



Northern Ireland
Assembly

Committee for Education

OFFICIAL REPORT (Hansard)

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

29 September 2021

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Mr Pat Sheehan (Deputy Chairperson)
Ms Nicola Brogan
Mr Robbie Butler
Mrs Diane Dodds
Mr Harry Harvey
Mr Daniel McCrossan
Mr Justin McNulty
Mr Robin Newton
Mrs Pam Cameron

Witnesses:

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

The Deputy Chairperson (Mr Sheehan): I welcome our guests today. With us are our good friend Pam Cameron MLA, who is the Bill sponsor; Ms Kerry Boyd, chief executive officer, Autism NI; Dr Arlene Cassidy, Autism NI; and Kelly Maxwell, Autism NI. There will be 10 minutes for your presentation, and then the Committee will ask questions. I presume you are kicking off, Pam?

Mrs Pam Cameron (Northern Ireland Assembly): Thank you, Chair. Dr Cassidy will present for a few minutes, and I will proceed with the rest. It might take a little longer than 10 minutes to outline the clauses, if that is OK?

The Deputy Chairperson (Mr Sheehan): No bother. OK. The floor is yours, Arlene.

Dr Arlene Cassidy (Autism NI): Thank you, Chair, members and Clerk for the opportunity. My name is Arlene Cassidy. 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 1992, I was employed to develop Northern Ireland's first autism charity, Parents and Professionals and Autism (PAPA), and that was later renamed Autism NI. I retired as CEO in 2017, and I am currently acting as an adviser to Autism NI and supporting its role as the secretariat to the all-party group on autism.

Today, my role is to remind us all why we must resort to the Northern Ireland Assembly and legislative solutions. Why are we here again for autism? Let me set some context. In short, we were late to discover autism in Northern Ireland and never really caught up. Until 1990, autism apparently did not

exist here. There was no diagnosis and support until PAPA, later Autism NI, was set up. However, autism services in England began in 1962, in 1965 in America and 1963 in Ireland. In the early 1990s, parents travelled to England for autism assessments. In Northern Ireland, autism was wrongly classified as a learning disability. The first funding for statutory autism services was in 2002, and that was for diagnosis only. By then, Autism NI had lobbied every board and trust, and autism strategies had been agreed, but then they were dropped as committed individuals moved on to other duties.

The impact is still evident today. Even by 2002, it was already too little too late as waiting lists for assessment and diagnosis averaged between two and four years, with autism data only available by a manual count. International research revealed that the cost of neglect to society, in human and monetary terms, is greater than that of actually doing something. The conclusions drawn from that dynamic crisis were that, first, there was a systemic reluctance and failure across government institutions to recognise, understand, resource and plan for autism services, and, secondly, that the Northern Ireland Assembly needed to make legislative changes and have an all-party group on autism (APGA).

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

The result of all 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, with no professional lobbyists. It 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. It amended the Disability Discrimination Act 1995 (DDA) to recognise autism. It mandated an ambitious, recurrent seven-year cross-departmental national strategy for autism. That law held so much promise. Job done? Unfortunately not.

The APGA has gathered clear and shameful evidence that those charged a decade ago with the implementation of the Autism Act 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 increases annually. According to Department of Health data, Northern Ireland has the highest prevalence rates of autism in the world and 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, so why are we here and what must we do? We have to address failures in the implementation of the legislation by setting down specific remedies. We have to address 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 in 2021. Thank you.

Mrs Pam Cameron (Northern Ireland Assembly): Thank you, Arlene. Chair, if it is OK, I will go ahead with my presentation.

The Deputy Chairperson (Mr Sheehan): Yes, Pam. Go ahead.

Mrs Cameron: Thank you for the time at the Education Committee this morning; it is very important. As many of you know, 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. Along with colleagues in the group, I 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 APGA 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 the fact 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 to initiate an independent study to explore the different rates of diagnosis across the five health and social care trusts has not been implemented. An Assembly question submitted by APGA members 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 Trust, yet the Southern Trust apparently takes 13 weeks?

No Department has submitted any 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 for an autism awareness campaign has been replaced by an optional in-house intranet exercise and coffee mornings instead of the implementation of initiatives recommended by the NI autism strategy's own 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. The high response rate is a huge indicator of the level of concern. Some 92% of respondents supported the idea of 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 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 any service they can find 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 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 area you live in.

All those critical issues indicate that the Autism Act (NI) 2011 must be strengthened. The Autism (Amendment) Bill will 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, and this should be in the form of an autism reviewer.

I will now outline the reasons behind the clauses of the Bill, with your blessing, Chair. Clause 1, "Autism strategy: consultations and data", seeks to ensure that autism prevalence data is expanded to include prevalence data on adults as well as 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 this time, 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 easy to analyse comparatively. At the minute we are comparing apples and pears, as Northern Ireland's prevalence rates are based on children, whereas England's are based on adults.

