, short care, OT or speech and language therapy. All those specialist services should be looked at, and families should be a part of planning for it.

Through our helpline, we are regularly told that that does not happen. Families have to go to local representatives. They have to push. We have 23 support groups across Northern Ireland. We regularly hear through participation, "Why does no professional tell you about these? Why do you have to hear it from other parents and carers?". Then, you are made to feel like a pushy parent for asking if you can access those services.

Kerry is absolutely right. There are lots of parents and carers who have not had a break in more than 14 months. They are caring 24/7, 365 days per year. Respite and short breaks were severely



impacted by the pandemic. Even before that, however, there was an issue of access to them and waiting lists. If we think of assessment waiting lists being two years, some areas for respite would have the equivalent.

It should never get to the point where the NHS is failing families so much that they use their own resources to take legal action and push for judicial review. The 'Broken Promises' report detailed that issue in 2006. It was an issue in 2011, when the Autism Act 2011 came in, yet, here we are, 10 years later. We have talked about outcomes-based accountability, and those issues have been exacerbated. I hope that answers your question, Cara.

**Ms Hunter:** That is very helpful, Kelly. Again, I put my thanks and my party's thanks for the work that you all do on the record. It is truly unforgivable that we have children and adults waiting years for a diagnosis and that families have to go into debt to get that diagnosis. We are really failing them. I thank you again for your hard work and your answers today.

**Mr Carroll:** Thank you for your contributions. I concur with Kelly's sentiments. The Department and the state are, ultimately, failing people with autism and the families of people who are seeking a diagnosis. The pressure means that people are forced to go and seek a private diagnosis, and that is really concerning. Obviously, that was highlighted a lot in the news by you, Kerry, I think.

It is the same determinant as the NHS waiting lists; it is determined by class. People are waiting on NHS waiting lists to get elective surgeries or to see consultants, but people are also waiting on a diagnosis of autism. It is the same principle: if people can afford to pay or are able to get into debt, then they can get access to services. That should not be the case whatsoever. It is an absolute failure in our current system.

Will someone tease out the impact of later diagnoses? Obviously, there is distress and worry, but are there any cognitive or developmental issues that come with a later diagnosis? It would be helpful if someone could speak to that.

**Ms Boyd:** You are all aware that early intervention is key. Therefore, a diagnosis and being able to gain those supports as early as possible is so important for a child's developmental abilities. There is an awful lot of focus on the waiting times. For me, as someone working in this area, the waiting times are only the start of the journey. Once the child has a diagnosis, you do not talk about waiting times to get a diagnosis. You usually talk about waiting times for support or treatment or whatever it is. Getting a diagnosis is only the start of it. We then need adequate support to follow that up, and we all know that those services are poor as well. There are so many issues. It is so bleak. Families wait two years to get a diagnosis and then come to Autism NI and ask what they do now. If we have the funding, we send out an early intervention team to their house to do a six-week intervention and to help with visuals and understanding autism. Quite often, a lot of that is funded by charitable trusts in England. It is not funded by the Government. Therefore, part of the private Member's Bill is to have a consistent early intervention service in place throughout Northern Ireland, which will get straight in there after a diagnosis.

It is so critical to get the diagnosis and supports in there as soon as possible. It is critical that parents get an understanding as well. Often they do not know whether their child has autism. Some do, some do not. They do not know how to support them. If they do not have a diagnosis, they do not know what to do. For those two years, can you imagine the frustration, worry and stress of guessing how to support your child or not knowing what is causing your child's behaviours? The delay in diagnosis is unacceptable for a number of reasons. Kelly, do you want to talk about why early intervention is so important?

**Ms Maxwell:** Assessment provides parents and carers with information about their child's development and behaviour and should enable them to tap into further support to meet their needs. Any assessment should be honest about the strengths and areas for support and should provide a framework for understanding that enhances knowledge of strategies to support an autistic person, including promoting positive autistic identity.

A lack of access to timely assessment and support may lead to individuals being unable to fully participate as active members in their community. Early intervention equips families with strategies. It looks at routines and how to meet the individual needs of a child. Some children have sensory differences. When that term is used, you very often need to look at what that might be, because parents who have not been in the autism world might say, "Well, I didn't know chewing the string of the

hood was a sensory need, and, when I took that off, my child just couldn't cope with being in a classroom". That was the case for a particular parent; they said, "Why did nobody explain this to me?". It is about getting down and looking at routines that can be implemented to support children.

