



Northern Ireland  
Assembly

Committee for Health

# OFFICIAL REPORT (Hansard)

Autism (Amendment) Bill:  
Mrs Pam Cameron MLA; Autism NI

16 September 2021

# NORTHERN IRELAND ASSEMBLY

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

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

**Witnesses:**

Mrs Cameron	MLA - South Antrim
Ms Kerry Boyd	Autism NI
Dr Arlene Cassidy	Autism NI
Ms Kelly Maxwell	Autism NI

**The Chairperson (Mr Gildernew):** I welcome Pam Cameron MLA, chairperson of the all-party group on autism (APGA) and sponsor of the Bill; Kerry Boyd, chief executive of Autism NI; Arlene Cassidy, who is a special adviser to Autism NI; and Kelly Maxwell, who is director of family support in Autism NI. Pam, please go ahead with your briefing.

**Mrs Pam Cameron (Northern Ireland Assembly):** Thank you, Chair. This all feels a bit odd, so forgive me if I blunder. I am glad to have colleagues from Autism NI on board. Dr Cassidy will give a short presentation, and I will follow straight after with a longer one. We will then take questions, if that is OK.

**The Chairperson (Mr Gildernew):** Yes. Thank you.

**Dr Arlene Cassidy (Autism NI):** Thank you for having us. Having worked as a social worker in east Belfast during the Troubles in the 1970s, I moved to Barnardo's in 1980 to work with children with learning disabilities. That is where my interest in autism began. In '92, I was employed to develop Northern Ireland's first autism charity, PAPA, later renamed Autism NI. I retired as CEO in 2017, and I am currently acting as an adviser to Autism NI and supporting it in its role as secretariat to the all-party group on autism.

My role today is to remind us all why we must resort to the Northern Ireland Assembly and legislative solutions for autism. Why are we here again for autism? Let me set some context. In short, we discovered autism late in Northern Ireland, and we never caught up. Until 1990, autism apparently did

not exist here; it was an autism-free zone. There was no diagnosis and no support until Autism NI/PAPA was set up by families and professionals, yet services had begun in 1962 in England, in '65 in the USA and in '63 in Ireland.

In the early 1990s, parents travelled to England for autism assessments, and autism was classified here wrongly as a learning disability. The first funding for statutory autism services came in 2002, and it was for diagnosis only. By then, Autism NI had lobbied every board and trust. Autism strategies were agreed and then dropped as committed individuals moved on to other duties. The impact of all that is still evident today. Even by 2002, it was too little, too late. Waiting times for autism assessment and diagnosis averaged between two and four years, with autism data available only by a manual count. International research reveals that the cost to society in human and monetary terms is greater through neglect than through doing something.

The conclusions drawn from that dynamic crisis were that, first, there was something wrong. There was systemic reluctance and failure across government and institutions to recognise, understand, resource and plan for autism services. Secondly, it was concluded that the Northern Ireland Assembly and legislative change were needed to deal with it. An all-party group on autism was needed.

The all-party group has its origins in the Autism NI nomination of cross-party MLA autism ambassadors in 2001. It was formally constituted in 2008 following a Northern Ireland Assembly delegation to Capitol Hill to meet the autism caucus and agree a memorandum of understanding on autism with the US Congress. That delegation was accompanied by the Celtic Nations Autism Partnership (CNAP), which was an amalgam of the autism societies in Northern Ireland, Wales, Scotland and the Republic of Ireland, which were committed to helping each other lobby each of their political institutions.

The result of that political activism was the Autism Act (Northern Ireland) 2011, a uniquely cross-party and innovative piece of legislation. The recognised catalyst for it was a parent-led, Autism NI-organised lobby seeded in each constituency without employing professional lobbyists. That Act was the first cross-departmental legislation here, predating the Children's Services Co-operation Act (Northern Ireland) 2015 by four years. It introduced the annual publication of the first regional autism data collection. Globally, it remains the most comprehensive, lifelong, cross-departmental single-disability equality legislation globally. It amended the Disability Discrimination Act 1995 or DDA to recognise autism. It mandated an ambitious, recurrent seven-year cross-departmental national strategy for autism. That legislation held so much promise. Job done? Unfortunately not. That brings us to why we are here today. The APGA has gathered clear and shameful evidence that those charged a decade ago with the implementation of the Autism Act (NI) 2011 have failed us all. It is true that the DDA change has increased the recognition of autism and that the annual collection of prevalence data is progressing in its sophistication and potential. However, the failures in implementation are many and avoidable. For further detail, I refer you to the 'Broken Promises' report published in 2016 by Autism NI and the National Autistic Society NI for the only independent commentary on and evaluation of the Northern Ireland autism strategy. The report, launched by the APGA five years ago, remains relevant but obviously does not take account of the continued deterioration in services as the gap between autism prevalence and resource investment widens annually. According to Department of Health data, Northern Ireland has the highest prevalence rates of autism in the world and has proportionately, therefore, the lowest investment in services. So what is going on?

We did not have to be here, and it did not have to be like this. Knowing what we know, why are we here, and what must we do? We have to address the failures in the implementation of the legislation by setting down specific remedies. We have to address the failures in leadership, ownership and motivation; tackle duplication across Departments and regional services; inject regional strategic consistency; address inequalities; and address the continued legacy of investment neglect.