Clause 2 is "Additional components of autism strategy". This 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 teaching staff in Northern Ireland as well as for mental health professionals working with autistic people. The next point 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 on a regional basis.

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. It 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. Combined with clause 3, that will 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, as many adults feel misunderstood, alone and unsupported. That is evidenced by the stark fact that an autistic adult is nine 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 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, as well as the voluntary and community sectors that represent them.

Clause 4, "Annual autism funding reports", creates a new requirement on 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. This provision will address the previous failure by all Departments to bid for investment to progress the NI autism strategy. It will also evidence the matching of data against investment: for example, whether rising prevalence of autism is being matched with rising investment.

The final clause I want to highlight is clause 5, "Autism reviewer", which creates a requirement to set up an independent scrutiny mechanism which will be known as the autism reviewer and have the following duties:

" (a) to monitor the ... effectiveness of the autism strategy"

and to advise the Assembly,

" (b) to assess the efficacy of the funding arrangements in respect of autism,

(c) to ... review the adequacy and effectiveness of the law and practice relating to autism,

(d) to ... review the adequacy and effectiveness of services provided for persons with autism, their families ...

(e) to commission independent research"

and to 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 research budget is an essential component 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 over the lack of objective scrutiny, accountability and motivation in the implementation of autism legislation.

I know that that was a bit lengthy, but thank you for listening, Chair. We are very happy to take questions.

The Deputy Chairperson (Mr Sheehan): No bother, Pam. That was a very comprehensive briefing for the Committee. I am going to kick off with a couple of questions. One of the frustrations that are often expressed is about the lack of cooperation between Education and Health in the provision of autism services. How do you see this Bill enhancing cooperation between those two Departments?

Mrs Cameron: Arlene might want to come in on this one. The autism review will be essential in making sure that the original Autism Act is actually implemented. What we are really looking at is a 10-year-old very good piece of legislation that has not come to fruition in the way that it should have. This additional private Member's Bill will bolster that legislation and make it work. The autism review will have a very important role in ensuring that this does happen across Departments. There will be an onus on the Departments to lay reports to the Assembly as well. Arlene might want to come in on that point.

Dr Cassidy: Thanks, Pam. I will reinforce what Pam has said. The autism reviewer is crucial in this. In the past, the Department of Health has appointed coordinators. Those coordinators, funded by the Department of Health, have had no authority to implement cross-departmental advice, motivation and reviews, although there has been an implementation panel with representatives from each Department. The autism reviewer will be crucial in making sure that the promise set out in the original Act comes to be. Those are my only comments, unless somebody else has anything to add.

The Deputy Chairperson (Mr Sheehan): Arlene, what is the process for the appointment of the reviewer?

Dr Cassidy: The process has yet to be decided. During Second Reading in the Chamber, some Members picked up on the crucial point that autism is the responsibility of all Departments and that, therefore, there should be cross-departmental Executive funding. That is the route for the money trail. A number of ideas have been floated about the placement of the autism reviewer in the system. However, that discussion is ongoing. We look forward to having those ongoing discussions. I am aware of the ministerial appointment system, and I find it to be a very vulnerable system, because the Minister appoints and can discharge. I was involved in the original legislation, and I just feel that there needs to be strong protection around the independence of the autism reviewer if they are to be effective. That is one of the reasons why Pam has stressed the research budget. We need to find objective answers to the questions that are puzzling us, instead of going round and round in circles, as we have been, with regard to the postcode lottery that Pam referred to and the inconsistencies between trusts. Everybody knows that there are questions, but nobody seems to be charged with finding the answers. Again, we are back to the reviewer, who will have a cross-departmental role.

The Deputy Chairperson (Mr Sheehan): Thanks for that, Arlene. I will move on to another issue: the mandatory training of school staff. The Bill extends that beyond schools, but I want to focus on mandatory training for teachers and school staff. I make it clear that it is not only teachers who need to

be trained. The Committee has heard harrowing evidence in recent times with regard to the issue of control and restraint, particularly of autistic children. You will be aware, Pam, of stimming — children making repetitive movements and so on when they come under stress — and, in some cases, actually being physically restrained by teachers, which in my view is unacceptable. You know that the Assembly passed a motion last year in support of mandatory training. Initially, the then Education Minister agreed with it, but he later changed his mind. Do you have any insight into the current Education Minister's view on that issue?

Mrs Cameron: That is a really important point. I am pretty sure that my name was on that motion for the mandatory autism training for all teachers and classroom assistants. We know that there has been progress with increased training, but we all still want to see it made mandatory. My understanding is that the issues with that were around the resource required to free up teachers' time and teacher cover for the training to be rolled out, but it still needs to be done. It is of the utmost importance. I have not had an opportunity to speak to the current Education Minister about it, but I imagine that, as an all-party group, we will write directly to the Minister to seek more clarity on the roll-out of that training, because it is vital.

