



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Autism (Amendment) Bill:
Department of Health;
Health and Social Care Board

18 November 2021

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Mr Colm Gildernew (Chairperson)
Mrs Pam Cameron (Deputy Chairperson)
Ms Paula Bradshaw
Mr Alan Chambers
Mrs Deborah Erskine
Ms Órlaithí Flynn
Mr Colin McGrath
Ms Carál Ní Chuilín

Witnesses:

Ms Judith Finlay	Department of Health
Mr Mark McGuicken	Department of Health
Mr Maurice Leeson	Health and Social Care Board

The Chairperson (Mr Gildernew): I welcome, via StarLeaf, Mark McGuicken, the director of disability and older people in the Department of Health. Can you hear us, Mark?

Mr Mark McGuicken (Department of Health): I can, Chair. Thank you.

The Chairperson (Mr Gildernew): We are also joined by Judith Finlay, who works in the learning disability unit in the Department. Can you hear me, Judith?

Ms Judith Finlay (Department of Health): *[Inaudible owing to poor sound quality.]*

The Chairperson (Mr Gildernew): We cannot hear you, Judith.

Ms Finlay: I can hear you, Chair.

The Chairperson (Mr Gildernew): We have you now, Judith. We had the same problem the previous day as well, but you are coming across loud and clear now.

Finally, we have Maurice Leeson from children's services planning in the Health and Social Care Board (HSCB). Can you hear us, Maurice?

Mr Maurice Leeson (Health and Social Care Board): Yes, Chair, I can hear you. Thank you.

The Chairperson (Mr Gildernew): Thank you, Maurice.

Mark, will you or Judith be making the opening remarks, will it be a combination of the two of you or, indeed, will it be Maurice?

Mr McGuicken: If you do not mind, Chair, I will make some very brief opening comments. I thank you for the invitation to brief the Committee on the proposals being brought forward in the Autism (Amendment) Bill and for the opportunity to share some of the work that is already being delivered by or that is planned in the autism strategy, much of which aligns with the amendments that are being sought.

I thought that it would be helpful to reflect on some of the substantial progress that has been made and to update members on the direction that we are committed to taking. Since the publication of the first autism strategy, awareness of autism has increased significantly, as has the need for services and support in our health and social care sector and wider communities. In the previous briefing, our trust colleagues noted that each trust area now has a dedicated autism coordinator, who, alongside a range of multidisciplinary clinicians, is responsible for the delivery and provision of autism services and the extensive support in each area. Recognising that progress can be achieved only through collaborative working, each autism coordinator has established a regional autism stakeholder forum, which comprises people with lived experience, community and voluntary sector organisations, clinicians, public bodies and local interested parties. The Department has a standing agenda item on the agenda of each of the forums and is consistently impressed by the collaborative work that is being taken forward in each area.

Since late 2018, the Department has appointed staff in my directorate who are dedicated to raising awareness and to working collaboratively across the Civil Service to maintain partnership working with Health and Social Care (HSC) colleagues and Departments more widely. Since taking up post, the staff recognise the importance of listening to and involving people with lived experience of autism. That engagement has informed and underpinned the actions and priorities that are being addressed. It has been pivotal in building excellent relationships and has led to the recent establishment of the autism forum. The forum is co-chaired by the Department and two autistic advocates and includes people with lived experience and community- and voluntary-sector organisations that support and represent them. It is important to thank publicly the two co-chairs for the time and commitment that they have given to the forum, ensuring that civil servants and others who are involved in the development of public policy receive input from people with lived experience of autism in their development of that policy.

It is our view that the strategy for autistic people should be informed and co-designed by people with experience, along with the regional autism stakeholder forums. We believe that it is those individuals who are best placed to monitor and measure progress on the implementation, delivery and evaluation of the autism strategy in a meaningful way.

In addition to carrying out extensive stakeholder engagement, my officials arranged a cross-departmental workshop in 2019 with representatives from all Departments to inform them of their role in complying, and their responsibility to comply, with the Autism Act (Northern Ireland) 2011 across government. As a direct result of that initial engagement, the Department of Health is now represented on many cross-departmental working groups in order to ensure that autism is continually considered on the agenda. I can assure members that there is recognition across Departments, particularly in front-line and public-facing areas, of the support that needs to be provided for autistic people.