Just how do we do that? By strengthening the Autism Act (NI) 2011 through the Autism (Amendment) Bill of 2021.

**Mrs Cameron:** As many of you know and as the Chair mentioned, I am the chair of the all-party group on autism. I have been in the role since 2016, and I am proud to be able to support the autism community in that capacity. I, along with colleagues in the group, believe that there is a huge gap in service provision that needs to be urgently addressed. Therefore, with the full support of the all-party group on autism, I have sponsored a private Member's Bill called the Autism (Amendment) Bill that will strengthen the Autism Act of 2011.

As Dr Cassidy explained, when the Autism Act was passed, it amended the Disability Discrimination Act to recognise and protect the rights of people with autism. It was the first legislation passed by the Assembly that mandated cross-departmental service planning and delivery across adult and children's services. As a result of the Autism Act, implementation of the autism strategy was a legal requirement. However, we are all too aware that that implementation has not happened at the speed or in the way intended. On numerous occasions, I have heard from organisations, autistic people and their families that there is little to no support for someone with a new diagnosis of autism. Even getting a diagnosis is extremely difficult, with many families waiting up to two years and adults waiting up to four years. However, that is only the start of the autism journey. As I will explain, there are many improvements that need to be made in order to support that vulnerable community.

Over the past number of years, the all-party group on autism has gathered evidence confirming the following points. Only one of the three action plans in the mandated NI autism strategy for 2013-2020 has been completed. The annual autism prevalence report produced by the Department of Health now reflects that we have the highest confirmed autism prevalence rate in the world, with one in 22 school-age children having a diagnosis of autism. The NI autism strategy progress reports are extremely subjective, generic and lacking in any measurable outcomes or targets. No independent research or evaluation has been generated to assist discovery, planning or delivery.

A well-publicised plan by the Health and Social Care Board (HSCB) to initiate an independent study to explore the different rates of diagnosis across the five health and social care trusts never happened. Assembly questions submitted by APGA members have confirmed that the causes for diagnostic inconsistencies across trusts remain unknown. We have a letter from the Health Minister acknowledging that his Department does not know why there are such inconsistencies from trust to trust. For example, why does it take up to two years for a diagnosis in the Belfast Health and Social Care Trust yet the Southern Health and Social Care Trust apparently takes 13 weeks?

No Department has submitted new bids for the funding of autism services in the last 10 years. No new funding was attached to the Autism Act (NI) 2011 implementation; indeed, the only published new recurrent funding injection was in 2016, when £2 million was allocated to Health towards diagnosis only. The Department of Health maintains a medical, rather than a social, model of disability. That has created a serious funding imbalance for conditions such as autism that require educational and social or community intervention.

The requirement in the Autism Act (NI) 2011 for an autism awareness campaign has been replaced by an optional in-house intranet exercise and coffee mornings by the Northern Ireland Civil Service (NICS) instead of the implementation of the initiatives recommended by the NI autism strategy's research advisory committee.

The impact of all that is best summarised by the reaction to the October 2020 public consultation on the Autism (Amendment) Bill. The public consultation received in excess of 1,800 responses, making that the highest response to draft legislation in Northern Ireland's history. The high response rate is a huge indicator of the level of concern. Some 92% of respondents supported the need for an independent scrutiny mechanism, as they believe that scrutiny, transparency and research in relation to autism services is inadequate; 95% of respondents supported a cross-departmental accredited autism training strategy coordinated to target key staff and reduce costly duplication; and 94% of respondents highlighted concerns about and the need for consistent adult autism services. Similarly, support was evident in the consultation for assessment and post-diagnostic services to be consistent across trusts. Significantly, there was overwhelming concern that the situation regarding support services had become worse. That obviously corresponds with the lack of investment, leadership, motivation and resources during a period of accelerating prevalence.

Another important issue is the financial cost to families. Private autism diagnosis clinics are on the rise as parents turn in desperation to find any service they can to access timely diagnosis and intervention. Many families cannot afford that route and are getting into debt to find answers and get help. That is damning evidence of the failure of our Health and Social Care (HSC) sector, which should be free and timely at the point of need for all autistic individuals. Also, the fact that private diagnosis is even recognised by our health and social care trusts, whereas 10 years ago it was not, can be interpreted only as an admission that they do not have the capacity to meet the need. It should also be noted that diagnosis at a private clinic often logically ties families into costly post-diagnostic early interventions. Meanwhile, the postcode lottery continues between our five health and social care trusts, with families reporting huge service inconsistencies, depending on which trust they live in.

All those critical issues indicate that the Autism Act (NI) 2011 must be strengthened. The Autism (Amendment) Bill would build on the 2011 Act by introducing measures to remove existing barriers to the full implementation of the law. Crucially, we need an independent scrutiny mechanism to drive forward future Northern Ireland autism strategies. That should be in the form of an autism reviewer.