You rightly mentioned seclusion and restraint. We know that early intervention works; the right level of training for autism could prevent some of those scenarios from arising. We want to see that training rolled out in the near future. The mandatory basis for it is still required. I do not know whether Kerry or Kelly wants to come in on that point.

Ms Kerry Boyd (Autism NI): The all-party group, Autism NI and the Education Committee wrote to Peter Weir to ask why the mandatory teacher training was not rolled out as we thought it would be. The debate was in January 2020, and there was unanimous agreement that we should look into introducing this. Minister Weir replied that he had introduced more training, so there is more autism training than there was before. However, it is all online and not interactive, and obviously it is not mandatory. It is in the teaching staff's own time that they can access it. It is great that there is more training and that it is more accessible than it has ever been. It is still not mandatory, however, and, with one in 22 school-age children in any classroom in Northern Ireland, we need to ensure that teaching staff understand those children's autism and are able to support them and that those kids are given the same opportunities as any other children. I keep saying this over and over again: it is where the child spends the majority of their day, so the person looking after and supporting them needs to understand them. Therefore it still needs to be mandatory. As a charity, and I am sure that the all-party group agrees, we cannot stop until this is made mandatory. The PMB will definitely strengthen the chances of mandatory autism training being brought in.

The Deputy Chairperson (Mr Sheehan): Thanks for that, Kerry. Has there been any discussion with the trades unions on mandatory training?

Ms Boyd: Yes, there have been discussions over the past couple of years, although not recently. When we campaigned for the introduction of mandatory teacher training at Stormont, representatives of the Ulster Teachers' Union spoke at the event. At that time, we were told that most of the trades unions supported mandatory training. In subsequent discussions, however, some of them said that they did not support it. I do not really understand why, because our helpline takes over 6,000 calls a year, and many teachers come to training on a Saturday morning and pay for it themselves. Obviously, they do it virtually now, but they did it to be able to understand the children in their classrooms.

The helpline takes so many calls from teachers who want extra support and help, and any teacher whom I have spoken to wants the training, so I really do not understand where the trade unions are coming from. I think that it is about taking on extra training in general and not autism training in particular, but I do not know any teacher who does not want to do the training. Kelly, who runs the helpline at Autism NI, will be able to talk to you about the number of teachers who call through.

Ms Kelly Maxwell (Autism NI): The helpline, as Kerry said, receives over 6,000 calls a year from autistic individuals, parents, carers and teachers. In that regard, *[Inaudible owing to poor sound quality]* restraint and seclusion should be avoided at all cost and *[Inaudible owing to poor sound quality]* will equip people with strategies and skills earlier, which, hopefully, will prevent things from going wrong. Our teachers tell us that they need that time and resource invested by DE and the Education Authority (EA). They also say that they want to see a culture change; we cannot continue *[Inaudible owing to poor sound quality]* the same thing without making improvements; otherwise we will just be spending money inefficiently. If we are committed *[Inaudible owing to poor sound quality]*

and want to invest in their *[Inaudible owing to poor sound quality]* them to reach the full educational potential that increases outcomes and turns the curve across their lifespan, we have to invest in training and make it mandatory.

The Deputy Chairperson (Mr Sheehan): Thanks for that, Kelly. Before I open the floor to members, I will probably have to be more strict in this session, as we have fallen behind time a bit.

Mrs Dodds: I thank everyone for their contributions to the Bill, which is a hugely important piece of work. When I talk to teachers, they say that dealing with children who are on the autism spectrum and getting the appropriate help for them is one of the most difficult issues that they face. We are looking at some of the mandatory training that teachers would have, but I find that one of the issues is dealing with the Education Authority. How would the Bill impact on awareness training for those in the Education Authority and the wider — I do not want to say ancillary, but I do not know what other word to use for it — group of people who support those who are in primary roles to look after and educate young people with autism?

I am sure that this is reflected across the political spectrum, but a huge number of parents contact me about a lack of facilities and a lack of access to mainstream education for their children. There are also transport issues, with a particular issue in Upper Bann over the past year. Sometimes, from talking to people, I am made aware that what children can or cannot do and what is safe for them to do is entirely lacking. I will be specific: is it safe to expect parents to organise their own transport for children who are autistic but for whom the Education Authority refused to organise transport? Those are the kinds of practical issues that come in to a constituency office. I would like the Bill to have an impact that is as wide as possible in explaining and training.

