



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

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

25 November 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 Gerry Carroll
Mr Alan Chambers
Mrs Deborah Erskine
Ms Órlaithí Flynn
Mr Colin McGrath
Ms Carál Ní Chuilín
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 Chairperson (Mr Gildernew): I welcome, via StarLeaf, Pam Cameron MLA, chairperson of the all-party group on autism (APGA) and the Bill sponsor.

I also welcome Kerry Boyd, chief executive of Autism NI. Kerry, can you hear us OK?

Ms Kerry Boyd (Autism NI): Yes, I can.

The Chairperson (Mr Gildernew): Thank you, Kerry. I also welcome Kelly Maxwell, director of family support in Autism NI. Can you hear us OK, Kelly?

Ms Kelly Maxwell (Autism NI): Yes, I can.

The Chairperson (Mr Gildernew): Thank you. I also welcome Arlene Cassidy, special adviser in Autism NI. Arlene, can you hear us OK?

We do not have Arlene on the call at present. We will keep an eye out for her and check back. I will go back to the Bill sponsor. Pam, will you tell us how you will brief us, and then we will go to members' questions.

Mrs Pam Cameron (Northern Ireland Assembly): Thank you, Chair. I should officially declare an interest as a member of the Committee. During this item, I speak as the Bill sponsor, not as a

Committee member. I thank Kerry and Kelly for being here. Hopefully, Arlene will be on the system soon. I will make some comments, and we are happy to take questions after that. Is that all right, Chair?

The Chairperson (Mr Gildernew): Yes, thank you.

Mrs Cameron: I thank the Committee for the opportunity to speak today as the sponsor of the Autism (Amendment) Bill and to respond to the evidence session on this private Member's Bill last Thursday. We have not had much time to consider the evidence that was taken last week, and we have not yet got hold of the Hansard report. I wanted to put that on the record.

I thank Professor Laurence Taggart and Professor Roy McConkey for their incredibly helpful contributions last week and for their commitment to attending the meeting, given that Professor McConkey joined us from South Africa. It was very much appreciated. I will briefly address some of the points raised by the professors in their submitted evidence and the Committee discussion. The professors welcomed the Bill's proposal of the creation of an autism reviewer role. They clearly set out how areas such as the commissioning of independent research to inform evidence-based practice could benefit from an independent scrutiny mechanism to ensure that existing research is utilised, existing practices are assessed and good practice is shared across Northern Ireland. I was concerned to hear the researchers report some of their experience of missed opportunities. I welcome their overall support and their conclusion that the Bill has the potential to provide more effective and efficient services to autistic people.

I also thank Alyson Kilpatrick, the chief commissioner of the Northern Ireland Human Rights Commission, for her engagement and contributions to the Bill. I will briefly address some of the points that she raised. The chief commissioner welcomed the Bill's proposal for increased engagement with bodies with an interest in autism. She suggested, however, that the autism strategy should expressly compel the Department to involve and consult autistic people, their families and carers. I wholeheartedly support increased co-production. I have welcomed the Department's creation of an autism forum that includes autistic adults with lived experience. I have begun discussions with the Bill Office about areas that we may want to look at amending to strengthen the Bill. I fully agree with the chief commissioner's emphasis on autism not being simply a health matter. We need to look at all of the needs of autistic individuals and ensure that there is effective cross-departmental coordination in assessing and addressing need.

Although the Department of Health is the lead Department on the Bill, it is important to recognise that this is cross-departmental legislation. We need to ensure that other Departments step up to the mark in their duties on autism. I appreciate that the chief commissioner recognised that part of the proposed function of the annual autism reports is to ensure that other Departments meet their duties in fulfilling the autism strategy. The commissioner welcomed the proposal of training initiatives for Northern Ireland Departments and bodies, suggesting that such training improves public awareness and understanding of autism. I argue that it could improve the everyday experience of autistic individuals. I appreciate Alyson's general support of and interest in further engagement in the development of the autism reviewer role.

I thank Shirelle Stewart for representing the National Autistic Society (NAS) and for her contributions. Shirelle has a wealth of experience in the area of autism. I thank her for her helpful contributions to the discussion. I will briefly address some of the points raised by NAS. It welcomed the inclusion of and focus on the needs of autistic adults, stating that previous strategies have failed to meet their needs. It offered suggestions for further areas that need to be considered. I agree with its suggestion that mental health needs and independent living skills need to be considered when setting out how the needs of adults will be addressed in the strategy. I believe, however, that those areas are addressed under the areas in the Bill on emotional and mental well-being, supported living and lifelong learning. NAS asked for clarity on the stipulation that the autism strategy must take a multidisciplinary approach. That stipulation intends to ensure that input into the strategy comes from a range of health and social care professionals from different fields; to ensure that the strategy draws appropriately from multiple disciplines; to consider a range of perspectives; and to assess, plan and manage in a more holistic way. NAS also raised the issue of co-production. It suggested that the Bill should provide clarity on how the autism reviewer is to engage with the autism forum in setting targets for the autism strategy.