At this stage, I want to outline the clauses of the Bill. Clause 1, "Autism strategy: consultations and data", would ensure that autism prevalence data is expanded to include prevalence data on adults as well as on children. Currently, Department of Health data focuses on children only. We also need to gather adult data to aid future planning and service provision for our autistic adult population. At the minute, we have no idea of the number of autistic adults we have, and therefore it is imperative that we develop our current data-collection system further. Also, as other parts of the UK count adults only, the prevalence rates will be easier to analyse comparatively. At the minute, we compare apples and pears, as Northern Ireland's prevalence rates are based on children, whereas England's are based on adults.

I will move to clause 2, which is headed, "Additional components of autism strategy". That describes the development of an autism training plan for staff across Departments and public bodies. It will reduce duplication and increase consistency, coordination and competency across agencies. It will enhance workforce professional development and introduce a tiered strategy from basic awareness training for the many to targeted accredited training for the few. Two of the most obvious examples are training for all teaching staff in Northern Ireland as well as for mental health professionals working with autistic people.

The next item in clause 2 is the development of a regionally consistent early intervention service in order to ensure regional consistency of ethics and practice that feeds into the autism training strategy. We all know that early intervention works and is cost-effective as it reduces later dependency on core services. There are also fantastic best practice models locally that need to be tapped into and delivered regionally.

Clause 2 further proposes the development of a regional information service. As the prevalence rates have risen, so has the imminent need for information and support. A regional information service will ensure consistency of advice and signpost autistic adults and families to services in their area. That should be available through different media types, such as by telephone, in person or virtually, in order to accommodate different circumstances.

Finally, clause 2 also outlines the focus with which adult services must be developed, and, combined with clause 3, that would ensure regional consistency, meaning the development of a regionally consistent range of adult support services. The extension of data relating to adults will improve the capacity to map need. For example, as only 16% of autistic adults are in full-time employment, which is less than half the total figure in the disability sector, we can all agree that that area needs to be invested in and developed. Social opportunities are also needed. So many adults feel misunderstood, alone and unsupported. That is evidenced by the stark fact that an autistic adult is eight times more likely to complete suicide than a neurotypical adult, and I believe that the lack of support services and opportunities may be contributing to that terrible figure.

I will turn to clause 3, "Methodology of the autism strategy". Along with regional consistency, the autism strategy must have measurable targets and outcomes to measure effectiveness. That speaks for itself. Ultimately, any truly effective strategy must be measurable in order to assess success and the improvements and changes that need to be made to achieve overall aims. The strategy should be a basis for ongoing transparency and accountability, and it will be an essential tool for the autism reviewer. Along with a general duty to consult, which is introduced by clause 1, clause 3 includes a specific obligation to consult organisations when setting measurable targets. The autism strategy, therefore, must be developed in consultation with the autistic community. That, again, is self-evident. Nobody knows the needs of the autism community better than our autistic people and their families or the voluntary and community sectors that represent them.

Clause 4, "Annual autism funding reports", would create a new requirement of the Minister to lay before the Assembly a report from all the Departments setting out how funding for autism has taken account of the NI autism strategy, the needs of autistic individuals, the current prevalence rates and the potential for partnerships with autism rights bodies. That amendment to the 2011 Act would address the failure by all Departments to bid for investment to progress the NI autism strategy. It would also evidence the matching of data against investment and ask, for example, whether the rising prevalence of autism is being matched with rising investment.

The final clause I want to highlight is clause 5, "Autism reviewer", which would create a requirement to set up an independent scrutiny mechanism that would be known as an "autism reviewer". That person would have duties including monitoring the effectiveness of the NI strategy and to advise the Assembly. That person would also:

- "(b) assess the efficacy of the funding arrangements in respect of autism,*
- (c) review the adequacy and effectiveness of the law and practice relating to autism,*
- (d) review the adequacy and effectiveness of services provided for persons with autism, their families and carers,*
- (e) commission independent research"*

and issue a report annually to the Department that must then be laid before the Assembly. I have proposed the appointment of an autism reviewer with a budget allocation similar to that of the mental health champion but with duties that protect the independence of the post from departmental influence or interference. A budget for research is an essential component in order to guarantee service and cost-effectiveness. Those measures and the accountability that will be generated from the requirement placed on the Department to submit an annual autism funding analysis to the Assembly will address proven concerns about the lack of objective scrutiny, accountability and motivation in the implementation of the autism legislation.

Thank you for listening. Between us, we are happy to take questions at this point.

**The Chairperson (Mr Gildernew):** Thank you. I have a few questions first, and then I will go to members. You finished your presentation by talking about the reviewer, Pam. What process have you in mind for the Department to appoint a reviewer?

**Mrs Cameron:** Kerry, do you want to take that?

**Ms Kerry Boyd (Autism NI):** We thought about it being on the same basis as the mental health champion. Our main issue with any sort of reviewer is that they have to be independent from the Department of Health. They have to be somebody completely independent who is there to review the strategy and ensure that the targets in it, which, again, need to be measurable and quantifiable — they are not at the minute — are met. One of the big issues that Pam mentioned was that the reviewer needs to have responsibility for commissioning research. Pam highlighted throughout her speech the difference between the health trusts in the number of children being diagnosed and the diagnosis waiting times. We need to look into all that, and there needs to be best practice with early intervention. The autism reviewer needs to have that responsibility. We are looking at a model similar to that of the mental health champion. It needs to be cost-effective and independent. The legislation we have had for 10 years should have been implemented properly. Only one out of three action plans was ever completed. We feel that, had there been somebody independently scrutinising and reviewing it, that would not have happened. That is the main issue with it.