Mrs Cameron: Thank you, Diane. That is a really useful contribution. You have highlighted the necessity of the Bill. We need training provision for all Departments and public bodies. It is not about training people to deal with individuals with autism; it is about training everybody to treat everybody in a different way that is inclusive of people with autism. That is a really important point that you make. We are looking forward to seeing what the calls for evidence from the Health Committee produce and what added value or suggested amendments there will be to the Bill. We have dates in the diary for October with the Health Committee to hear from other interested individuals about the Bill to see what comes from that.

It is vital that training be rolled out across all Departments. That is the point. The original Autism Act has not been implemented. That has been the problem. There have been no bids from any of the Departments for new funding for autism in the 10 years since the Act was introduced. That is where it seems to have fallen down; it has not been implemented or acted on. That is what we want to see happen.

I do not know whether Kerry or Arlene want to come in on the back of that.

Dr Cassidy: The Bill refers to the need for a Northern Ireland autism training strategy. That is about addressing duplication, about making economic and efficient choices, and about assessing the need across Departments for training and the tiered system of delivery that Pam referred to earlier.

Mr McCrossan: Pam, thank you for that detailed presentation, and thanks to Arlene and Kelly as well. This is an important piece of legislation that I am wholly in support of. I am looking forward to helping to shape it so that we fill all the potential gaps and ensure that we meet the needs and interests of those with autism in Northern Ireland. Some of the details that you shared are extremely interesting. A lot of people are engaging and are interested in the legislation, Pam, so well done on taking it further.

The Bill makes provision for mandatory autism training for teachers and classroom assistants. A significant number of people fully support that, and for good reason, but some sincere people are fearful that, as a result of the concentration on autism, other special educational needs may be inadvertently neglected through a lack of response or resource for teachers. What would you say to that, and can you allay their fears?

Mrs Cameron: Thank you, Daniel, for your kind words.

The original Autism Act has not been acted upon. It is not that we are introducing something completely different. That inaction is not right and needs to be addressed.

This is about strengthening the original Act; it is not about discriminating or competing with other conditions. This is about making legislation that is already there in law work, making it act, and making lives better for everyone. There is no competition here. This is about enacting legislation that is already in place, and that is right and proper.

I do not want to get too distracted by, "What about this, and what about that?". This is about making improvements and lives better for all of us who live with autism.

Mr McCrossan: The requirement for mandatory training will initially involve some 18,000 teachers [*Inaudible owing to poor sound quality*] substitute teachers plus classroom assistants. Do you see other school staff receiving training? For example, should building supervisors and school secretaries be trained? Do you have any idea how much it will cost initially or have you discussed with the Minister or the Department where the necessary resources will come from?

Mrs Cameron: We have not had recent conversations with the Education Minister, but the previous Education Minister's departmental officials expressed concerns about the cost of the mandatory roll-out. That, I believe, is why we have not got to that point yet.

There should be a commitment by all Executive parties to recognise that this is not an issue simply for Education; it is cross-departmental. The Autism Act was cross-departmental, and the full burden of costs for this should not be placed on one Department. We all know that early intervention works; we know that training will help. Intervention should actually save money by improving lives and skilling individuals to live a full, fulfilled, happy, productive life.

Mr McCrossan: How long will it take to roll out the training?

Mrs Cameron: Kerry, do you want to come in on that one?

Ms Boyd: While you were talking, I was looking up old proposals. When Peter Weir was Minister of Education, we had meetings with him. We had already gone through costings, and they were minimal. The biggest issue is enabling staff to take time off. We suggested that they could use one of their Baker days but were told it was up to each school to choose what they used their Baker days for, with issues to be trained up on. Our response was, "But could you not influence them into using one of them for autism?", and we were told no.

The main issue is getting the time to train staff, not the actual cost of training, so to speak. What we proposed, as Autism NI, is that we are a training provider ourselves, and I know you have Middletown sitting there waiting to go, which should be doing it. There are approximately 1,200 schools in Northern Ireland, and we think you could do it in three years with three fulltime staff. It would then be on a rolling basis, where they would have to be refreshed every three years.

Middletown and ourselves could draw up a job proposal tomorrow. It is more about getting the commitment from the Minister plus making sure that schools will do it on their own time, with one of the Baker days.

We have been through this a million times, Daniel, with the same questions asked over and over again. It is not a big cost; it is more about the time off that the teachers need to do it.

Mr McCrossan: In relation to the time off —.

The Deputy Chairperson (Mr Sheehan): Daniel, can you finish off quickly, please?

Mr McCrossan: No problem, Chair. I know that the time off is important, but that could be resolved quite easily. However, have we the capacity and expertise to provide the training?

Ms Boyd: Yes. Middletown could do it. Autism NI could do it tomorrow. We just need the go-ahead and the funding. Funding is the least of your worries because the costs are minimal. The costs are for trainers to do it. The issue is time off, Daniel. At least, that is what we have been told over the past two years.

Mr McCrossan: Very briefly, could the training be accredited?