When drafting the Bill, we were concerned with ensuring that all those with an interest in autism would have the opportunity to contribute to and engage with the planning and implementation of the autism strategy, which is why we were careful to include the phrase:

"Without limiting the generality of consultations required under section 2(2)"

when stipulating bodies with an interest in autism that should be consulted on it. I welcome the work of the autism forum. It would be most beneficial for the autism forum to work with the autism reviewer and the Department. I believe, however, that the autism forum might be considered to be a body with interest in the rights of persons with autism and should be consulted.

The National Autistic Society also echoed a concern that I have heard raised on a number of occasions: how best to ensure that the autism reviewer role is an effective scrutiny mechanism. NAS has argued that the reviewer must be independent of the Department in order to ensure credibility and avoid a conflict of interest. The reviewer must have the ability to work with the Department of Health and other Departments. What is meant by "independence" and what that will look like are important. As I mentioned, I am open to looking at suggestions for possible amendments that will strengthen and improve the Bill. I intend to have a more in-depth discussion with the Bill Office in the coming days on how that can be achieved.

NAS highlighted how waiting lists for adults are worse, as sufficient money has not been devoted to assessment and diagnosis, and it noted large disparities between the services for children and adults. That is not acceptable. That is another area where the autism reviewer is essential to make improvement. Part of the proposed functions of the reviewer is to review autism funding arrangements, the law and practice relating to autism and the adequacy and effectiveness of services.

I thank all the representatives from the health and social care trusts and from the Department for their engagement and constructive contributions. The trusts' evidence also highlighted that adult services are severely challenged and in need of significant investment and measurable targets in order to judge efficacy. They stated that the services in place for the assessment and diagnosis of children are inadequate to meet the current need. Though that is not new information for us, it supports the rationale for collecting adult data in order to inform service provision. However, they should be focused not on either adult or child services but on timely access to assessment and intervention for all autistic individuals.

I welcome the reports from trusts saying that there are aspects of data collection that could easily be improved without too much added resource. All the trusts stated that they had the capacity to collect data on private diagnoses and integrate it into their current data collection without much difficulty. I am one of many who are concerned about the disparity in autism rates across Northern Ireland, and it is essential that we begin to improve how we collect and use data to inform and improve services. The trusts and the Department confirmed that the absence of consistent, recurring funding is a barrier to effective service planning and the functions of the autism reviewer in the Bill, combined with the duty on the Minister to lay an annual autism funding report before the Assembly, could help to address that.

It has been evident throughout the process that there is a genuine need for improved autism legislation and a desire for change in our services and systems in order to improve the lives of autistic people, their families and carers. I am incredibly grateful for the support that I have received so far for the Bill, and I appreciate the constructive engagement that I have had with various individuals, bodies and organisations.

I will leave it there, and, if there are any questions, we will be happy to answer them.

The Chairperson (Mr Gildernew): Thank you Pam. We have now been joined online by Arlene.

I will open the meeting to members' questions, but, before that, I want to say that this is an area of huge concern. I have raised it in the Assembly, and I know that the all-party group has been actively raising, as have many organisations and individuals over a long period, the difficulties that the lack of services, diagnoses and support has for the people who have to live and deal with the situation on a daily basis.

I am seeking to draw out a little more detail on this, but, in the evidence session, you touched on the possibility of forthcoming amendments on the reviewer's independence. How might that be strengthened to ensure that we have rigour and independence in the appointment of any reviewer?

Mrs Cameron: We have had so little time from last week that we have not had an opportunity to meet the Bill Office, but we are setting those meetings up now.

We do not want to throw stuff out there that is not accurate or appropriate. That is something that we have been concerned about from the very beginning, and I am cognisant of the need to ensure that independence in that role. It is just us trying to work out how best to achieve that. That is why we are interested to hear everyone else's views on how that would work best, but it is vital that that independence is there. It is just working out how best to slot that role in and finding out where it would sit. It is still up for some debate.

I do not know if Arlene or Kerry want to add their view on where that role would sit best. We are dependent on meeting the Bill Office to further consider any wording in an amendment, but we absolutely need to amend it to strengthen that independence part.

The Chairperson (Mr Gildernew): Kerry, Kelly or Arlene, do you want to contribute to that?

Ms Boyd: Arlene, can you speak there? I cannot see you.

Dr Arlene Cassidy (Autism NI): Can you hear me?