**Dr Cassidy:** My understanding is that the autism reviewer will drive the legislation across Departments. The evidence the all-party group has is that none of the Departments has made specific bids for autism in terms of their obligations under the implementation of the Northern Ireland autism strategy. It is about having a driver. It is to be somebody who, as Kerry said, can produce evidence that can be presented. Progress could then be measured rather than having what we have at the moment, which is the subjective opinions and views of each Department.

**Mrs Cameron:** We were conscious during discussions and in the drafting process that we could have gone for an all-singing, all-dancing expensive post, such as a commissioner-type role. We were conscious that we did not want to take away from autism services or place a harsh financial burden on the system, which is, at times, already problematic. The reviewer was the preferred option during our discussions and the drafting process. We think that it could work.

We are really at the beginning of the discussion about the technical appointment process. It is really about why we need to introduce the legislation and talk about its principles and aims. The main aim of all of it is to look back at the really good legislation that we have in the Autism Act, which is 10 years old, look at why it has not worked and then look at what we can do to fix it and make it effective and really great legislation. That is what we aim to do through the Bill.

**The Chairperson (Mr Gildernew):** We are all conscious of the huge burden on families. The postcode lottery has been discussed in the Assembly. People are paying for private assessments.

Thankfully, the Department has agreed to start measuring that as a first step, but there are huge issues.

You mentioned cost, Pam. Has there been an assessment of the overall costs that would be associated with the implementation of the Bill?

**Mrs Cameron:** Research and Information Service (RaISE) is working on that research for us. It is not yet complete. I believe it is waiting for some more detail to come back from the Department of Health. We hoped that we would have it for this session and, indeed, for the debate next week, but we are not sure whether it will be there. The aim is to keep the costs as low as possible while maintaining independence from the Department to ensure that the role can be as effective as possible.

**The Chairperson (Mr Gildernew):** How will the Bill ensure that the outcomes and impact you seek to achieve are measured?

**Ms Boyd:** As Pam said, the strategy is a legal requirement in the Bill. We have an interim strategy at the minute, and there is consultation on a new autism strategy. As the reviewer is part of the new Bill, they will oversee any autism strategy in Northern Ireland to ensure that it has measurable targets attached to it. If we cannot measure what is happening and do not know what is happening, how can we plan for the future?

We are looking at statistics from Autistica, which is a research charity in London. It, as well as the National Autistic Society, basically says that 16% of adults with autism are in part-time employment and 22% are in any type of employment. We use statistics from over the water to help us plan here. We need to know exactly what happens here and how many adults are in employment. We also need to count adults. We only count children in Northern Ireland. We can say that one in 22 children are coming through. To be fair, England does not count children, so they are going on the adult prevalence rate, which is one in 100. We need to be able to plan, and the only way to do that is by counting how many adults are coming through.

Any strategy has to have targets. We cannot just say that we will improve social opportunities for adults. How will we do that? We cannot just say that we will improve employment opportunities. How will we do that? How many adults with autism do you want to see in employment in five years' time? That is the type of thing that I am thinking about. Will we be training front-line staff who are working in employment opportunities or training employers to support an adult with autism in the workplace? I want to see proper, measurable targets set out. That is what the reviewer will do, and it will be in the new Bill as part of the strategy.

**Dr Cassidy:** The Bill sponsor and Kerry have stressed the independence of the reviewer, and the independence and the cross-departmental duties of the reviewer are crucial. Those are the two things that set it apart and that would strengthen the original legislation. As we move forward, those are core elements for making the legislation effective, so that we do not have to come back to it.

**Ms Bradshaw:** Thank you for bringing this forward, Pam. We all get a lot of emails from parents who are frustrated at the lack of services and the delays, so it is timely.

I wonder how this will sit alongside the consultation on the strategy, as Kerry has just outlined. Could some of what is in the Bill be in a strategy as opposed to a legislative format? My second question relates to workforce and how the proposals will impact on a workforce that already has a lot of vacancies. Have you engaged with trade unions and the relevant representative bodies on how those gaps could be filled quickly if the Bill is passed?

**Ms Boyd:** I am sorry, Paula, I am struggling badly to make you out. It is not clear at all.

**The Chairperson (Mr Gildernew):** There is a bit of echo. Please could you repeat that, Paula?

**Ms Boyd:** If you can give us the short version, that would be fine.

**Ms Bradshaw:** I will. This is the short version. First, why can some of the proposals in your Bill not be put forward in a strategy format? Secondly, how will you identify — through assessments, for example — how workforce gaps will be filled in the short term to meet the needs of this legislation?

**Mrs Cameron:** To be brutal, Paula, the workforce element is a problem for the Department of Health. We know that intervention, help, diagnosis and all the good practices relating to autism can help everybody to live fuller, quality lives. I suppose it probably goes back to the fact that we are not counting or gathering evidence of what is required. Until we have that absolute baseline of what is needed in Northern Ireland, it will be difficult to assess what the impact on workforce will be. That is my point.