Ms Boyd: Yes, it could be. Definitely. As Arlene said, there could be different levels of training for teachers, dinner ladies, the receptionist or whoever else is helping around the school.

Mr McCrossan: Thank you.

Mr Newton: First, I apologise to Pam and the witnesses for my unstable network connection, which does not allow me to see you. For you, that is an advantage. I thank Pam for the very detailed outline of her Bill. I know how passionate she and the other witnesses are. I welcome the Bill. I do not really want to ask any questions. I am an enthusiastic supporter of work experience for our young people, and, apart from during the pandemic, I have pupils in my office or working with me every year. I have been particularly keen to offer opportunities to boys with autism. I have seen the problems that they have endured, and I have seen the talents of some of the young people.

By coincidence, one has just left my office. He was fortunate in that he got good school support. He has come to me on two occasions for work experience. We have kept in contact. Indeed, he was in the office to tell me that he has got a good job in Scotland and that he heads off to start next week. I know about the breadth of autism, but we sometimes neglect the potential that young people who have autism have to make a full, positive contribution to society. I am enthusiastic about addressing the matter, and I really do hope that the Bill is successful and, indeed, makes a contribution to the quality of life not only for those who have autism but to everyone in the family who surrounds them.

Mrs Cameron: I thank Robin for his very kind comments. I think that that really sums up the intention of this private Member's Bill because it is right and proper that we value every member of society. Many of us have autism or live with autism, and autism is part of us. That is not necessarily a negative thing. We need to embrace that as a fact and ensure that there is provision and help so that we can all live out our lives in fullness. It is right and proper that we do that, and that we make this good piece of legislation from 10 years ago, better and make it work.

The Deputy Chairperson (Mr Sheehan): Thanks for that, Pam. I invite Robbie Butler to ask a question. Robbie, will you keep it to five minutes, if possible?

Mr Butler: I will. I have been a participant on the APG since 2016 but, sadly, have not been able to attend many meetings in the past 12 months or so. Congratulations to Kelly, Kerry, Arlene and Pam. I also have to mention Eileen. She is no longer part of the APG, but she was a stalwart, and she journeyed with us.

Pam, congratulations as the chair of the APG. You have worked with a very energised and good APG. It was good to see the Bill in the Chamber recently and to talk about it. I will keep my comments brief, Chair. I do not know whether it was Arlene or Pam who talked about the regionally inconsistent approach to autism. I see that with ADHD as well. This is the Education Committee. Is there any take on a regionally consistent approach in the education sector, geographically or by sector? Has there been a look at that, or are we generally content that it might not be brilliant, but that it is even and everybody has the same approach?

Mrs Cameron: I will let Kerry or Kelly come in on that.

Ms Boyd: Kelly, do you want to answer that? Obviously, the parents come through to the helplines. What is your take on that? Is it pretty much the same throughout Northern Ireland?

Ms Maxwell: *[Inaudible]* take over 6,000 calls on the helpline. Autistic individuals and their families have described the education system as a battle. That is the reason why mandatory training for all teaching staff is required. We know that. Significant numbers of autistic children and parents have to go to a tribunal in order to access supports and their right to education. Each family's experience is different. Whilst there may be a regional framework, the distress and impact on whole family units is different.

Ms Boyd: I agree, Robbie. We are basically hearing the same things throughout Northern Ireland. A lot of children are on reduced timetables, which I do not think is recorded. Autism NI did a quick survey in 2015. It involved only 120 parents, but two thirds of them said that their kids were on reduced timetables. That is going on. We also know about social opportunities. We hear about kids not being allowed to go on school trips, for instance. It does not matter where they are based; it is the same throughout. Teacher training and understanding would improve that.

Mr Butler: I agree. I want to ask about the availability of statementing. The EA has been going through significant change over the past two or three months. I feel that it has made great progress and has caught up quite a bit on the statementing backlog and other issues. Do you agree? Where do you see that? When people are waiting for lengthy periods for a statement, it puts increased pressure on the home and the child. Do you agree that we are in a better place today?

Ms Boyd: Kelly will agree that the statements are being done within the time period. How long can they hold out on that? They seem to be under a lot of pressure to get them done within the time. Kelly, do you have anything to add?

Ms Maxwell: You asked whether we are in a better place. I would struggle to say yes, because we have had COVID-19, and autistic individuals and their families have been disproportionately affected by that. We do not have mandatory training in place, and if we really want a whole-school approach to change that enables autistic individuals to reach their full potential, we require mandatory training to provide the skills and strategies that they need to access education.

Mr Butler: OK. Thank you for that. Can I, as the chair of the all-party group on ADHD, ask a cheeky question? It is about training. We have been round the issue; we had a chat on it previously, guys. Obviously, ADHD is also very prevalent for a lot of young people. Has there been any scope to include elements of other conditions in the mandatory training and teacher awareness, such as ADHD?

