



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Autism (Amendment) Bill:
National Autistic Society Northern Ireland;
Northern Ireland Human Rights Commission;
Ulster University

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 Sharon McDaid	National Autistic Society Northern Ireland
Ms Shirelle Stewart	National Autistic Society Northern Ireland
Ms Alyson Kilpatrick	Northern Ireland Human Rights Commission
Ms Emily Mills	Northern Ireland Human Rights Commission
Professor Roy McConkey	Ulster University
Professor Laurence Taggart	Ulster University

The Chairperson (Mr Gildernew): I welcome, via StarLeaf, Professor Laurence Taggart from Ulster University. Can you hear me OK, Professor Taggart?

Professor Laurence Taggart (Ulster University): Hello, yes. Can you hear me?

The Chairperson (Mr Gildernew): Yes, we can.

We are also joined, via StarLeaf, by Professor Roy McConkey, who is also from Ulster University. Can you hear me, Professor McConkey?

Professor Roy McConkey (Ulster University): I can indeed. I hope that you can hear me: I am calling from Cape Town, South Africa. Forgive me: the video is not working on my system.

The Chairperson (Mr Gildernew): You are coming across loud and clear on the audio, Professor McConkey, so thank you for that.

We are also joined, via StarLeaf, by Ms Alyson Kilpatrick, who is the chief commissioner in the Human Rights Commission. Are you able to hear me, commissioner?

Ms Alyson Kilpatrick (Northern Ireland Human Rights Commission): Perfectly well, thank you.

The Chairperson (Mr Gildernew): I also welcome, via StarLeaf, Ms Emily Mills, who is policy and research officer with the Human Rights Commission. Can you hear me, Emily?

Ms Emily Mills (Northern Ireland Human Rights Commission): Yes. Good morning.

The Chairperson (Mr Gildernew): We are also joined, via StarLeaf, by Ms Shirelle Stewart, who is the director of the National Autistic Society (NAS). Can you hear me, Shirelle?

Ms Shirelle Stewart (National Autistic Society Northern Ireland): I can, yes. Thank you.

The Chairperson (Mr Gildernew): Finally, I welcome, via StarLeaf, Ms Sharon McDaid, who is an education and transitions advice officer in the NAS. Can you hear me, Sharon?

Ms Sharon McDaid (National Autistic Society Northern Ireland): Yes, I can. Thank you.

The Chairperson (Mr Gildernew): You are all welcome to the Committee. Thank you for attending and giving us your time this morning: we appreciate that and look forward to the session with you. I advise all panel members to use a headset, if you have one, as that usually helps with the sound. Given that we have a big panel and a number of evidence sessions on the Bill to get through this morning, I ask that one member of the panel identifies themselves as the principal respondent to any questions that might arise. If there is additional information that people want to follow up with after that, they can do so if necessary. I ask Committee members to be as succinct as possible, given the depth of analysis and scrutiny that we need to apply to the Bill. I ask panel members to be as succinct as possible, given the time available.

You are all very welcome. Tá fáilte romhaibh uilig go dtí an Coiste Sláinte.

Professor Taggart, as the first person listed, I come to you first. Are you or your colleague making remarks for your organisation?

Professor Taggart: I will speak on behalf of myself and Professor Roy McConkey from Ulster University.

The Chairperson (Mr Gildernew): OK. Go ahead, Laurence.

Professor Taggart: I thank the Committee for the opportunity to highlight our support for the Autism (Amendment) Bill. We congratulate the Assembly on passing the original Act, which, at the time, was the most comprehensive legislation related to autism on these islands. In the intervening 10 years, a great deal of further learning has been accumulated locally and internationally on how the needs of children and adults with autism can be effectively and efficiently met. In particular, we want to highlight the contribution that research and evaluation have made to that.

We particularly support the proposal to have an independent autism reviewer, as we see that as being a key vehicle by which evidence-based practice can be consolidated in health, social care and educational support in Northern Ireland. That is essential to furthering the Executive's transformation of Health and Social Care (HSC) services, ensuring more cost-effective use of existing resources and helping to guarantee that new resources are applied in more timely, local and efficient new forms of service delivery.

Since the 1990s, a series of research and evaluation studies has been conducted by Ulster University, particularly by my colleague Professor Roy McConkey, in conjunction with the health and social care trusts and voluntary organisations. Those resulted in improved assessment and diagnostic practices, family-based early intervention strategies, training courses for families and practitioners and innovative wrap-around community supports for transitions to adulthood. However, the uptake of those insights was variable across the trusts and non-statutory providers. A list of those projects and publications is given in the appendix of the briefing document.

An autism hub was established in the centre for intellectual and developmental disabilities at Ulster University led by me, bringing together practitioners from multiple disciplines who have identified future research priorities and instigated a number of projects. The Department of Health established a

Northern Ireland autism strategy research advisory committee (NIASRAC), chaired by Dr Arlene Cassidy, of which Professor McConkey was a member. However, its work was temporarily paused by the Department of Health in March 2018 and has not been resumed, and that is regrettable.

A recent analysis of school census data collected in the four UK nations has enabled comparisons to be made of the number of pupils identified as being on the autistic spectrum. The steady increase in numbers from 2011 to 2019 occurs in all nations, but Northern Ireland consistently has the highest prevalence rates, reaching 3.2% by 2018-19 compared with 1.92% in Wales. A further analysis of census data in Northern Ireland showed that Belfast, Northern and South Eastern areas had markedly higher rises and prevalence rates than the Southern or Western areas. In all areas, pupils living in locations with greater social deprivation had higher rates of ASD. That information was shared with the Department of Health in October 2017 by NIASRAC. The variation in a small region such as Northern Ireland is suggestive of inefficiencies in the systems, but that does not appear to be being addressed. An autism reviewer would help to ensure that research is undertaken into those unacceptable and potentially inequitable variations. In particular, an urgent examination of the costs involved in the provision of assessment and diagnostic services across the five trusts and of their operating procedures is needed.