Do you want to answer that first point, Kerry?

**Ms Boyd:** Yes. Why can the proposals not be put into a new strategy? They can. We will respond to the Department of Health about that. The point is that we had the original strategy, although it did not have targets attached. It has to have measurable targets. Somebody needs to implement it, Paula, as it has not been implemented. The legislation has taken 10 years, and things are still not implemented. Of three action plans, only one has been implemented over 10 years, so somebody needs to take the reins and take control. I see that being an independent person to review the strategy to make sure that Departments work together.

When we see the prevalence rates quadrupling in five years, we need to make sure that Departments bid for funding. Five years ago, we were looking at one in 50 school-age children; we are now looking at one in 22. Has any Department asked for extra funding to support that? No. The referral system for diagnosis was created to deal with 1,500 referrals a year; it is now looking at 4,500. It is not fit for purpose. We need somebody to take control, take the reins and look at the issue as a whole to see what is happening with the autism community and what its needs are. That is the difference. Yes, all the proposals can go into a strategy, but, if nobody takes ownership of it, we are back to square one.

**Ms Bradshaw:** Thank you —.

**Dr Cassidy:** If I could —.

**The Chairperson (Mr Gildernew):** Yes, go ahead. Arlene was coming in there, Paula, sorry. Go ahead, Arlene.

**Dr Cassidy:** I will follow Kerry's point from the secretariat of the all-party group on autism's point of view. The all-party group has written at least twice, I can reliably say, to the Department of Health, asking it to engage with the Bill sponsor and the all-party group on the formation and draft of the strategy. The pro forma was sent to the Department for comment, but none was forthcoming. An invitation was also sent to the Department of Health to attend some of the all-party group meetings. That invitation was taken up, but the COVID situation terminated that. The all-party group on autism has tried to engage on the issue, Paula, so that we could go forward in a joined-up way, but the Department of Health has basically declined.

**Ms Bradshaw:** OK. I appreciate that feedback.

May I go back to the workforce issue? I understand what Pam said, but my question was more about how she and the Bill's supporters in the room have engaged with the representative groups of the relevant allied health professionals (AHPs) about how the workforce could be ramped up to meet the needs that come out of this work.

**Mrs Cameron:** At this stage, Paula, we are looking at the aims and principles of the Bill; we are not at the detail yet. I imagine that there will be a lot more activity on that, should the Bill pass its next stage. It is a good point. I do not think that we had any responses on that from the consultation.

**Ms Boyd:** As Pam said, it was the highest consultation response in Northern Ireland's history. Eighteen hundred people and organisations responded. We do not know whether they commented on the workforce, although I am sure that you will look into that. There are lots of parts to the Bill; there are lots of things that have not been done. That is one of the important ones, so I am sure that you will look into it at the next stage.

**Ms Bradshaw:** That is absolutely fair. It is a genuine question. Thank you very much for your work to date.

**Ms Hunter:** I thank the panel and Pam for being here this morning, and thank you, Pam, for bringing this important Bill forward. In my time as an MLA, I have noted that many individuals who are diagnosed as adults with autism have said that they and their families have struggled to find support, so I thank you for raising that important point.

It is sad to hear of the historical challenges and elements of systemic discrimination that people with autism continue to endure. You discussed basic awareness training for mental health professionals: does that include working with first responders such as paramedics and the police? You touched on the importance of a cross-departmental approach and the role of the Department of Education. In what way do you feel our curriculum could change to ensure that we assist in creating a fairer and more inclusive society for those living with autism?

**Mrs Cameron:** Thank you, Cara. Training for paramedics and the police is exactly the type of thing that we want to see. The provision of training for teachers and mental health professionals is just an example; it is the tip of the iceberg. Autism training, at a basic level, will be good for everyone. That is one of the reasons that we tabled a motion calling for mandatory autism training for teachers and classroom assistants. We recognise that that type of training is good for everyone. It is not about singling out autistic children; it is about teachers changing how they deliver, becoming all-encompassing and recognising that there are autistic individuals in front of them. That is good for everyone. We aspire to see that kind of basic training rolled out to all the organisations that deal with people daily. It is good for everyone to have that awareness.

Sorry, what was your second question, Cara?

**Ms Hunter:** What more can we do, through the Department of Education and the curriculum, to make pupils and students more autism-aware and to contribute to a more inclusive society?

**Mrs Cameron:** That leads back to my answer on the call for mandatory autism training for teachers and classroom assistants, which was supported by all parties in the Assembly. We should aspire to get to that. I know that there have been improvements in that direction, but we can do more across society. I do not think that that is — Kerry may want to mention more about this — seen to be a huge burden on the curriculum by any stretch of the imagination; it is just a matter of catch-up on that training. We want to see it included at teacher training colleges, and we want to see rolling training, as there is on all sorts of topics in that profession. We do not envisage any great burden on the curriculum at all; in fact, if anything, it should make things easier. Do you want to comment on that, Kerry?