A number of actions in the autism strategy can demonstrate that. I will give a few examples. Jobs and benefits offices have been working on a project to make sure that their offices and services are more autism-friendly. The Make the Call service will be working towards an Autism NI Impact Award. The Careers Service is developing an app specifically to assist autistic people and their carers in making career choices. The employment strategy will consider jobs, opportunities and support in the workforce for people with autism.

In the past couple of years, the Northern Ireland Civil Service (NICS) autism working group, on which the Department is represented, was formed to highlight awareness and support autistic individuals or carers of family members with an autism diagnosis across the Civil Service. The group arranged a very successful autism open day, which was held on World Autism Awareness Day 2019. The event attracted over 200 members of staff, with support organisations providing information and advice throughout the day. A further event was planned for April 2020. Discussions on that were paused as a result of the COVID pandemic, however. As we have moved to a more virtual environment over the past 18 months, a number of awareness-raising sessions have been held, and bulletins and articles on individuals' experience of autism have continued to be published regularly. Most recently, an online

seminar was provided to NICS staff, with over 300 civil servants registering for the event. Following the positive feedback from that, it is intended that a further seminar will be held in the near future.

Although I have focused on the ongoing work that is being progressed, on occasions, the debate on the previous autism strategy and the proposals that are being brought forward in the Bill can often ignore that work. At times, the picture that is presented is noticeably different from the work that is being delivered. On occasions, it feels as though the emphasis is on the perceived failings of the autism strategy, with minimal focus on the significant progress that has been made. That having been said, the Department has been open and honest in stating that more could and should have been done. We have acknowledged in our lessons learned report, which was published with the interim strategy, that the lack of an overarching action plan post 2017 has reduced the drive for and focus on cross-departmental actions. We must acknowledge that that lack of a robust reporting and monitoring mechanism has resulted in limited presentation of the progress that has been made and achieved.

That does not mean, however, that the work to support autistic people, their families and their carers has ceased. In fact, it is the reverse. Many examples have been included in the responses that the Department and the trusts have provided. Although I could speak for much longer on the actions that we have been and are undertaking to support autistic people and their families and carers, that would represent only a snapshot for members. I hope that you will agree, however, that it far exceeds some of the coverage of the events that have been reported on.

Unfortunately, owing to work pressures and the recovery from the impact of the COVID pandemic across Departments and our health and social care sector, actions have been delayed. That has had an impact on the publication of the action framework for the interim strategy, which would have demonstrated a much bigger picture. Work on it is under way, however. A subgroup has been formed in the autism forum, and it is currently collaborating on the development of measures for associated actions. Once that it completed, the Department will be happy to share it with the Committee.

I am also aware that Mrs Cameron, the Deputy Chair, wrote to the Minister to advise him of her intention to introduce the Bill and to share the necessary proposals that were being considered. In his response, the Minister suggested that a meeting could be arranged with officials to discuss the proposals. Such a meeting would have allowed us more time to share a fuller picture of the extensive work that is being undertaken. We are still open to having a meeting with the Deputy Chair should she wish to discuss that work.

In the Minister's response to the recent Assembly Second Stage debate on the Bill, he emphasised that we are "committed to driving change", because change is needed, and:

"the changes have not been driven by legislation or the need for further legislation."

The responses from the Department and the trusts that are before members outline the work that is already being delivered and how the proposed amendments will impact on those services for autistic people, their families and their carers.

We are happy to take comments and questions from members on any aspect of the papers or on the wider work that is being delivered. I am grateful to Judith and Maurice for being here. They have much more experience in the area than I have. They will assist in answering members' queries.

The Chairperson (Mr Gildernew): Thank you, Mark. Has the Department costed how much resource will be needed if the Bill is passed by the Assembly?

Mr McGuicken: Chair, recognising that autism is a cross-departmental issue and not one just for the Department of Health, the Minister recently wrote to all Executive colleagues asking for their views on the impact that certain aspects of the Bill would have. Certainly, the responses that we have received from trusts suggest that the Bill could have a significant resource implication, particularly around recording and reporting what is being done and the services that are being delivered. That would have a significant impact, but we have not given an exact cost for it yet, Chair.