Ms Boyd: Do you mean to bring it in with the autism training, Robbie?

Mr Butler: As you and I understand, people often think they are the same thing, when they are absolutely not.

Ms Boyd: No, they are not.

Mr Butler: They are two separate entities. However, there are young people who have comorbidities, if you like, and have both conditions and so on, so expertise is required to identify the prevalent issue that needs to be addressed. Finding that individualised plan is quite complex sometimes. If we are looking at a pupil-centred approach —

Dr Cassidy: I will revert to a comment Pam made. The Bill is about strengthening the original legislation and ensuring that it is implemented. Forgive me for having tunnel vision on autism, but, having said that, my experience tells me that, as time moves on, a lot of the strategies that have been included in the training for teachers who work with children and young people with autism are generically applicable. Therefore, there will be a generic benefit to a range of children who have anxiety issues etc. Although I say I have tunnel vision, I have to revert to the fact that the Autism (Amendment) Bill is about strengthening legislation that is already in place, and that is where our focus has been. However, yes, humanly speaking —

Mr Butler: You do yourself a disservice in saying that you have tunnel vision. You are passionate about making a difference. However, I understand what you say, Arlene. Obviously, we will tease that out a bit more as the Bill progresses.

I have a final question, Pat; I know you gave me only five minutes. I want to ask about the longitudinal piece, and we had Pivotal on before looking at pathways into employment. Some of the studies show that autistic adults probably make up only 16% of the working population. What will the Bill achieve, through that longitudinal piece, for autistic people through education and into the lifelong workspace?

Ms Boyd: Do you want to take that one?

Mrs Cameron: What can —

Ms Boyd: Who is going to answer this? Basically, Robbie, employment is specifically in the Autism (Amendment) Bill — the PMB. Our big passion is, obviously, to see as many autistic adults as possible go into employment. That 16% is less than half the number— it is nearly a third — of the disability sector that is in employment. It is completely baffling to us why, in 2021, we have so few autistic adults in any type of employment.

One of the areas in the PMB is about employment. We want to see more employers trained up in autism understanding and being able to employ more people with autism. In the current autism strategy, there are areas that relate to that, but they are not quantifiable. That is one of the big issues with the current autism strategy and why we need this amending Bill to come in. A strategy needs to be quantitative and qualitative and to be on an outcomes-based accountability (OBA) model. We need to see change happen, and one of the areas would be to see more adults with autism in employment. We want to see a quantifiable number of such people as well. It would be about working with employers, obviously, to employ more adults with autism. The Bill covers lifelong autism. We know that autism does not stop at the age of 18, and we do not want to see adults with autism sitting in their bedrooms with their parents, worrying about their mental health. We know that an adult with autism is nine times more likely to complete suicide than a neurotypical person.

We know all that, and we know the reason for it. It is because they are probably not getting up every day to go to work and they do not have anything to focus on. That is in the PMB as well. It is about all the Departments working together to give that lifelong support.

Mr Butler: That is really good. I really appreciate that answer, Kerry. Thank you, guys.

Ms Brogan: Thanks for your attendance this afternoon, everyone. Pam, you know that I am widely supportive of the Bill. I spoke in the debate at Second Stage. It is a great Bill. There are some things in it that I could at least ask you about, but I really appreciate that you put the effort in to bringing it before the Assembly. There are two points I want to make. The first is about early intervention, and the second is about the regional information service. Those are two key aspects of the Bill.

Early assessment, early diagnosis and early intervention are key for young children with autism, their families and their carers. That is a massive issue at the minute. As well as that, the delay in assessment and the disparity between trusts is really frustrating, because of the fact that you get a different level of service depending just on where you live. I am glad that is being focused on. That relates to the information service that is available. As I said in the Chamber, it is a complete minefield for, in particular, the parents of young children with autism who want to know where to turn to, what services are available and what the first steps are. It is a complete maze, so any additional assistance would be really helpful for those parents, people with autism and professionals.

I want to move on to the role of the reviewer. In your opinion, will a sole reviewer be sufficient? Have you considered the use of a review panel instead?

Mrs Cameron: Thanks, Nicola. Thank you for your comments, for your support of the Bill and for speaking at its second reading. That was much appreciated. Of course, absolute thanks has to go to the entirety of the all-party group, which has been passionate about this, with the incredible support of people like Dr Cassidy and Kerry and Kelly from Autism NI. We have managed to keep the subject alive for an incredible amount of time. It is a very successful APG, and the Bill has come off the back of its work. It is a wonderful piece of cross-party work that benefits everyone in Northern Ireland. I just want to put that on record.