**Ms Boyd:** Autism NI led the campaign a couple of years ago for mandatory teacher training. We thought that it would have been implemented by now, but it has not. It is exactly as you say, Cara: it is about helping a teacher to support a child with autism in order to provide that child with the best possible educational opportunities and outcomes. A lot of teachers do not understand autism. A lot do, but there are still some who do not. It is about being able to support a child in the school environment. Such training will bring about a culture change in schools, because, if teachers understand autism better, so will the other children. As a result, a teacher will not say that an autistic child is being badly behaved and put them on a reduced timetable, and the kids will not say, "Oh, that child has been put out of the class again" or "That child was sent home". It is about a full culture change. It is bigger than just teaching staff training. Children are our future, and they are in classes with kids who have autism, so they need to understand it too. That starts with the teachers. That is why it is a bigger issue than just training teachers.

**Ms Hunter:** I completely agree. Thank you.

**Dr Cassidy:** Cara, you mentioned first responders. Pam referred in her presentation to the models of best practice that already exist in Northern Ireland. Those could be tapped into, brought together and utilised, especially if there was an autism reviewer to capture all of that information. It is about partnership. The best outcomes mentioned in the progress reports produced by the autism strategy were those that occurred when the Departments worked hand in glove with the autism advocacy sector. Actually, there was a project with the Department of Justice that was targeted at first responders and setting in information to raise a red flag for individuals with autism in emergency situations. The legacy of that project was the training for trainers. However, unless there is a strategic oversight with someone like the autism reviewer, that sometimes is lost as staff move on, and it is not captured in research, potentially, and developed.

**Mr Buckley:** I thank Pam and, indeed, those presenting for coming to the Committee today on this important topic. How will the Bill make autism services more person-centred? Given the conversation that has just been had about autism training in schools, which is definitely a requirement, can you outline what conversations have been had with universities, particularly our teacher-training universities, that can help to better inform teachers as they progress towards the classroom, given that we are, essentially, tackling the lack of information and training in relation to autism at an early stage?

**Mrs Cameron:** Thank you, Jonathan. I do not know what conversations there have been with universities, but I will let Kerry speak to you about that in a second.

On making this more person-centred, it is integral to understanding autism that no two people with autism are the same. It is important to recognise that each individual is uniquely impacted and that any attempt to provide information or services to autistic people and their loved ones must consider their individual needs. In fact, clause 3, which deals with the methodology of the autism strategy, explicitly states:

*"The autism strategy must take into account that persons with autism, and their families and carers, have individualised needs".*

That is vital. The Bill further outlines how training should be provided to Departments and other public bodies to ensure that staff have an understanding of autism and can adapt their practice to ensure that they work in an autism-friendly and person-centred way. I hope that that answers your question, Jonathan. Kerry might want to speak to the university question.

**Ms Boyd:** I was going to talk about the person-centred aspect and the new provisions in the Bill on the information service that will be available for adults with autism. Autism NI has a helpline, and, in the past number of years, we were getting more and more adults calling, wanting information on supported housing, employment, social opportunities and things like that. That information service will be the link to the person-centred approach where they can find out exactly what a person needs and can support them. Moreover, the autism reviewer's role will be to work with autistic people as well as the various voluntary organisations to ensure that the Department leads on and completes the strategy and the action plans attached to it. It needs to be person-centred throughout. Adults with autism and their families need to have input into the strategy. I know that that is what the Department is doing at the minute. However, our issue is whether it is actually completed or done.

I know that some universities already have initial teacher training. Kelly, can you come in on that?

**Ms Kelly Maxwell (Autism NI):** The all-party group on autism was lucky to have a presentation from the Ulster Teachers' Union on its concerns about teacher training. It said that its members wanted it, parents and carers wanted it and autistic individuals felt that it was needed but there were concerns that there was not consistent training, certainly in the universities. Given the statistic that one child in 22 in Northern Ireland is autistic, every teacher will have an autistic child and perhaps more than one in their classroom. We need to equip them so that they can equip children to reach their potential so that, as autistic adults, they can contribute fully to society. That means that we should have not only enhanced awareness but supports and reasonable adjustments in workplaces.

**The Chairperson (Mr Gildernew):** Thank you.

**Mr Buckley:** I have another two questions.

**The Chairperson (Mr Gildernew):** Briefly, Jonathan, please.

**Mr Buckley:** Obviously, the huge backlogs have driven the public debate on the lack of an autism Bill and the need for the Bill that you are bringing forward. You mentioned statistics surrounding the Southern Trust and its capability of delivering assessments, compared with others. Is there any conclusion as to why there is that disparity? For example, are there things being done well elsewhere that could be applied regionally? Secondly, what are the main deficiencies in the collection of data that the Bill aims to address?

**Mrs Cameron:** As I have mentioned, we had clarification in a letter from the Health Minister that they did not understand why there were those inconsistencies across the trusts. We do not have an answer

to that. I presume that Autism NI has its own theories about why that is the case, but we do not have an official answer.

Data is collected very differently. I have been listening to Kerry and Arlene talk about this for many years. It is apples and pears. We are not comparing like with like, so it is difficult to plan services or to workforce-plan, given that you do not have the information that you need. We need to start from a base. It is important that that is addressed. That is why the legislation aims to ensure that we get the data that we need and know what we need to do with it so that it can inform us on how to support autistic individuals in Northern Ireland.