The Chairperson (Mr Gildernew): OK. In your remarks, Mark, you rightly highlighted the fact that there is, in many ways, a focus on the failings. That is natural, because that is where improvement comes from. Clearly, the things that are being done well are welcome, are in place and should be and are being supported. That is what good legislation does, however: it identifies failings and seeks to address them. In light of that, do you agree that the Bill is necessary?

Mr McGuicken: In our response, we have accepted the majority of the clauses, and work is already ongoing that complements the Bill's tone. We have concerns about a number of issues in the Bill, and they are laid out in the response before the Committee today, Chair.

The Chairperson (Mr Gildernew): OK. You made a comment about the other Departments. Do you recognise that the Department of Health is the lead Department, given the cross-departmental nature of the subject? I accept that housing, education and lots of other issues relate to autism, but what is your view, as the lead agency, of how other Departments have engaged with the strategy?

Mr McGuicken: I will turn to Judith on that one in terms of the work of the forum.

Ms Finlay: Chair, I am happy to update you on that aspect. I will also let you know that we sent the Bill out across Departments to get their views on it, because we are very conscious that it is a cross-departmental Bill. We need to make Departments aware of where the responsibilities in the Bill lie and also to recognise the work that they already undertake that supports it.

Yes, we fully recognise and acknowledge that the Department of Health leads on the Bill. That acknowledgement underpinned part of our reason for establishing the autism forum. It also underpinned our acceptance of participating in a number of cross-departmental steering groups so that we could ensure that autism was always kept on the agenda and that any actions being planned were inclusive of autistic people. We fully acknowledge that the lead responsibility lies with us.

The Chairperson (Mr Gildernew): OK. I appreciate those responses and that they have been succinct, because we are under time pressure. However, we have just had a session with the trusts. I am not sure whether you were able to follow any of it, but the issue was raised of measuring how many people have to go private to get an initial diagnosis and assessment. The Minister previously gave a commitment to the Committee that he would look at the issue. What engagement have you had with trusts? How is the issue being moved forward? When can we expect to see the correct information being gathered?

Mr McGuicken: Sorry, Chair, I missed part of that question.

The Chairperson (Mr Gildernew): It is very clear that no information is being gathered on how many people are having to go private to get a diagnosis. The Minister had previously committed to looking at the issue to see how it might be addressed. Can you give us an update on what the Department is doing, in communication with the trusts, to address it?

Ms Finlay: Chair, I am happy to answer that question. We will look at that in relation to the interim strategy. There is a commitment within that to look at the data that is being collected at the moment. It is a complex process; the trusts have highlighted that. They collate it manually, so we will have to look at ways in which we can collect that information. It may not be as straightforward as we would hope.

The Chairperson (Mr Gildernew): OK. I will reiterate the point that I made earlier: the old saying that what gets measured gets done is equally true in the reverse. What does not get measured does not get done, so it is important that the data issue is addressed.

I will go to other members now. I will go to Deborah first, and then Órlaithí. *[Pause.]* I think you are on mute, Deborah. Just check your sound, please.

Mrs Erskine: Sorry; I hope you can hear me now. Thanks to the panel. The Department's response acknowledges the need for an information service and alludes to exploratory discussions on the development of an autism navigator role. Can you provide more information on those discussions? Will the role provide a regional service, as described in the Autism (Amendment) Bill?

Secondly, what discussions has the Department or the Health and Social Care Board had with research and development and the Public Health Agency (PHA) regarding autism research needs? For example, why does Northern Ireland have the highest autism prevalence rates in the world?

Ms Finlay: Would you like me to pick up on that, Maurice?

Mr Leeson: Yes, please.