The simple answer to your question about the reviewer model versus a review panel is that I do not know yet. We are about to commence taking evidence at the Health Committee, of which I am Deputy Chair. It will be interesting to see what comes out of that, what contributions others make on the private Member's Bill, what other amendments come forward and what suggestions are made. We are open to looking at all the options. We basically want to make the original Act work in its entirety. The aim of the private Member's Bill is to make the original Act work well. We were very conscious that we did not want to add financial burden to an already very difficult sell on health provision. We were conscious that we did not put in for an all-singing, all-dancing commissioner that would have been an expensive model. We tried to look at something that does the job practically. That is how we ended up with the recommendation of looking at a reviewer role within the implementation of the Autism Act.

It is all up for grabs at this point. There are more conversations to be had. We have just passed the second reading, and we are now into the process of looking at more of the detail. We are all looking forward to seeing what comes out of that, what suggestions there are and what the Departments have to say.

Ms Brogan: Thanks for that, Pam. That is fair enough. I know you want to keep the costs as low as possible, but I am glad you are open to the idea of a review panel, because I think it is a good

suggestion and could work well. As a follow-up to that, what enforcement powers do you see the reviewer or a review panel having, if those powers are made available?

Mrs Cameron: I am not sure about the enforcement powers or whether —.

Ms Boyd: The enforcement powers would be the legislation itself.

Mrs Cameron: Yes.

Ms Boyd: Nicola, you are talking about a panel. For the past 10 years, we have had a panel of different people taking charge of the strategy. We probably need one person working with a team to implement the strategy and to get it done. We have waited too long. We cannot wait any longer. We have been waiting for 10 years for something to be done. Only one out of three action plans has been completed. I will repeat what I said to the Health Committee: I have listened to thousands of families throughout Northern Ireland for the past 12 years, and, personally, I feel that somebody needs to take the reins and to be solely responsible, like the mental health champion and the different commissioners. It is not a commissioner job. It needs somebody to solely ensure that the strategy gets done. It needs to be one person, and the enforcement will come from them ensuring that the legislation is implemented. Arlene, you probably have a better *[Inaudible owing to poor sound quality]* than I do about all that.

Dr Cassidy: There has been a panel. We are running out of options for alternative ideas. Three implementation structures were set out in the original strategy: a research committee; a senior officers committee; and, in the middle, a multidisciplinary panel. Initially, the multidisciplinary panel included representatives from each Department who were responsible for taking the strategy forward in their own Department, as well as people with autism and representatives from autism organisations. The panel was reconstituted without some of the stakeholders from autism organisations. There was maybe one person with autism or a parent. There has been a panel structure. I know there are panels and then there are panels. It is all about duties and obligations. I will go back to what Pam said: it is there for discussion as the Bill evolves and as other people put their heads together with Pam.

Ms Brogan: Thanks, Arlene. Going back to your point, Kerry, I am sure we are all in agreement that we want changes to be made. We are all singing from the same hymn sheet. We know that people with autism, their families and carers need support. We all want to see that, but it is about finding the right way. That is why we are having these discussions. We need to take everyone's opinions on board.

Robbie touched on the other point I wanted to raise about helping people with autism as part of the strategy for 14- to 19-year olds, encouraging them into the workforce and looking at supports for them. That is an important avenue to discuss, but I know we are short on time, so I will leave it there. Thank you all for attending and for all the information.

Mr McNulty: Hi, Kerry, Arlene and Kelly. Arlene, how did you describe the Act that was brought forward by my predecessor and Bessbrook man, Dominic Bradley?

Dr Cassidy: It was landmark legislation. It is the most comprehensive, lifelong, cross-departmental single-disability equality legislation in Europe and in the world. The Autism Act 2009 was enacted in England, but it impacts only adults, whereas our legislation is lifelong. There are other pieces of legislation across the world, but the Autism Act (Northern Ireland) 2011, which Dominic drafted and which Autism NI worked alongside him to lobby and campaign for, was so comprehensive. That made it unique. That is why hopes were high and were disappointed. We are where we are.

Mr McNulty: OK. I am proud of my predecessor, Dominic Bradley's, work on that. At the same time, I am disappointed that the 2011 Act has not delivered on its full potential, let us say.

Dr Cassidy: I will just add that, in the presentation that Pam and I made earlier, not to take away from the 2011 Act, we noted that things changed because of Dominic's efforts. There was no counting, no data, no government-owned data. That legislation brought those in. It also changed DDA so that autism was recognised. Suddenly, it had a seat at the disability table, and some things started to change in terms of reasonable adjustments for people with autism.

Change did happen, but the thing that did not happen was the strategy that was in that legislation because it was handed over to a lead Department to have responsibility for it. Whether that Department underestimated the fact that it was in charge of a cross-departmental strategy and, therefore, a lot of effort needed to be made in order to work that way, I do not know. We are where we are with the strategy being the part of that legislation that was not implemented. I agree with you, but it is not all doom and gloom.