Parents across the UK are not satisfied with the support that they receive after their child is diagnosed as being on the autism spectrum. Northern Ireland is no different, as highlighted in the 'Broken promises' report of 2017, but attempts have been made to address that. Three innovative projects funded by the Big Lottery Fund and undertaken by Autism NI, the Cedar Foundation and Positive Futures provided home-based, family-centred, post-diagnostic support to children and families from 2017 onwards. Detailed evaluations of the outcomes for children and families were made, and those have been reported internationally in peer-reviewed journals. The health and social care trusts referred around 800 children with the assumption that, if the services proved effective, the trusts would assume the running costs. That has not happened, and the projects will have been or will soon be suspended. Even when evidence is presented to justify the costs and outcomes of the service, it is not acted on, but existing provision continues, even when it is not evaluated nor the cost determined. A research reviewer could call commissioners and providers to account.

The growing number of children identified on the autism spectrum will invariably mean an increase in the number of adults with the condition who will need support, notably in further education, vocational training, employment and leisure pursuits. A report commissioned by the Health and Social Care Board (HSCB) in 2010 highlighted the need for action, but many of the recommendations have yet to be implemented. Of particular concern are the increased mental health issues that are being experienced by teenagers and young adults and the long waiting list times to receive professional help. A project undertaken by the Western Health and Social Care Trust and the Cedar Foundation, with support from the adult ASD team, has demonstrated the impact that a person-centred, low-cost intervention can make and the potential for preventing costlier interventions being needed. A research reviewer would help to ensure that good practice is shared across Northern Ireland, with preventative projects having priority, rather than more money being invested in secondary and tertiary provision, as happens currently.

A research reviewer as the Northern Ireland champion for autism will be strengthened by being underpinned by legislation. However, the role would be enhanced by the Department reviving the research advisory committee, with nominees from universities, the Public Health Agency (PHA), trusts and the community and voluntary sector. The research and development office in Northern Ireland could assist in funding research and development projects or signposting applicants to National Institute for Health Research (NIHR) and United Kingdom Research and Innovation (UKRI) competitive funding streams. Transnational research projects can be especially insightful. The Northern Ireland Assembly Research and Information Service (RaISe) could hold copies of pertinent research and evaluations for Members to access, and it could be commissioned by Members to collate information relating to issues raised by the research reviewer.

To sum up: the Autism (Amendment) Bill has the potential to re-boost more effective and efficient services to people on the autism spectrum. We know what needs to be done and what could be done, but the basic problem is that it is not being done.

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

Alyson, which of you will make brief opening remarks on behalf of the Human Rights Commission?

Ms Kilpatrick: I will, Chair. I have been the chief commissioner at the Human Rights Commission since September. I am joined by Emily Mills, a lawyer who has been working on this issue and related issues. She is here to assist with questions, if necessary. I will keep my comments brief, as I know that you are tight for time.

The core function of the commission is to review the adequacy and effectiveness of law and practice relating to the protection of human rights in Northern Ireland. In doing that, we give advice on legislative and other measures that ought to be taken to protect human rights and on whether proposed legislation is compatible with international human rights standards. In the context of the Bill that is under consideration, the commission has considered, in particular, the European Convention on Human Rights (ECHR), the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), the UN Convention on the Rights of the Child (UNCRC) and the part of the Belfast/Good Friday Agreement on the right to equality of opportunity in all social and economic activity regardless of disability. Those are the most directly relevant, but we use other instruments to help us to interpret the law.

As you know, the commission has a new statutory responsibility under the protocol on Ireland and Northern Ireland to ensure that, as a result of leaving the EU, there is no diminishing of the rights protected in the Good Friday Agreement. Article 2 of the protocol commits the UK Government to keep pace with certain provisions of EU equality law, including the employment equality directive, which prohibits discrimination on the grounds of disability in employment and vocational education. The commission can say that, while no breach of the protocol has been identified, the commission recommends that the Committee and the Department consider the employment equality directive and continue to monitor relevant European Court of Justice (ECJ) jurisprudence insofar as it is relevant to the proposed autism strategy relating to employment and vocational education and, in doing that, ensure that the UN Convention on the Rights of Persons with Disabilities is used to interpret the protocol.

Given that autism spectrum disorders come within the definition of disability and the Bill reflects many of the obligations deriving from the relevant convention, we welcome it as being a positive Bill. If enacted, it should ensure more human rights approaches being taken to disability assessment and provision generally and specifically in relation to autism, because the focus is on individuals. The starting point is always the person, not the disability or impairment. Consideration is then given to the barriers that hinder their full and effective participation in society on an equal basis with others. It is good practice in all public administration, clearly, that citizens have easy access to good information about the system and their rights. In the case of disability assessments, autism spectrum disorder assessments and benefits, it is even more vital to ensure that such systems are accessible for users.

The UN Convention on the Rights of Persons with Disabilities expressly requires states to collect appropriate data to enable them to formulate and implement policies that give effect to that convention. Similarly, as part of the implications of the UN Convention on the Rights of the Child, states are required to set up and develop mechanisms for collecting data that are accurate, standardised and allow disaggregation and reflect the actual situation of adults and children with disabilities, including autism. Therefore, the commission strongly welcomes the inclusion of a proposed duty on the Department to request health and social care trusts to provide data on the prevalence of autism both in adults and in children. The commission's experience in all areas of its work is that you do not tackle inequalities unless you know exactly the scale of the issue that you are dealing with. We are particularly pleased to see the Bill promoting the collection of data, followed by the analysis of that data and the sharing of data and information. We say that that is necessary if a human rights approach really is to be adopted, because the strategy that follows must be based on evidence of need, both systemic and individualised.