We also have autistic adults who have waited 40 or 50 years or longer and are being diagnosed. Some will say that an assessment was pertinent because there was the risk of home placement breakdown or relationship breakdown, or there were issues with employment. Getting their autism diagnosis has not only enabled them to understand years of having different labels or perspectives of individuals placed on them, but it also provided a framework by reaching a community that connects them. That is probably the first time that they have felt that they connect somewhere to something. That means that they can start to understand their autism in a way that they could not before because they were always on the periphery.

**Mr Carroll:** Thanks, Kelly and Kerry. Kerry, I think that you said that it does not end with the diagnosis. That, obviously, is true. We know that the NHS is 2,000 to 3,000 nurses short of meeting capacity as it is. Do you have any sense of what is needed to equip the support systems that are required for people with autism?

The process of statementing is wider than autism. My experience from dealing with constituents is that it is a very long and arduous process to get support in education. Will you speak to that?

I think that Kerry said that we have the highest, or one of the highest, levels of autism here. Apologies if I did not hear you correctly. If that is the case, is there any understanding or reason for that?

**Ms Boyd:** The easiest question to answer is the one about the prevalence rates. One in every 22 school-age children is being diagnosed in Northern Ireland. That is, from my understanding, the highest in the world. The stats say that, in Hong Kong, one in every 27 school-age children are diagnosed, and they are officially the highest in the world. The Department's most recent stats state that our rate is one in every 22, so, officially, we have one of the highest autism levels in the world. One of the reasons is, as we all know, that autism was not diagnosed 30, 40 or 50 years ago. Kelly said that so many adults are coming through with autism who are maybe 40 or 50 and are getting their diagnosis later in life. It was not diagnosed in Northern Ireland until the late 1990s. Arlene will be able to tell you about that. Those adults are coming through only now. Previous to that, they were not getting a diagnosis.

Autism NI and Arlene did a lot of work, over the years, when leading the lobby for the Autism Act. There is now better awareness, so people understand better that that child was not being odd in class and that those behaviours were not just strange; it was because they did not understand or were picking things up wrong because they had autism. If all of us think back to our primary school classes, we will probably realise that there were one or two children there who were on the spectrum but did not have a diagnosis. I feel that that is why the prevalence rates are so high: it is through better awareness. The Autism Act was one of the things that really escalated it, because Autism NI and other charities raised people's awareness and understanding. We are lucky to have that awareness and the Act, but we are not doing anything to support the children or adults after the diagnosis. What is the point of diagnosing all of these children and adults with autism, if there are not adequate support services after the fact?

You are right about statements. We all know that there are issues with getting the right support in school, as well. That is why we are leading the lobby to try and change things and get mandatory teacher training implemented. We feel that that should be done. We feel that, for teachers, good autism practice is good practice for all kids. The teachers whom we have spoken to want and need this. There are just so many issues, Gerry. However, the prevalence rates are definitely due to the awareness that we have now.

If there was the same awareness in other parts of the world, the rates would probably be the same. In England, the prevalence rate is officially one in 100. In Northern Ireland, with the Autism Act, we count children, whereas, in England, they do not. In England, they take a sample of the population and, therefore, you are comparing apples and pears. If they counted children in England, I would say that the rates there would be the same. That accounts for the difference.

I cannot remember what your other questions were. I am sorry. What was the first question that you asked?

**Mr Carroll:** Sorry, there was a lot of questions. The first was about capacity. We are 3,000 nurses short in our NHS given the waiting lists. Have you any sense of how many staff it would take for the state to provide that assistance after diagnosis? Do we have that information?

**Ms Boyd:** The short answer is no, I do not. I run a charity with nearly 30 staff. We all have targets to meet. I do not know. The waiting list is two years long, so the Department must know how big or how small their teams are to be able to deal with that. I do not know whether their teams work full-time or part-time, or what is happening. What I do know is that an awful lot staff are moving from the NHS into the private sector, and diagnosing there. There probably is a lack of specialists. Is that right, Kelly?

**Ms Maxwell:** Yes.

**Ms Boyd:** People are moving from the NHS, and that worries me too. Obviously, the less expertise they have, the less able they are to diagnose and the less capacity they have to diagnose. That is happening too. However, I do not know the figures for how many would be needed. That is up to the trusts. They need to sort that out.