Ms Boyd: Yes, we can hear you. Do you want to speak on that?

Dr Cassidy: You go ahead. I am having technical difficulties here. I think that I am frozen on the screen.

Ms Boyd: We can hear you OK.

Basically, the number-one priority is that the reviewer be independent from the Department of Health. The original Autism Act was brought in 10 years ago. We are now in 2021, and the Act was brought in in 2011. We know that the autism strategy has basically failed, as it has been sitting with the Department of Health. Therefore, we feel that anybody who is scrutinising it should be independent from that Department. I do not know if it is possible for it to sit with the Executive Office, but, we feel that it definitely needs to be independent of the Department of Health. It needs to be somebody who has knowledge of government policy and how to implement strategies. It should not be with the Department of Health. I do not know what you think about that, Pam.

Dr Cassidy: Can you hear me?

The Chairperson (Mr Gildernew): Go ahead, Arlene, briefly.

Dr Cassidy: It is maybe a blessing that you cannot see me.

I just want to reinforce what Kerry has said. The Department of Health has appointed a number of coordinators and an autism lead. It has tried various strategies, and we are where we are with the lack of implementation of the original Autism Act.

Shirelle Stewart from the National Autistic Society made a good point at her evidence session when she reinforced the need for the person to be independent of the Department of Health to restore credibility in the process and in the Northern Ireland autism strategy. The failure has been so profound that something dynamic needs to be done to get us out of this logjam. The Department of Health has employed people internally, and, still, we are where we are. I just want to reinforce everything that Kerry has said.

The Chairperson (Mr Gildernew): The structure of the reviewer was raised in the Committee during its scrutiny of the Bill. It touches on the cross-departmental nature of the role and the fact that there are implications for Education and other Departments. What are your thoughts at this stage, having heard evidence? I know that there are different views on it, but what are your thoughts at this stage on a panel approach to the reviewer in order to bring in a wider range of expertise?

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

Ms Boyd: I think that it was brought up in a previous Committee session that we had. I do not feel that a panel would work; I feel that, again, you would dilute the role. One person needs to take the reins on it. We have had enough time to get it right, and we have not got it right. A panel approach would mean sharing the responsibility amongst a number of people, whereas a single reviewer, whose job would

be solely to ensure that the strategy is done once and for all and that everyone gets the right support, is the way it should go.

Dr Cassidy: May I add to that, Chair? A panel would introduce an element of duplication that would be unhelpful and would not really be cost-effective. As referred to earlier, a number of bodies and stakeholders are already involved that can be consulted. There is no doubt that the autism reviewer would need support, because there is an operational side and a research side to the process. Within the dynamic of the autism reviewer office, those are the key dynamics that are required to move it forward. That is it, in essence: if we introduce a panel approach, we introduce duplication. There are structures already in place that need to be utilised more effectively, driven forward and coordinated. That is what the autism reviewer is there for.

The Chairperson (Mr Gildernew): OK. In general, you have touched on some of the suggestions that Shirelle from the National Autistic Society made on some of the other areas. Pam, you have indicated that you are talking to the Bill Office: can you give us any indication, broadly, of the areas that it may be of benefit to amend to strengthen the Bill?

Mrs Cameron: Primarily, it is about strengthening the assurance that the reviewer must be independent. That is the most important amendment that we see coming through at this point. We already have really good legislation, as Kerry touched on, but it is 10 years old. The Bill is about making that work, and that is why a panel is probably not the way we should go. We have good legislation there; it is about how we implement it and make it work across Departments and how we ensure the independence of the reviewer so that we get the best outcomes from that really good legislation.

Mrs Erskine: Thank you Kerry, Kelly and Arlene. I also thank my party colleague Pam Cameron, who is bringing the Bill forward. It is such important legislation. We all know that many families struggle and would benefit from the extra support that may come as a result of the Bill.

My question is simple. The evidence from the Ulster University professors, NAS, the trusts and the Department outlined that services are not sufficient to cope with the current demand for autism assessments and interventions. We know about the huge backlogs in the waiting list for autism assessments. How will the Bill, if implemented, bring about the practical changes to those circumstances?

Mrs Cameron: Thanks, Deborah, for your kind comments. I reiterate, as the Chair did at the beginning, that I am the current chair of the all-party group on autism. That is where the private Member's Bill originated. This is not solely my Bill; I am heading it up in support of the all-party group, and I am grateful to all the parties for their continued support on the issue. We all recognise the need for the Bill.