The commission also welcomes the intention to closely consult and actively involve persons with disabilities, including children, in the development and implementation of policies, and that is an express requirement of international law. While clause 1 aligns with those requirements, the commission recommends that the autism strategy compels expressly the Department to involve and consult people with autism spectrum disorders, parents and carers of children and adults with autism and representative organisations in the sector. Importantly, they should be included not only in the development of the strategy but in its monitoring and implementation.

The Human Rights Commission and the Equality Commission are jointly designated under the Convention on the Rights of Persons with Disabilities as the independent mechanism for Northern Ireland, and that is for monitoring the realisation of the rights of the convention. For that purpose, we have an established independent disability rights forum to assist us, and, while that mechanism is in

place and is proving to be useful, it is not, we say, a substitute for the direct involvement of persons with disabilities at the heart of government. The independent mechanism's role is to monitor. For that reason, we are interested in clause 5 and how that may work in practice. That clause provides for the appointment of the autism reviewer, which is positive in principle. The commission will be keen to work with the reviewer, and we would appreciate more information on how the role will feed into implementation of the convention by way of the independent mechanism.

Finally, the commission would like to simply restate that the overall purpose of legislation, if it is to comply with human rights standards, must be to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. I say that because it cannot be limited to health provision. That ignores the individual person and puts their impairment beyond their rights to human dignity. We say that there needs to be a comprehensive and coordinated approach to implementing all obligations under the convention. The strategy truly should be cross-departmental and include adults and children. To implement the UN convention, everything should be considered, including education, housing, employment, health and justice. We know of the anticipated regional disability strategy from the Department for Communities, and that seems to be an opportunity to run the strategies in tandem. There will almost certainly be issues of overlap between the two, and they should complement each other.

Really finally, the self-evident fact is that, if the Bill is to make any difference, the allocation of resources will require close attention. They need to be adequate, coordinated and proportionate both for the autism strategy and for the overall disability strategy.

Unless Emily wishes to add anything, I will leave it there. I am happy to answer questions, if and when you have them.

The Chairperson (Mr Gildernew): Thank you, chief commissioner.

Shirelle Stewart is the director of the NAS. Go ahead with your opening remarks, please, Shirelle.

Ms Stewart: Thank you very much for inviting my colleague Sharon McDaid and me along today. For those of you who perhaps are not familiar with the work of the National Autistic Society, I say that we are the UK's leading autism organisation. Our aim is to change the lives of people with autism and their families and to improve the support that they get. I will give you an idea of the scale of our reach: 5 million people visited our website last year, and we have 116 volunteer branches across the UK supporting 20,000 people. In 2019, in Northern Ireland, we opened the first autism centre that caters for the needs of autistic adults and children and their families.

Before I go into our comments on the private Member's Bill, I state that the National Autistic Society Northern Ireland is supportive of any legislative proposals that will make life better for autistic adults, children and their families in Northern Ireland. While some good work is going on across Northern Ireland, autism services are still the Cinderella of services, and adequate funding has never been put in place to address that imbalance.

During the COVID pandemic, I presented to various Northern Ireland Assembly Committees. One of those presentations was about our 'Left stranded' report, which looked at the impact that COVID has had on autistic people. That impact has been devastating, and people with complex needs have particularly suffered. COVID basically highlighted the injustices that exist for autistic people across Northern Ireland. The lack of services and support has been there for many years, but COVID brought it to the fore. Even now, services for many autistic people and their families have not been re-established. Respite services are still closed, and a number of them have been repurposed to house children whose family lives have broken down due to the lack of support being provided. Adult day services are still not open to take people for their allotted time. In some trust areas, adults can wait for up to five years for an assessment and diagnosis. For children, that wait can be up to three years. I just wanted to give the context of the situation that we are dealing with in Northern Ireland. Frankly, the situation with support and services has not been tackled adequately, and autistic people, children and their families suffer as a result.

I will go through some of the clauses on which we have provided comment. First, although we support the Bill, we feel that the private Member's Bill has missed an opportunity with regard to training. According to the report 'Prevalence of Autism (including Asperger Syndrome) in School Age Children in Northern Ireland Annual Report 2021', the prevalence of autism in schoolchildren was 4.5%. Given that figure, it is likely that most educational professionals will encounter a child with autism in their career. Autism training is therefore essential to ensure that autistic pupils meet their full potential.

Those children will become adults who will use Health and Social Care services throughout the course of their life. The National Autistic Society Northern Ireland believes that the private Member's Bill should contain a mechanism to make autism training mandatory for educational professionals and Health and Social Care staff. There are duties in the statutory guidance of the Autism Act 2009 in England whereby there will be mandatory training for health and social care staff. We would like to see that applied in Northern Ireland.

The National Autistic Society questions why, in clause 2, provision is limited to "early" intervention. That implies only young children, but autistic people are diagnosed at all ages, including in adulthood, and they need services and support. We feel that that should be reworded, and we recommend the following:

"The autism strategy must set out how the Department is to make provision for an autism intervention and support service."

That would cover both children and adults.

Presently, in Northern Ireland, there are extremely long waiting lists, as I said, for children and adults to have an autism assessment. The Bill should address that by inserting wording such as:

"The autism strategy must set out how the Department is going to address the length of time persons with autism are waiting for an autism assessment."