**Ms Maxwell:** Gerry. It is important to remember that, while we can always look at the gaps and at what we do not have, we also have to look at how people are struggling whilst they are on waiting lists for assessment, and at the impact that that is having across lifespans. Autism is not a mental health condition, although many autistic people have co-occurring conditions. In actual fact, through our helpline, people will report having to reach crisis point before anything is done. One autistic person said, "If I was physically sick, I would not have had to wait as long". We have to keep the focus on needing to do better earlier, and not on picking up the cost of late intervention. For some of those autistic individuals, we will not be able to do that due to the life expectancy gaps.

**Mr Carroll:** Thank you.

**The Chairperson (Mr Gildernew):** I am conscious of the time. Members should be as brief as possible with their questions, please.

**Mr Chambers:** I appreciate the presentation and found it very informative. Kerry answered my questions in her response to Gerry. She made a reference to 1990. I have only become aware of autism over the last 30-odd years. It was never talked or written about. I was going to ask whether it has always been as prevalent as it is now. Was it known by other names or simply not recognised? Is there any local, or even international, research into the current prevalence of autism throughout the world? Could it be in any way connected to some aspect of modern living?

**Dr Cassidy:** Autism NI was formed in 1990, basically because a number of parents started to read newspaper reports about a condition that seemed to somehow marry up with what they were experiencing in their lives. Autism NI is over 30 years old. Awareness of autism began in the UK and other parts of the world 30 years before that. We were late to the table on awareness. Part of that was, I feel, to do with our preoccupation, quite naturally, during the years of the Troubles. A number of social and economic issues suffered as a result of that. A lot of professionals, and their knowledge, did not come to Northern Ireland because they did not want to risk it. One of the first jobs for Autism NI was to headhunt throughout the world to bring experts on autism over here to speak at conferences. We have had a long-standing interest in training, expertise and research. I hope that that answers your question, Alan.

There has been a chequered history with regard to autism. In the early days, a lot of people wrote very harmful pieces stating that autism was caused by parents who could not bond with their children and all that sort of stuff. We came out of that dark period, got a bit of sensible information and moved forward. We have been building up the expertise, but there has been a legacy of neglect in knowledge, which I referred to, and in funding. The Autism Act in 2011 was the first time that the Government here were mandated to count. Without counting, you cannot plan. That has been a constant theme throughout our discussion today. It is about measuring and counting, because you cannot allocate resources without knowing what the need is. The Department of Health and the other Departments have gotten away with not implementing the Autism Act — it is cross-departmental legislation that they are all obliged to implement — in that they have not adhered to operationalising that counting and what that actually means in resource terms.

Yes, there has been a lot of research into prevalence. Kerry addressed that, and I defer to her on it. I have been at conferences, and, at one stage, South Korea had the highest prevalence rate. It is important to note that one of the main impacts of the Autism Act in 2011 was to require the Department of Health to publish annually prevalence and incidence rates on autism. Unfortunately, it still bases those on the school census figures. Until the Autism Act in 2011, and after it, clinicians were having to do a manual count because the IT software was not adequate to take on board the diagnosis information and make that data available for planning. The annual prevalence report that is published by the Department of Health, as the lead Department, focuses on children. The private Member's Bill on autism seeks to widen that to adults and, as was referred to earlier, strengthen the Autism Act. The private Member's Bill has sought to identify the obstacles that have prevented the implementation of the existing Act.

**Ms Ní Chuilín:** *[Inaudible owing to poor sound quality]* skills, knowledge and ongoing advocacy for children, adults and their families. My experience in Belfast, going through the journey with some of the children and their families, has been one of frustration. The multidisciplinary teams in Belfast appear to be having difficulties retaining staff for autism diagnosis. For example, the child development clinic used to lead the services; now the psychological specialities do.

Another issue is that assessments using the autism diagnostic observation scale have been postponed so many times, particularly since COVID, that there is a massive backlog and delay. I am delighted that under-fives can be assessed face to face. I appreciate that getting a diagnosis is only part of the journey, but it is by far the most pressing issue about which families come to me as an MLA. I want your comments on that.

**Ms Boyd:** As we have said throughout, the diagnosis waiting times were completely unacceptable before the pandemic, and the pandemic has exacerbated the problem. We know that an awful lot of practitioners are leaving the public sector, moving into the private sector and setting up diagnosis clinics. That expertise may be lost; I do not know. The trusts do not have the capacity to address the waiting lists. We need to know the reason for that, which is why we came to speak to you today. We hope to get your support with the forthcoming private Member's Bill as well.