Ms Finlay: In respect of the autism navigator role, I am not sure if you are familiar with the role of dementia navigators, who are in place across Northern Ireland in each of the trusts. The purpose of the dementia navigator is to provide people with information and advice to signpost them to services and support that are available to them, dependent on their need. We envisage that the autism navigator role will be similar to that of the dementia navigator. They will be someone that a person can contact if they are on a waiting list and need advice regarding autism. If it is post-diagnosis, they need to know about services and support and where to go next. That navigator will be accessible to them in whatever way they need them to be, whether it is to meet or to discuss by phone, on a digital platform etc, to best suit their needs at a time when they could be feeling quite vulnerable and unsure of which steps to take next. We thought that it would be a very good role to have in place for autism. I will admit that it is at a very early stage of discussion, and we will have to cost that out, but we think that, rather than a static information service, signposting to services will be a more flexible and accommodating role for individuals and families who may need it. I hope that gives you some sort of insight into that role.

With regard to research and development, we have our recently established autism forum, and we will be looking to it for proposals for research. We will be getting the necessary people who can undertake that research involved. In the past year, we have linked up with Queen's, which was doing some research on autistic young people throughout COVID, and we were able to share some comments. We have made contact with Ulster University twice over the past year, but unfortunately we have not had a response yet. However, we are very keen to find out what sort of research it is undertaking at present.

Maurice, is there anything further that you want to add to that?

Mr Leeson: Yes, I will just make two points. First, Judith has asked that the board does some early scoping into how much a navigator scheme would cost and to give some ideas about how it would work in practice. So we have been asked to do that, and we will carry that out. To make a general point, we work very closely with the Public Health Agency across all the work that we are doing, and the Public Health Agency co-chairs our regional emotional health and well-being framework group.

Ms Flynn: Thanks to the officials who have come to the Committee today. Just a couple of questions. The Human Rights Commission has said that it is seeking the strengthening of clause 1 so that it will be completely clear that the Department will have to, and should, consult people with autism, parents, carers and the community and voluntary sector. The consultation that the Department is carrying out was touched on in the previous answer. What are your views on the recommendation from the Human Rights Commission that clause 1 be strengthened?

Also, has the Department of Health done any work with the Department of Education to try to address some of the back-and-forth that children are being faced with? When they try to access support, there can be a back-and-forth between Education and Health. Have you had any conversations with the Department of Education on that, specifically, to see how some of that can be streamlined? Finally, the Department's response states the importance of implementing the emotional well-being service framework for children and young people, and, obviously, all the things that that could try to address. How can you explain the relationship between the emotional well-being service framework and *[Inaudible owing to poor sound quality.]*

Ms Finlay: Maurice, do you want me to pick up on the first two questions?

Mr Leeson: Yes, and then I will take over.

Ms Finlay: Apologies; you were breaking up quite a bit there, so I hope that I have caught all of that.

I was nodding my head continually as the Human Rights Commission representatives were speaking this morning, because what they are suggesting is very much the approach that we have been taking. Since being appointed to the post, I have been determined, along with my colleague, from the outset that anything that we did would be informed by autistic people, their families and carers, and by the community and voluntary organisations that represent them. We spent an awful lot of time carrying out a lot of stakeholder engagement, particularly over the first year. If you are familiar with the autism strategy, you will know that we provided an annex of that stakeholder engagement and the topics that were covered. We feel that autistic people and their families and carers are entitled to exactly the same rights and access to services, supports, community availability, recreation and employment as everyone else. When we were developing the interim strategy, it was underlined by our feeling that

society needed to adapt to the needs of autistic people, rather than autistic people needing to adapt to the needs of society. That has very much underpinned everything that we have done. Our interim strategy very much sets a direction whereby, whilst we recognise that there is a very important health application that needs to be made, for obvious reasons, there is a wider picture. Dr Meekin put it very well; she referred to it as the "wider lens". We think that that is something that really needs to be addressed. We need greater understanding in our communities, workplaces and organisations, and we need autistic people to be supported more within their communities. A lot of our councils are recognising that and working towards autism-friendly council status, which cascades into business, employment and recreation to ensure that they are supported. I hope that that provides some reassurance on that question.

Mr McGuicken: Judith, I will add to that. Given that autism has impact in other Departments, we will need to see the exact text of what the Human Rights Commission is suggesting and take views from other Departments on the impact that it would have on them. As Judith said, we have been committed to engaging with people, carers and organisations for autistic people from the very start of this. Sorry for interrupting you, Judith.

Ms Finlay: It was not a problem. When our action framework is published, you will see evidence of that as well.