I move on to new subsection (4D). The National Autistic Society welcomes the specific inclusion of adults in the legislation, as previous strategies have failed to address their needs adequately, but we suggest some amendments. The reference to "supported living" in new subsection (4D)(e) should be changed to "housing", as there are many housing options that autistic people may want to avail themselves of, not just supported living. We also feel that a number of issues should be added to that list to strengthen it. For example, "mental health needs" should be added to the list, given the high rate of coexisting mental health problems experienced by autistic people, both children and adults. "Physical health" should be added to the list, as should "independent living skills".

With regard to the methodology of the autism strategy, the National Autistic Society would welcome clarity as to the meaning of this section. New section 3A(3) states:

"The autism strategy must take a multidisciplinary approach."

We are not clear what that means in this context, and we would reword it to say:

"The autism strategy must set out how it will ensure consistency of practice across the health and social care trusts."

On new section 3A(6), the National Autistic Society suggests that it is not just:

"bodies with an interest in promoting the rights of persons with autism"

that should be involved in developing the measurable targets. For genuine co-production to take place, it must also involve autistic people and their families and carers.

The Department of Health has set up an autism forum that comprises the voluntary sector, parents, carers and autistic people to co-produce the next autism strategy. That forum is co-chaired by two autistic people. The National Autistic Society suggests that clarity should be sought around how that forum is consulted in setting those measurable targets. We also suggest that there is a role for the autism reviewer in setting those targets.

I will move on to annual autism funding reports. The National Autistic Society is unclear as to how that could be accomplished, as funding for people with autism can come from a number of sources. For example, if there is a coexisting mental health or learning disability, it will come from those streams. There is confusion as to how accurate those funding reports would be. The National Autistic Society Northern Ireland believes that the autism strategy should come with its own budget, as is the case in England, which has a £73 million budget for this financial year. We have to measure not just how that money is being spent but how it impacts on the lives of autistic people and their families.

New section 3C(1) states:

"The Department must appoint a person as the autism reviewer."

The National Autistic Society suggests that the autism reviewer should be independent of the Northern Ireland Departments to ensure credibility and to avoid a conflict of interest. New section 3C(2) states:

"The reviewer must issue a report annually on the exercise of their functions".

We suggest that the report should be on the progress of the implementation of the strategy.

On the functions of the autism reviewer, as outlined, the Department of Health has instituted an autism forum that is co-chaired by two autistic advocates and comprises autistic people, parents, carers and the voluntary sector. The National Autistic Society suggests that the following be added to the functions of the reviewer: to work with the autism forum and lay the annual report before the forum; and to make recommendations to the Northern Ireland Assembly.

The National Autistic Society is basically stating its support for the private Member's Bill, but we are also asking for changes to strengthen what is there.

The Chairperson (Mr Gildernew): Thank you very much, Shirelle. I thank each of our witnesses. It is interesting and useful to hear those different perspectives. I have a couple of questions, and then I will go to members.

This is to either Shirelle or Laurence: how can we ensure that intervention for children is provided at the earliest opportunity? Also, how can we improve intervention and early intervention for adults?

Professor Taggart: We need to identify the evidence-based interventions that have been proven by research. We need to identify children as early as possible and then implement those interventions in nursery school, Sure Start and primary education and work with families on that. Professor Roy McConkey has done a lot of work on that, so I will ask him to develop what I have said.

Professor McConkey: One of the issues is that, if there are waiting lists for diagnosis, some form of intervention should take place while those people wait. A project in Fermanagh provides that. Finding that has been a great source of reassurance to families. The fact that they have encountered developmental difficulties with their child means that they have already identified issues that they find difficult to deal with. We need a system that is sensitive to parents' concerns and provides an opportunity for those to be addressed in a family-based context. Health visitors are often the ones who pick that up, but they do not necessarily have the wherewithal to make any form of referral other than that for assessment and diagnosis. Through the project in Fermanagh in which Positive Futures is involved, workers trained in autism advise families on activities that they can do at home and put them in touch with other families as a way of providing that support. We have to be imaginative about the types of intervention. We cannot just rely on the statutory services to meet the need; rather, we need to mobilise that need through the community and voluntary sector, as Shirelle and others said.

The Chairperson (Mr Gildernew): OK. Thank you. Shirelle, do you want to comment?

Ms Stewart: Yes. Everybody has mentioned that children and adults are not being assessed and diagnosed in what is seen as a reasonable time frame. At the moment, the ability to access intervention is still problematic. Intervention should happen at the point at which people have been identified as having problems. We have to be blunt about this: not enough early intervention services have been put in place for children, and they definitely have not been put in place for adults. Again, funding has to be put in place, because at the core of all the issues is a lack of funding for services and support for autistic people.

The Chairperson (Mr Gildernew): Thank you. I think that everyone mentioned the role of the reviewer, so there may be a range of comments on this question. How does each of you see the role of the reviewer linking with other statutory bodies and stakeholders? Indeed, in recognition of the complexity of the areas involved — education, health, training, as well as lots of other areas — how do you see the role of the reviewer linking with other statutory bodies? Does anyone want to volunteer to go first?

Ms Kilpatrick: The commission is part of the independent mechanism for monitoring the convention, so perhaps I can make a brief suggestion. One reviewer, in our view, is sufficient; in fact, there is some benefit to having a single person, as long as you get the right person who is sufficiently independent. That person will need support, so they will need backup and staff, with access to all the departmental officials whom they need.

In respect of how that reviewer can pull everyone together, the commission, through the independent mechanism, will be keen to offer its support and to hear what, the reviewer thinks, is necessary. The reviewer should have some official, direct ties into every Department and should be able to require the production of information, documentation etc. The reviewer also needs to have transparent, structured and regular engagement with people with autism. They must have formal links with the representative bodies and individuals. If the right person is in place, one reviewer is enough, but they must be supported, given autonomy and have what they need to link in with the sector.