**The Chairperson (Mr Gildernew):** We will go now to Gerry, and he will be followed by Órlaithí.

**Mr Carroll:** Thanks, panel. I have a couple of questions. I will go through them quickly. What engagement has been happening or do you perceive will happen with Education on the autism strategy? I was looking at some figures: 14% of people with autism in schools have no SEN. I do not know the figure for inadequate support, but I presume that it is high as well. There is also a concern about the use of restraint and seclusion mechanisms in schools. Have those points been considered? What is the expected or hoped-for engagement with the Department of Education?

**Mrs Cameron:** Kerry, do you want to take that?

**Ms Boyd:** Kelly, do you want to speak about the seclusion and restraint? We take over 6,000 phone calls a year. We have 22 support groups throughout Northern Ireland and, every day, we hear about those things that you are talking about. Kelly is the director of family support

**The Chairperson (Mr Gildernew):** Kelly, before you start, will you speak as closely as you can into the microphone? I am conscious that people online might not hear you. We are hearing you fine, but it might be more difficult online.

**Ms Maxwell:** Gerry, you are absolutely correct: 86% of autistic children in Northern Ireland have special educational needs, from stages 1 to 5 on the code of practice. Restraint and seclusion have been brought forward through the Autism NI helpline and through our support groups. As Kerry mentioned, we have over 20 support groups that deliver over 240 support group meetings per year. The themes and issues that come through do not affect just the autistic children; they affect whole families, due to stress and the lack of access to supports. The APGA has engaged with the Department of Education and the Education Committee to raise concerns. I will pass back to Arlene or Pam for progress on the responses that came in.

**Dr Cassidy:** Autism NI has presented to the Education Committee as well as to the Health Committee. The APGA engagement with the Department of Education has been through correspondence, so it has not been excluded, but I do not have any information for you to enlighten you on the topic.

**Ms Boyd:** A letter went out about restraint and seclusion well over a year ago. We highlighted a data policy. What you are asking now highlights the amount of work that goes in. Literally hundreds of letters go out every year from the all-party group through the secretariat that Autism NI provides. We could sit here all day talking about it, and that is why we need it sorted. It is why there needs to be an autism reviewer. We are a charity doing this.

Yes, there has been back and forth over the past number of years. Debates have happened. We have presented to the Education Committee about the issues that you raise. Nothing has really changed, however. Mandatory teacher training has still not been implemented, and it does not look as though it will be. That is why we feel that the only way out of this is to amend the original Act to strengthen it and to ensure that somebody can take the lead. Autism NI does an awful lot of work supporting the all-party group through writing letters and presenting, but we are here to run a charity as well. There is only so much that we can do, and that is why we feel that the only way to do this is through somebody taking the lead. It cannot be the Department of Health, because that has not happened in the past 10 years.

**Dr Cassidy:** My memory has twiggled. The best response is to look at the progress reports that have come from the Department of Health and at what the Departments say that they have done. The official response that we get from the Department of Health and the Department of Education is that

they do not need the legislation, because they are doing everything perfectly fine. I do not wish to take away from the tremendous work being done by the committed professionals who work there. It goes back to the point that it is about the ownership, the leadership and the drive and motivation to implement the legislation, as services are drowning in need.

**Ms Boyd:** May I make a correction there? The all-party group did not send a letter about restraint. If I remember correctly, MLAs who were part of the all-party group took it forward as part of the Education Committee — Chris Lyttle et al — so that is what happened.

**Mr Carroll:** I have a quick final point to make, Chair.

Thank you for your answers. It was either Pam or Arlene who touched on the disparity in autism support and diagnosis services between areas. The postcode lottery is a major problem. The Bill does not have financial significance or strings attached to it, but, presumably, there will be a need for more assessments and more support services. If that is not in the Bill, has there been any other consideration of it?

Should anybody want to comment, the BBC reported that, in the 10 most deprived areas, autism is 37% higher than the Northern average. What services and resources are required, even if the Bill cannot have them all in it? Has there been any consideration of that?

**Mrs Cameron:** Before I hand over to Kerry, I will say that that type of question is what drives the Bill. We do not have the information that we need. Departments cannot plan to meet a need when they do not know what that need is. That is apparent. In the three years in which the Assembly was down, the all-party group met regularly. It had incredibly long meetings and great attendance and participation from all parties. We took the opportunity to question Departments and to drill down into what action they had taken and what information they had. I remember almost every response being like a copy and paste of an initial response. Departments should welcome the addition to the legislation, as it would allow them to focus on gathering the vital data that is required to meet needs.

We all know, as elected representatives, autistic individuals, families and charities that do great work helping people with autism work their way through their life. Until we have that basic level of data, however, we cannot plan, spend and make differences, changes and improvements. We cannot help people to live their life to the fullest if we do not have that basic information. If a teacher were to mark the original Autism Act and commented, "Could do better", that would be going lightly on its performance. We want to see good legislation, compared with what was brought in 10 years ago. We want to see the legislation enacted, working and implemented in full.