In answer to your question, the autism reviewer is intended as a scrutiny mechanism that will be able to review the Department and trust practice. Part of the reviewer's role will be to ensure that the law on practice in Northern Ireland and services relating to autism are fit to meet the need. The regional information service and the early intervention service are intended to provide individuals with support as soon as they need it and as soon as that need is identified. The idea is that individuals across NI will be signposted to advice and support and will receive appropriate intervention as soon as possible. The Bill strengthens the data collection and the provisions of the autism strategy and outlines the needs of autistic adults that must be met in core areas.

The Chairperson (Mr Gildernew): Was there anything else, Deborah, or did anyone else want to contribute to that answer?

Dr Cassidy: Deborah, one of the elements that came out of the evidence from the health and social care trusts was the failure of the existing Northern Ireland autism strategy to address the cross-departmental imperative in the original Autism Act. That, again, is another relatively fertile area for development. Out of the words of the trusts, I think that that reinforces our feeling, and it would be within the remit of the autism reviewer to look at the cross-departmental dynamic. Therefore, there would be a knock-on effect with the possibility of joint planning and joint funding of services, because that has not really been driven either.

Ms Ní Chuilín: Thank you very much again for coming before the Health Committee. When the legislation was introduced all those years ago, some of the concern I had was that it went to the Department of Health. On the basis of the points that you have raised continually, it may have been better going to OFMDFM then to ensure that its cross-departmental nature was adhered to.

An issue that one of the trusts also mentioned was that the reviewer should be independent of the third sector. Maybe that is not what the trust said, but that is certainly what was hinted at. One of the issues that I have is that, while we all agree that we need independence, unless you bring other skills and expertise in, you are very much relying on that one person. How can that be achieved? I am aware that it is down to the Department to ensure co-production and co-design, but how would that happen with a one-person reviewer? That is key. Also, where is there a role for people with autism in that area?

Mrs Cameron: Thank you, Carál, for your questions. We are now getting into the complexities of the Bill. To reiterate, the Bill is not about reinventing the wheel. *[Interruption.]* Here are my dogs featuring now; I knew that they would not be too far away.

The Bill is about making what is already good legislation work, bringing it to the fore and seeing its outcomes. It is about strengthening what is already there and making it work. I suppose there may be more conversations to be had on the role of the reviewer and how best that could work. In my head, I see the mental health champion very much as a good example of how a single role can be effective, especially if it has been embraced by all the Departments. That has happened with the mental health champion, so that is probably a good example of how everybody needs to be bought into the same subject. We obviously have a lot more work to do on the Bill to tidy up where we are with that reviewer role and to really define how best it could work. We do not want extra layers of complication. We want to drive through the changes that need to be made so that autistic individuals get what they need on the ground at as early a point as possible.

Ms Boyd: Can I come in?

Ms Ní Chuilín: Yes, please.

Ms Boyd: As I have said all along, the reviewer needs to be one person. One person needs to have responsibility. Every organisation and every committee anywhere has somebody leading it. I feel that the reviewer should be the person who has responsibility to lead on the matter and to be independent. They also need to work with the autism community, autistic adults, the voluntary sector and the Departments to find out exactly what is going on. They need to get the full picture. They will obviously also do that in the background.

As Pam said, panels, forums and all that have been done before over the past number of years. We need one person who has the experience and understanding to drive the process forward and to not only have that overview of what is going on but to work with other organisations, people and the autism community to make sure that you guys, as a Government, do what is needed for the autism community. I seriously think, however, that the role needs to be taken on by one person who has the experience to do the role and can drive the process through.

We cannot wait any longer, basically. We have done all this before. We have had forums, meetings and panels, and everyone has different views. The Bill is our chance to get it right and to have that person in place who has the passion to drive things forward.

The Chairperson (Mr Gildernew): Have you anything to add, Carál? No.

Ms Bradshaw: Thank you for the update, panel. It has been helpful. I do not really have a question; it is more of a positive response to Pam's commitment to look at the amendments that Shirelle Stewart brought forward. Her paper is excellent and has some really robust and tangible suggestions to embolden your Bill. I just wanted to put that on record and to thank all the ladies on the call for their hard work on the subject.

Mrs Cameron: Thank you, Paula. I agree. As I said in my remarks, Shirelle has a wealth of experience. She is exactly the type of person that we need to listen to in order to ensure that we make the improvements that are required. Thank you for your comments.

The Chairperson (Mr Gildernew): That is all the indications that I have from members. I thank you all very much for contributing to the evidence session this morning and into the afternoon. I thank Pam for sponsoring the Bill. That is all there is by way of questions, Kerry, Kelly and Arlene. The Committee can continue its consideration of the Bill, but thank you for your attendance. Thank you very much.

Mrs Cameron: Thank you.

Ms Maxwell: Thank you.

Ms Boyd: Thank you.

The Chairperson (Mr Gildernew): Thank you.