Ms Stewart: I very much agree that the reviewer has to be independent. The autism strategy is meant to be cross-departmental, and the reviewer must be granted the ability and power to ask for and get information from all the Departments. It is vital that the reviewer involve autistic people, their families and carers in the process.

The Chairperson (Mr Gildernew): Thank you. I appreciate —

Professor McConkey: May I come in?

The Chairperson (Mr Gildernew): Go ahead, Roy.

Professor McConkey: I fully agree with the notion that one person will have those responsibilities. In Northern Ireland, we have a wealth of talent with the experience of undertaking those activities. Therefore, it is a matter of coordination and finding mechanisms for the autism reviewer to have the support, as Alyson said, of the research community, the practitioner community and the service user committee. All those elements are present and ready to be mobilised, and we need a mechanism to get that mobilisation under way quickly because that is a big lack at the moment.

The Chairperson (Mr Gildernew): OK. Thank you. Roy, can you use the "Raise hand" function? I cannot see you. I can follow indications from the rest of the panel fairly accurately. If you can use that function, that might be easier.

Professor McConkey: Thank you.

The Chairperson (Mr Gildernew): Shirelle, you made suggestions that relate to my final question on amendments. You made some interesting suggestions that will bear further examination. I appreciate that. Can members of the commission or academic members suggest any other useful amendments?

Professor Taggart: In the briefing paper, we have made suggestions on how to use research more appropriately to explore the needs of this population going forward. We have suggested how to implement the research in practice, and that is one of the difficulties. Good research has been undertaken in Northern Ireland, but it has not been implemented. There are low-cost community interventions. The autism reviewer could hold trusts accountable to ensure that good practice is implemented.

The Chairperson (Mr Gildernew): OK Thank you.

Ms Kilpatrick: I have a short addition to that. The commission has set out its suggestions in its written submission. When looking at the strategy and enacting the Bill, I encourage the Committee to start from a human rights basis. You look at the rights of an individual person to housing, education and full participation in society despite their autism. Do not confine autism to a health and medical issue but look at fulfilling the human rights of those people first, and everything else will fall into place. As Shirelle said, look at the individual first and look at the training of those who work with them.

The Chairperson (Mr Gildernew): Thank you. In my social work background, I worked on a training team that used the rather jargonistic term of a biopsychosocial approach. That means that you take every element of the person's life, needs, wishes and ambitions into account, and that is the right approach. Thank you.

I will move to other members. Lean ar aghaidh, le do thoil, Órlaithí.

Ms Flynn: I have a couple of questions that touch on some of the issues raised by the panel. First, does the panel have a defined understanding of the autism reviewer's job role? People have said that the role is positive in principle and could have an impact on research, and the person will work with the autism forum. If that role is to be implemented after the legislation is enacted, the job description will be crucial, as one person will handle the coordination for a lot of issues.

Secondly, I think that you, Laurence, identified future research priorities. Some of that work has been delayed and has not yet been resumed. Where would all that sit with the Bill, if it were passed? You also touched on the inefficiencies in the system. Would you attribute that to us in the North having the highest prevalence rates across these islands? Are you attributing any of it to the overall issue of health inequalities and how the Bill could help to address them?

The amendments that Shirelle mentioned are useful. Will you elaborate a bit more on what you said about mental health needs not being addressed? Specifically, what practical measures could we put in place or add to the Bill to make sure that we also protect the mental health needs of those who live with autism?

Professor Taggart: About three years ago, we started an autism research hub at the university. It is multidisciplinary in the university, and it involves the trusts, the voluntary and statutory sectors, service users and families. We identified five hubs or areas. One was looking at the health inequalities of children and adults with autism. The second was around the educational needs of children with autism, and teachers and classroom assistants. We have three PhD students: one is looking at the role of classroom assistants in primary schools; the second is looking at a whole-school approach to autism; and the third student is looking at children with autism in primary school who are transitioning to secondary or grammar school. We are looking at the use of virtual reality. Although there is no research funding, we are trying to identify some funding in the university and trying to seek PhD students to carry out some of that work.

We have another hub around the use of technology to support children and adults with autism to transition and integrate into the community, but that has not taken off. We have identified research areas in the university, but it is restricted to where we get our funding from.

We have worked with people across the water on health inequalities. We have done a systematic review of health inequalities around people with autism, including those who also have a learning disability. There is a wealth of information to show that people with autism have a range of physical and health inequalities and do not use the health service as efficiently as ordinary members of society.

Roy has been doing some research around early intervention and why it has not been implemented.

The Chairperson (Mr Gildernew): Roy, are you able to come in on that?

Professor McConkey: I hope so. I cannot find my "Hand" function, so I am afraid that it is the voice that I am having to use.

We have been doing an evaluation of innovative schemes in which you try to provide timely interventions in a situation that is, essentially, trying to prevent crises from arising. The project that we talked about in the west with the adult ASD team involved young adults with potential mental health issues who were able to be supported into leisure activities, employment activities and vocational training activities. By doing that through an experienced worker, who, as it happened, was employed by Cedar, you were working outwith existing systems but linking and signposting people into those systems. The coordinating function that the individual worker provided was a way in which families could get timely support, just as the young people themselves were getting that support. However, the project was time-limited. We have not evolved systems that allow for sustained funding to be provided to those innovative projects. We have shown the value of them, but, because the system is already stretched in terms of models of provision that we do not think deliver the goods, we do not have the money to invest in the new forms of service that are potentially much more cost-effective. We certainly have a systemic issue, and the hope is that the Bill and the role of the autism reviewer will highlight some of those inefficiencies, suggest ways in which they can be addressed and lobby for the support of advocates to make that happen. The front-line professionals are often the people who are aware of how the system is not working. The change needs to come from management and senior management levels to bring about a systemic change in the Transforming Your Care agenda.