**Dr Cassidy:** We would not have the figures on deprivation areas that you quoted had it not been for the original Autism Act. It seems to be the case that we have to spell things out to make them happen. The data was not being collected. At one stage, it was a manual count by clinicians. The Autism Act introduced a responsibility to publish an annual report. To the credit of the people who publish that annual report, they are becoming increasingly analytical about the information. They need the cooperation of the health and social care trusts. There is still great reliance on the school census figures. Cooperation is still needed, and the amendment is partly about strengthening what has already been started, as well as being about, as Pam said, including adults in the data.

**Ms Flynn:** Thanks very much to Pam and the team for briefing us on what is a really important Bill. I am sure that we all have family, friends and constituents who are dealing with these issues and have diagnoses across all the levels of autism.

I will follow on from a couple of Gerry's points. I understand what Pam says: when the needs analysis has not been done, you do not know what the need is, and it is then hard to set targets and to know what specific interventions you need to make. We have the same issues, as you know, around the data that we hold on mental health issues and suicide levels. If there is information available about levels of autism being higher in areas of deprivation, can there be specific recognition in the Bill of the need to deal with health inequalities and deprivation? Can the Bill try to help with there being more targeted interventions in those areas? If in place, that may be a role that the autism reviewer can take on. That is an important point to make.

Gerry asked about the engagement that you have had with other groups. What feedback have you had from some of the grassroots organisations that deal with the issues? I appreciate that the bigger charities do great work, but there are also a lot of community groups on the ground that work closely

with families who struggle daily or have relatives who are dealing with autism. Have you picked up any local knowledge from those groups?

Clause 2 mentions an autism early intervention service. Pam said that there are some best practice models already out there. Are you aware whether the Department has done any work to initiate an early intervention service? Does that factor into the autism strategy anywhere, or has none of those initiatives been lifted by the Department yet?

Finally, I want to ask about the funding reports, which are in clause 4. It was mentioned earlier that progress reports on the autism strategy have been done. Do those reports include any reporting on funding? Perhaps the reason that you are aiming to put into legislation that there should be annual autism funding reports is that you do not have any of that information at the moment.

**Mrs Cameron:** Thank you for your comments, Órlaithí. You have asked lots of relevant questions. We are just at the beginning, however. We need you to vote the Bill through to the next stage of the legislative process next week in order that the Committee can then look at all those issues. When we gather the data, it will become apparent what the issues are. I imagine that autism is an issue for areas of deprivation. The inequalities need to be addressed.

Until we know and have something on paper in front of us to show what the need is, how do we begin to look at it? Most of your questioning was about the grassroots work. That local knowledge is held by the third sector: charities such as Autism NI, which do such great work. Autism NI deals with this daily and hears a variety of queries and concerns and hears about need, so I will pass you over to Kerry.

**Ms Boyd:** You asked about areas of deprivation, and those were highlighted in the most recent Department of Health report. We need to know why the prevalence of autism is 37% higher in areas of deprivation than in other areas of Northern Ireland and why there is a massive difference between rural and urban areas. Research will be so important. We need to know why there are those differences. We need to know why there are three times more diagnoses happening per head in Belfast than in the Southern Trust area. Those are the types of questions that we have asked the Minister of Health, and he has said that he does not know. That is another important reason that an autism reviewer needs to come in, look at the research and find out why that is happening in the various areas.

You mentioned early intervention. Lots of good models of early intervention are out there. Autism NI has a fantastic model of early intervention. Each trust area does it differently, however. Services are commissioned differently in each area, and some areas may get a more comprehensive early intervention service than others, and that is why the parents talk about there being a postcode lottery. Similarly, some families wait for up to two years to get a diagnosis, whereas, in other areas, they wait only for up to 13 weeks. Instead of having those differences, areas need to have a uniform, regional early intervention service that is tailored to each family's needs and comes in straight after diagnosis. People cannot wait up to two years for a diagnosis. I heard this morning that a family in one of the trusts had waited up to four years: we cannot let that happen any longer. Early intervention has to happen straight away after diagnosis. There are best practice models out there. The problem is getting the trusts to work together. Somebody needs to come in to help them join it all up, look at the research, see why certain areas have a higher prevalence than others and decide what needs to be done in them.

You asked about grassroots organisations. Obviously, we are one such organisation. We work on the ground and have 22 support groups throughout Northern Ireland. We have been here for 30 years. We work with the likes of the National Autistic Society and Autism Initiatives. We also work with the smaller groups. Kelly will be able to tell you about some of the groups.

**Ms Maxwell:** We work across voluntary, community and statutory supports. No one organisation can do everything. We provide menus of options that include partners from those organisations. It is clear that a multimodal approach is generating conversations around increased needs for autism families before, during and after diagnosis. Those needs have heightened since the pandemic. We are a member of family support hubs across Northern Ireland. Some of those have written to locality planning groups to raise the issues of the needs of autism families in their area and the need for supports from statutory organisations. Our helpline does that. It is there for autistic individuals, parents, carers and professionals. Professionals ring daily for support for families. That includes our MLAs.

**The Chairperson (Mr Gildernew):** Thank you, Pam, for introducing the Bill and for taking questions from the members. Thank you, Kerry, Arlene and Kelly, for appearing before the Committee and for your assistance in our consideration of the matter. I wish you all the best in the time ahead, and we look forward to working our way through the formal Committee scrutiny of the Bill.

**Mrs Cameron:** Thank you, Chair.