In relation to streamlining the interfaces between the Department of Education and the Department of Health, we now have a special educational needs steering group, which is co-chaired by the Department of Health and the Department of Education. One aspect of that steering group is to improve access to support in education that is dependent on need rather than a diagnosis. We are very much looking at how to streamline those services and improve the interfaces. A special educational needs framework is being implemented, and that will work towards addressing a lot of those issues. Over the past two years, there has been a much stronger and more integrated working approach between the Department of Health and the Department of Education. If there could be a positive from COVID, it has been that that relationship has actually strengthened, because there has been so much inter-agency working to try to address the problems with children who needed additional help at school throughout the pandemic.

Mr Leeson: I will pick up the question on the emotional health and well-being framework. We have a regional group which supports that. The regional group is co-chaired with the Public Health Agency, and it is inclusive of all the trusts and education providers. Our purpose there is to look across a broad range of autism, ADHD and emotional health and well-being. We are looking to integrate and streamline the operational systems that are there. We are very conscious of the fact that some families can wait for an ADHD assessment and may then be told that they actually need an autism assessment, and then have to move to a separate waiting list. We are looking to streamline that to one single point of entry — you may have heard the trusts refer to that in the previous session — so that, as I say, there will be one way for families to enter our system, have their assessments and then have access to support.

Ms Finlay: It is probably also worth noting that Education is represented on that group as well.

Ms Flynn: Thank you, Judith and Maurice.

Mrs Cameron: Thank you, panel, for your attendance at the Committee today. It is much appreciated. Just a couple of questions for you. Obviously, my colleague Deborah has already touched on research. Does the Department agree that independent research is vital to exploring more efficient working practices that will pay off in human and financial terms in the long run? For example, when the Health Minister was questioned about the rate of private ASD diagnosis and its impact on the disparity across Northern Ireland, he responded that the Department could not answer the question because it was not collecting the data.

On the back of that question, it strikes me that we are talking a lot — Órlaithí mentioned it as well — about data collection, and we questioned the trusts about how they collect data on private autism diagnoses. Where is Encompass in all of this? We have not heard about that for a long time. You might not be the right people to ask, and I will appreciate it if you could take it back to the Department. Obviously, Encompass should improve how we do everything — how we transform, how we collect data, how we use that data and how we plan for the future. Do you have an update on Encompass? Where is it, and why have we not heard about it for so long? Since the pandemic started, I have not heard about Encompass at all, and that is a huge concern for me.

Ms Finlay: Will I pick up on that?

Mr McGuicken: Yes, and I will say something about Encompass.

Ms Finlay: Good. I am afraid that my knowledge of Encompass is very limited, other than when data is discussed. I am usually told that Encompass may address this when it is introduced, but I am afraid I am not familiar enough with Encompass to discuss that.

I agree that independent research is required. We need to very clearly identify what research is required. Possibly one of the aspects of the previous strategy was — I am going on what I have learnt about that, because I was not in the Department at the time. There was a lot of research being discussed, but I think, given the climate that we are now in, that we need to determine what research is needed. Once we determine what research is needed, we should pursue ways of looking at how we can do that. We will need to consider that as part of the longer-term strategy.

Mr Leeson: I am not an expert in Encompass either, but I want to reassure the Committee that work continues on the development of Encompass, and community services are engaged with that.

The Chairperson (Mr Gildernew): Thank you.

Mr McGrath: I have a question about the gathering of data and maybe the reliance by the Department on using Education as the main place for getting the information, whereas the 2011 Act suggested that maybe the Department should be trying to gather that information. Is that something that the panel is aware of, and is it something that they are seeking to address?

Ms Finlay: In terms of the prevalence of data in Education, it is trying to get the data set that the data can be extracted from that is probably what underpins it all. I am not a statistician, so I cannot tell you any more than that. I can look into it in the Department and provide a written response to you if that would be helpful.

Mr McGrath: It is part of the 2011 Act that the Department is to comply with that. If it is simply using its own Education data, it is not operating fully within the guidelines of the Act. It would be good to find out what has been set up to check that we are sticking to those guidelines.