The Chairperson (Mr Gildernew): Órlaithí, there was another element to your question on the job description or role of the reviewer? Was that picked up on yet?

Ms Flynn: Some of that was touched on in the answer on the role that coordination can play and the change that needs to come from senior management.

Could Shirelle from the National Autistic Society address the point on how we can better address mental health needs in the Bill?

Ms Stewart: Órlaithí, thanks for raising that. It is a fundamental problem that is not being adequately addressed for autistic people. To give you an idea of the extent of the difficulties, 94% of autistic adults have experienced anxiety and almost six in 10 have said that that affects their ability to get on with life. Almost two in three autistic adults have a clinical diagnosis of anxiety, and 83% have experienced depression.

Mental health issues are not a part of autism, but they coexist with it. We have to tackle the reasons why autistic people experience such high rates of mental health problems. It comes down to a lack of support. For example, if you are waiting for a really long time for an assessment and diagnosis, you are not getting to grips with what is bothering you and cannot access the right support. Autistic people are isolated in society, so we need to introduce programmes that will address that isolation because we all know that it can lead to poor mental health. Autistic children are more likely to be bullied in the school environment and often do not receive the support that they need in that environment. Again, that is a contributory factor in not having good mental health.

There is also a major issue around the mental health services that we have in place. Quite a lot of the therapies and interventions are not suitable for autistic people and need to be adapted. That goes back to an earlier point: those therapies cannot be adapted unless you have well-trained practitioners who understand autism and can adapt the interventions in an appropriate way that enables autistic people to access them. We published a mental health guide in conjunction with Mind to highlight to professionals how they should adapt their practices to best meet the needs of autistic people.

The other thing that I suggest is practical. Autistic people struggle to access mental health services. We know that children have great problems in accessing child and adolescent mental health service (CAMHS), and adults have problems in accessing adult mental health services. That is because a lot of practitioners suggest that the problems are to do with their autism and do not recognise that it is a coexisting mental health condition.

Quite a lot of funding is in place for the mental health strategy, and autistic people are given a slight mention in it. The problem is that we have no funding for the autism strategy, which is where we should tackle the causes of mental health problems for autistic people, such as the lack of support, intervention and training. We are looking at funding for an autism strategy as well. If we want to address the core issue of why mental health is a big issue for autistic people, that is what we need.

The Chairperson (Mr Gildernew): Thank you, and thank you, Órlaithí. If there are questions or detailed answers that we do not have time for today or where forwarding a written response would do the question more justice, we can do that via the Clerk. Members and panel should bear that option in mind.

Mr McGrath: I welcome the opportunity to discuss this really important issue. Autism is prevalent in all our constituencies, and we are regularly contacted by families about it. I commend the Bill's sponsor for introducing the Bill to try to update our provision of support.

There has been reference to isolation and the community support that is available. I want to plug, in addition to an autism diagnosis, having an ADHD diagnosis as well. In my constituency, an ADHD hub in Newcastle does sterling work in reaching out to and providing support for young adults who have that diagnosis and their families. Like many of the services provided, the hub tends to be run by voluntary organisations. They struggle to provide the services that they do.

Laurence, from an academic perspective, has any research been done on the wrap-around services that were referenced? Do we know how supportive or helpful they are? Has there been any backup from the academic world for those? That would help us to put to the Department the need to provide support for those services.

Shirelle, through your organisation, have you had real-life experience of the help provided by the wrap-around services that are available in our communities?

Professor Taggart: I will ask Roy to answer that. He was involved in research on the wrap-arounds.

Professor McConkey: Colin, you make a very important point. Our systems are so siloed that it is difficult to achieve that across the statutory services. The voluntary and community sector has been much more adept at doing that.

The best of the wrap-around services in Northern Ireland, particularly for early years, were in the Southern Health and Social Care Trust area. The trust mobilised a lot of community support, parent-led organisations and NGOs that were involved in that sector. The trust facilitated that, and its personnel were key players in it. The whole concept was trying to look again at how we provide a point of contact for families: individual workers who could link into other services as needed. That model has been used in many countries for other marginalised groups as a way of bringing services to them.

There certainly is a wealth of demonstration projects that we could point to. In many ways, I do not put a great deal of faith in changing people's attitudes to that multidisciplinary, cross-sectoral way of working until they are convinced that the systems need to be redeveloped and reassessed. Sometimes, if you are in a marginalised group, as people with autism are — despite their number, they are still a minority group — it is the dominant service models used for the wider population that often determine what trusts and statutory agencies see as what they can viably achieve. They are much keener to try to fit the marginalised, specialised work into their existing framework. What you hear from us is that we need to have a new way of looking at issues for people who have different and somewhat more complex needs.

Yes, we have those models, and they have been tried in Northern Ireland and internationally. It is about how we change the system at the highest of levels. Alyson emphasised how important it is that we do that from the perspective of rights and individuals. We then make our systems responsive to those rights and needs.

That is where the transformation needs to come. Goodness knows, we have talked for a long time in Northern Ireland about transforming social care, in particular, but where has been the will to implement transformation and start to make those changes? Legislation, because it provides the accountability mechanisms that we have been lacking, is one approach in which we can put some faith. It has been done informally, and we have tried to do it through the regulator, but that has not led to transformation, particularly. We are looking for an avenue that could make an impact and facilitate the transformation that has been long talked about.