Mr McNulty: OK, that is excellent. That is why the new legislation is so important and why we should be grateful to Pamela for bringing it forward. Pam — I am calling you Pamela, I apologise.

I want to give Pam forewarning that I have spoken to the Bill Office about tabling an amendment that will involve the inclusion of a note to ensure that there are opportunities for participation in organised sport for children and young people as well as adults. I have recently witnessed the impact that that has, and I mentioned it in the House during the debate on the Bill's Second Stage. I have seen how positively it impacts children and young people, and I believe that the strategy should contain that provision. I hope my amendment will get cross-party support. It is about not just adults' but children's needs. Well done on bringing the Bill forward, and well done to Kerry, Kelly and Arlene for the support you have provided.

I recently asked the Health Minister a question about the number of individuals who have received a diagnosis in Northern Ireland. There are very stark figures for children. Between 1 April 2014 and 30 June 2021, 14,059 children received a diagnosis of autism, and between 1 April 2017 and 30 June 2021, 630 adults received a diagnosis of autism. There is a lot of work to be done in identifying adults in the North who have autism.

I have no further questions. I just want to say well done and best of luck going forward. I think everybody is on board with the Bill, so it is now about delivering for children and adults with autism so that they can reach their full potential.

Mrs Cameron: Thank you, Justin. You are welcome to call me Pamela; it is on my birth certificate, so that is fine.

You are absolutely right. We cannot get past the importance of collecting the data and doing research on the topic. That is necessary going forward, because we cannot begin to provide and support if we do not know what we need to do, what the numbers are or the scenarios we are dealing with. It is really important that we gather that data, and that is part of the Bill as well.

Thank you for your comments and your support and for the good work of your party colleagues in the past in leading on the issue. I am very proud to be heading up the all-party group, and I will continue to say that this is a good piece of cross-party work from us all. It is something the entirety of the Assembly can be proud of if we can get it passed. We look forward to working with you and seeing what comes of your amendment on the sports side of things. Thank you for your contribution.

Mr McNulty: Thank you.

The Deputy Chairperson (Mr Sheehan): Thank you, Pam.

Mr Harvey: Thank you, Pam, and I thank your group for bringing forward the Bill and for attending today. We have had some detail on the role of the reviewer on funding. I presume the reviewer would be able to comment on funding allocation but would not hold any power to make a funding direction. If underfunding was a problem, would it fall to the Executive to address it?

Mrs Cameron: You have probably gone into more detail than we have got to yet. We are at the stage where the Assembly agreed that the Bill could go to Committee Stage so that we could get into the nitty-gritty and get more detail and suggestions about how to go forward. That is all up for discussion, and we need to work out how that would happen, but I would like to think that the entirety of the Northern Ireland Assembly — the Executive — would have responsibility for funding, recognising that it is very much a cross-departmental and a lifelong issue that needs to be addressed by all Departments. I would like to think that the Executive would, if necessary, take on responsibility for the finances.

Mr Harvey: OK. Thank you. What form do you envisage the early intervention service taking? Will it be centred around general practice, or will it be provided by the trusts?

Mrs Cameron: Kerry, do you want to come in on that? It is probably much wider than that, because we are talking about autism as an issue across all Departments.

Ms Boyd: Pam, I am sure we agree on what we are looking for. At the minute, it takes maybe two years for a child to get a diagnosis of autism; two years is quite common. During that time, the child is developing and getting older. Straight after diagnosis, they have to wait again for early intervention. What the trust gives in different areas throughout Northern Ireland is completely different, so how good a service you get in early intervention depends on where you live. As you all know — I am sure that you, as MLAs, have heard this a million times — early intervention is key, and that is particularly the case with autism.

Getting in at the start and putting in structure and strategies is really important, and lots of good models are sitting there already. Autism NI has a fantastic early intervention service that we provide with the trusts, but it is about getting in there straight away and putting in support for a family. It needs to be uniform throughout Northern Ireland. Some trusts do it very well; some trusts do not do it so well. That is why we talk about the postcode lottery and why we feel that is a really important element of the PMB. A lot of people focus on the diagnosis waiting times, but that is only the start of the journey. The main issue is getting support and services straight after diagnosis. That is what we are talking about.

Mr Harvey: That is great. Thank you all very much.

The Deputy Chairperson (Mr Sheehan): That is the end of our questions. I thank you all for coming in today. It has been very useful. You know, Pam, that there is wide support for the Bill to go through the Assembly, and we look forward to seeing it on the Floor of the Assembly soon. I agree with you that it would be a feather in the cap of the whole Assembly if the legislation was to get through, and I am sure it will. Once again, thanks to everyone: Kerry, Arlene, Kelly and Pam.

Mrs Cameron: Thank you.