Ms Finlay: We are not solely getting data from Education. There is the annual report on the prevalence of autism in school-age children that comes out, but any additional data — We publish a fairly comprehensive data set on the Department's website. The Department of Health's statistics unit and the Health and Social Care Board work together with the trusts to provide that data, so we are meeting some of the responsibilities in the Act.

Mr Leeson: The Health and Social Care Board collects data from the trusts relating to waiting time returns, so information is gathered there as well.

Mr McGrath: OK. Well, as I say, if you maybe just drop —

Mr McGuicken: We will come back, Colin.

Mr McGrath: OK, thank you very much.

Mr Chambers: I commend the Department on its work to date on this important issue. It is great to see that the Department has committed itself to developing measurable targets through the autism forum on which the autism strategy can be assessed. Does the Department have a set of approved measurement tools that it is required to apply routinely in monitoring actions that fall under the watch of the Programme for Government? Did Mark say that those are or could be submitted to the autism forum subgroup for comment?

Ms Finlay: I can pick up on that. Thank you for the question. We have a set of measures that are produced under the Programme for Government. It is called the outcomes delivery plan, and it bases measurements on what the action was, when it was done, what difference it made and who did it. A lot of it is based on collaborative working as well. We have shared those measures with the subgroup from our autism forum. In fact, one of the people in the forum is our outcomes delivery plan contact in

the Department, so we are being very well advised on that. However, it is making it workable as well, and making it easily understood, and the measures that we might propose as government may not be those that the community and voluntary sector wants to see. It might want to see that a specific number of autistic people have been addressed through a specific programme. Sometimes, the evidence that we need to provide is more qualitative as opposed to quantitative. It is about trying to get an understanding of that. We will be working, as Departments are supposed to, towards the outcomes delivery plan targets.

Mr Leeson: You will have picked up from the submissions from the trusts the issues of developing an outcomes framework, pointing to a willingness to be involved in that and identifying some of the other stakeholders as important to be engaged in that discussion.

Ms Ní Chuilín: I thank the panel for their contributions. This may be a simple question, but, for me, it is a really important one. What do you all believe is the underlying reason for amending the Autism Act 2011? Does the Department believe that it needs to be amended?

Mr McGuicken: Chair, I will try to cover the member's questions. We believe that we are delivering significant elements of what we are supposed to be doing on the autism strategy. I have already reflected that there have been delays. We know that more can be done, Carál, and we are trying to do more and to develop more, particularly around the autism forum. I think that the work of the forum is a significant step forward. We have published the interim strategy and are working towards the full strategy by March 2023. We are trying to eke out more resource to put into this. As with all Departments, we are currently struggling with filling vacancies, and that has impacted our ability to deliver some of these aspects. We are working towards putting additional staff onto this. We recognise the importance of it, and I do believe that the interim strategy and the full strategy for 2023 will significantly move forward our responsibilities under the Act.

Ms Ní Chuilín: I respect what you are saying, Mark, but the issue is that, from 2011, I think people, particularly families and advocates, have been very generous around the implementation of the 2011 Act. Obviously, there are gaps, and I think that everybody is coming from a place where they want to try to ensure that those gaps are filled and those needs are met. However, unless there is legislation, our experience has been that it will depend on budgets. That is why we are taking so much evidence and providing so much scrutiny and support to this. Nobody wants any child or any adult left behind, so primarily, that is why we are asking.

Going back to the point that Alan made, it is critical that not only is it in the Programme for Government but that, when the Department does its screening and, hopefully, its full equality impact assessments, this issue will be raised. We are sitting with children having a three-year wait for diagnostic services and adults having a five-year wait. Nobody wants that to continue. As we heard from the Belfast Trust, annually, the increase is now 70% compared with where it was before. There is no sign that that is easing at all, so it is quite obvious from my point of view that the amendment to the legislation and, hopefully, the statutory duty and obligation to meet those amendments will be met by the Department and, indeed, will be cross-departmental where appropriate.

The Chairperson (Mr Gildernew): We have now heard from all members. I thank the panel for your remarks, your presentations and your answers to members' questions. We can carry on with our consideration. Thank you for that, Mark, Judith and Maurice, and please all take care in the time ahead. Good luck.