Ms Stewart: When you look at services, you see that it is the third sector that has been more agile in its ability to respond to the needs of autistic people and their families. A lot of the services that are being delivered by the voluntary and community sector cover, or try to cover, the whole sphere of people's lives. We are running Support for Life, a project that looks at provision for young children. We offer education advice, provide family support and independent living skills training, and work with adults to try to address such issues as socialisation. It is key that those programmes are put together with the input of autistic people and their families. It has to be them telling us about the type of services that we need. That needs to be key in any kind of service provision. It should not be the case that autistic people and their families are being asked to fit; that is like putting a round peg into a square hole. Basically, the services need to be adapted to and fitted around the autistic individual and their family. Again, however, the difficulty with the third sector providing those services is that it makes a funding application and runs the services for three years; the funding then runs out, and the cycle begins again. To address these issues, there has to be some continuity in the funding and commissioning of services. However, at the core, we should be listening to the voices of autistic people and their families and carers.

Mrs Erskine: I apologise. I have had some technological issues with broadband. Hopefully, you can hear me.

The Chairperson (Mr Gildernew): Yes, we can hear you, Deborah.

Mrs Erskine: I thank the panel for its constructive comments on the Bill. First, I have a question for the University of Ulster representatives. Are there particular research findings or recommendations from previous studies that the professors would like to see taken forward? Is there scope to address those within the framework of the Bill?

Professor Taggart: There is a lot of research, as Roy identified. Over the past 10 or 20 years, he has been involved in a number of early intervention research projects that have been shown to work and that would be effective. They would be low-cost community supports. Others also mentioned them. There are good projects. They are funded for a small pot of money, but, when the pot of money finishes, the trust does not take them on. It is about trying to get the trusts to be accountable and say, "Here's best practice. This is what should be implemented". There are a number of projects and early interventions with families of individuals with autism that could be taken on. Roy, do you want to expand on that?

Professor McConkey: Yes. *[Inaudible owing to poor sound quality.]*

The Chairperson (Mr Gildernew): We are not hearing you, Roy, but we will try again. Go ahead. *[Long Pause.]*

Professor Taggart: He is in South Africa.

The Chairperson (Mr Gildernew): I think that we have lost Roy. Do you have another question, Deborah? We will go back to Roy after that.

Mrs Erskine: Yes, I do. Thank you, Chair.

Do you feel that there is a need for the Department of Health to urgently re-engage on autism issues? Related to that, what do you believe are the main obstacles to ending the regional disparities observed in autism diagnosis, and are those substantively dealt with in the Bill?

The Chairperson (Mr Gildernew): I will go back to you, Laurence. We are still not hearing from Roy.

Professor McConkey: I have just come on stream again, Chair.

The Chairperson (Mr Gildernew): OK. Go ahead, Roy.

Professor McConkey: Sorry, my call keeps dropping out. I have more problems than Deborah has, I think.

Deborah, the issue has been that the trusts do not always know what is happening vis-à-vis other trusts. One of the purposes of having regular monitoring, which the autism reviewer might do, would be to highlight, even for the trusts themselves, the variation in their practices and to start the process of discussion on what best practice we should commonly be following to remove some of those disparities. In the Belfast Trust area, a number of families and children need help, but, in the Southern and Western Trust areas, they are being denied that help. In a small place like Northern Ireland, there are those inequities of access. In some ways, there has to be an internal process within trusts to question what they are doing and how they are meeting needs, but we also need to look at spreading good practice across trusts. I have 20 plus years' experience of looking at service delivery in Northern Ireland, and we still see big disparities between our trust areas. Even when the Department knows and recognises that — the Public Health Agency and the Health and Social Care Board recognised it — nothing gets done about it. That needs to change, and that is the role of the autism reviewer as, at least, another strategy and another way of tackling that.

Mrs Erskine: Thank you for that, Roy.

Ms Stewart: Deborah, that is why we also suggested that the clause that deals with the methodology of the autism strategy should be reworded so that it has to outline how it will ensure consistency of service delivery across Northern Ireland.

Mrs Erskine: OK. Chair, may I ask a few final questions?

The Chairperson (Mr Gildernew): Briefly, please, Deborah.

Mrs Erskine: I know that we are tight for time.

Shirelle, maybe you can take this question. Apologies if you have covered it already; my line dropped out quite a bit earlier. Which bodies outside the autism sector would you like to see included in the duty to set out measurable targets for the autism strategy?

Ms Stewart: It is the role of the autism strategy to look at intervention across Northern Ireland. Bodies must have a role in looking at things like education provision and health and social care services, but, as we touched on earlier, there are also mental health issues among autistic adults, and things like employability and employment are key issues that impact on people's mental health.

The autism strategy was set up to be cross-departmental, as outlined in the Autism Act, and that is, perhaps, being lost in this next strategy. We need to look at how we address that. We need to make sure that all those bodies are involved and that the reviewer has access. It is also about looking at the role and powers of the autism reviewer so that that person can access the health and social care trusts, the Department of Education and all the different Departments.

Ms Ní Chuilín: A lot has been said, and I appreciate all the commentary. I have a couple of quick questions. The way in which diagnoses happen at the minute is grossly unfair and causes additional inequalities. Families have to pay for private diagnoses, which is ridiculous, to say the least. In your opinion, what do we need to include in the Bill to ensure that that does not happen? What else do we need to do with regard to international best practice on human rights standards?

We scrutinise all the budgets that come before the Committee, and we have consistently pointed out that the Department has engaged in equality screening rather than a full equality impact assessment (EQIA). We have commented on that and said that it is wrong. In the Department's screening, disabilities and inequalities are described as being major or minor. When it comes to children, elderly people and others, they are described, even by the Department, as major. What can we all do through the opportunity of the Bill — it is an opportunity — to cut down on discrimination, promote equality and ensure that diagnoses are based not on the ability to pay but on need.

The Chairperson (Mr Gildernew): Who wants to pick up on those issues?