We know that a lot of investment is needed in the Belfast, Northern and Western Trusts, in particular. Carál, we also really want to know why there are such differences between those three trusts and the Southern and South Eastern Trusts, why the waiting lists are so short in the Southern and South Eastern Trusts, and why there are fewer children being diagnosed overall in those two trusts. The percentages confuse me, and we do not have an answer for that. It definitely needs to be investigated.

We totally understand the pressures that parents are under to seek a private diagnosis; they just cannot wait for two years. In the case study that I talked about, the parent, whose child was three and about to start nursery in September, needed to be able to tell the nursery workers how to support the child, whether the child was autistic or not, etc. She wanted all of that to be confirmed, so she borrowed money from her family and friends to get the diagnosis.

I totally understand all the issues that you guys are all listening to on, I am sure, a daily basis. As you also said, diagnosis is only the start of the journey. The backup support service after diagnosis is the important thing: how we support the entire family as well as the child or adult who has autism.

**Ms Ní Chuilín:** Yes. While you are here on autism and we all appreciate that, the same gap and pattern in waiting lists exists in relation to things like occupational therapy and mental health. In Belfast, the inequalities and disparities are getting wider. A number of former Health and Social Care staff now work in the private sector. That is not only about money; it is about terms and conditions, respect and teamwork. It is also about capitalism; the people who have left have seen a market. I have heard from former staff that it is less hassle to work in the private sector. That should not be the case. That is a loss to us all.

The issue for me, and Gerry touched on it, is that working-class families, particularly those from areas of multiple deprivation, cannot afford to pay for healthcare and autism diagnoses, and they should not have to. You mentioned the Executive at the start. As well as asking us about the waiting lists, what discussions have you had in relation to closing that disparity? The pattern has been there for too long, and it will continue unless the waiting lists are grasped.

**Dr Cassidy:** One of the saddest things is that the Department of Health has not reached out, as is highlighted in the 'Broken Promises' report. Over the seven-year period since the first autism strategy,

it has failed to engage with the autism voluntary sector. The community and voluntary sector is an untapped resource that has been totally ignored by the Department of Health. There is engagement with the trusts — Kerry and Kelly can talk to you more about that — but, regarding the strategy, the failure in leadership, ownership and rolling out a plan that can best manage scarce resources lies at the Department of Health.

That is what the autism private Member's Bill hopes to address. It would have been easier if the Department of Health had worked in a cross-departmental manner, because this is not a responsibility of just the Department of Health or the Department of Education. Autism is a lifelong condition, and everybody needs to chip in to do their bit. That has not happened. With the lack of ownership and leadership, we are where we are. We are in a worse position. I am not saying that things would have been perfect by any means, but the evidence that the Department has not tapped into what the voluntary sector can do is a criminal shame.

**The Chairperson (Mr Gildernew):** There are no more questions. I thank each of you very sincerely. That was a very important session on a matter of huge concern. In the week in which the motion was brought to the Assembly, I spoke to hundreds of families and carers. The pressure that they are under is phenomenal. The key theme that emerged was that people are fighting for services and battling to survive. That is the type of language that was being used. People are at the end of their tether. It is significant that this session is taking place in carers' week, because, as well as the individuals who have autism being impacted on, a host of carers are being let down as a result of the inadequate provision.

It is an issue that we are deeply concerned about. Pam is bringing forward her Bill, and the Committee has asked that there be a focused and dedicated meeting of the Executive, and a health summit, on waiting lists. It is vital that autism waiting lists are included as part of the urgent consideration and cross-departmental Executive approach that will be needed to deal with the many issues that arise, regarding not only the difficulty in getting diagnosis, as you have eloquently stated, but what service follows the diagnosis and what supports are provided while people await diagnosis. That is another very important issue.

Panel, thank you for coming along, for bringing the issue to light in the North over 30 years ago, as you said, and for continuing to advocate for, and push for, those services. It is a matter of regret that we still are where we are with the difficulties, but you have certainly played your part, as have other advocates. I acknowledge and thank each of every one of you. Thank you for your attendance today.

**Ms Boyd:** Thank you.

**Ms Maxwell:** Thank you.

**Dr Cassidy:** Thank you.