Ms Stewart: I can say a little about assessment and diagnosis. It is unbelievably unfair that the only people who are able to access an assessment and a diagnosis are those who can afford to do so. That is such a big inequality. The problem goes way back, and it is like continual firefighting. Back in 2016 — perhaps before that — additional funding was given to address what we identified at that time as a crisis in the assessment and diagnostic programmes in Northern Ireland. That funding was, however, £2.6 million, which, when spread across all trusts in Northern Ireland, was, quite frankly, inadequate, and nothing else has been put in place to address the issue. That was for children's assessment and diagnostic services.

What you now find is that, with the assessment and diagnostic services for children, the waiting list can be about three years, which is exceptionally bad. For adults, however, because sufficient money was not put into the assessment and diagnostic services for them, it is even worse — up to five years. When you look at the money provided by the trusts for children's services and adult services, you will find a big disparity between the two. Also, trusts are required to report on the waiting times for autistic children but not on the waiting times for autistic adults. That also has to be addressed. Those are my initial comments in response to the question.

Professor Taggart: Carál, I will speak to your last question about what we can do about the health inequalities of people with autism. In England, a few years ago, there was a young man called Oliver McGowan. He had a learning disability and autism. His mother had informed an acute hospital that he was allergic to a medication. Unfortunately, when the teenager was admitted, he was given that medication and died a horrific death. His mother campaigned to the health committee at the Department of Health in London, and it has initiated mandatory learning disability and autism training. It is running an initial project for something like 40,000 staff in acute hospitals. I cannot remember how many hospitals are involved, but those staff are getting mandatory training in learning disability and autism. That involves between three hours and six hours of training. We have just done a recent project with the health education authority in England; I cannot remember its name. We have said that training itself is not enough to change clinical practice and improve the quality of care of people with autism or a learning disability.

A number of system changes have to take place. That is what the Bill is about. The autism reviewer's role would be to ensure that places like acute hospitals and others in the statutory sector put in place a

range of system indicators that allows staff who get that training, be it through Education or Health, to ensure that the clinical care of people with learning issues and autism is implemented. That is one of the biggest barriers. We need to change the systems. We also need to assess the systems regularly to identify what is not working as well as what is working. People need to be held accountable to ensure that those outcomes are achieved.

Ms Kilpatrick: Carál mentioned international best practice. Certainly, it is recognised that people with autism are not enjoying many of their other rights, because, if there is no diagnosis, the barriers to their accessing rights cannot be identified. Therefore, those barriers are not overcome, and society does not put in place the measures that they need. They are rights holders in their own right, as are their families, and that is not always recognised. International best practice and human rights standards require every policy, law and practice to be screened so that it can be identified whether there is a disproportionate impact on people with autism. It is certainly hoped that an autism reviewer might be able to do that.

Linked to that is data collection. It is about not only gathering the information to identify who needs what and when but reporting on, monitoring and reviewing that information. That allows people to be held to account.

Linked to both of those is training, and that is key. The only way to make sure that autistic people are rights holders and get to enjoy their rights is to make sure that those who provide access to housing, education, health etc have been properly trained. I have to confess that I have seen too many bad practices, where people simply are not equipped to deal with, for example, an autistic person who is making an application as a homeless person. The whole thinking needs to be flipped on its head. There are experts who can help you to do that, and you have heard from them today.

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

Mr Chambers: Over recent years, the public have become more and more aware of autism. We all know people in our immediate social circle who have an autistic family member. It is great that we, as a society, have become serious about helping and supporting young people with autism to go forward and live a full and productive adult life. I certainly back every aspect of the Bill. The way in which to address the issue that Carál raised is to ensure that there is capacity in the system. That is what we have to work towards: having that capacity so that people do not have to go private.

Some 30 or 40 years ago, I had not heard of autism. It was not a subject that people spoke about or that you read about. For my personal knowledge, what was the outlook 30 or 40 years ago for young people who had autism? Was it recognised? Did those in the medical world then diagnose it as autism, did they have some other name for it, or did they just not know that the condition existed?

The Chairperson (Mr Gildernew): Who wants to pick up on that?

Professor McConkey: That is a good point, Alan. What has happened is that we have become more sophisticated in the way in which we identify the different disabilities that children might present with or the problems that they might encounter. One of the issues in the past was that they were generally lumped together as having some form of intellectual disability called mental handicap or whatever. We were not very good at recognising some of their talents as well as some of their deficits. Over time, we have become better at doing that.

There is still the difficulty of being confident that a diagnosis is clear-cut. The concept of comorbidity is that, often, children do not present with a discrete disability but have a constellation of difficulties, and when you see a certain combination of those, you might use the label "autistic spectrum disorder", which is typified more by communication and social disadvantage.

What is happening worldwide, and we see evidence for it in Northern Ireland, is that there is a risk that children are being overdiagnosed as being on the autism spectrum when another condition, such as a global developmental delay or ADHD, may be a better way of accounting for their problems. That raises this issue: do we really need a lot of specialised diagnostic services for each impairment condition, or should we be investing in quality diagnostic services that will cover a range of need? So, in Northern Ireland, we set up specialist ASD teams to work with children at the same time as we had other child development teams working. We run the risk of putting too many resources into the diagnostic process and not having any money left over to help with supporting families post diagnosis. The crisis that I see is not necessarily the waiting time for a diagnosis; it is the waiting time to get

support that is targeted at the children's difficulties and at supporting families in helping themselves as well as their child. That is where the stresses and strains are in the system. The solution will not, I think, be more investment in diagnostic professionals; it will be more investment in a system that combines assessment, diagnosis and intervention. That is where we need a multisectoral, integrated approach to make the best use of the investment that we have already.

Mrs Cameron: I do not have a question. I just want to restate my declaration of interest: I am the sponsor of the private Member's Bill. I am, however, here as a Committee member, not as the sponsor. I thank everybody, especially the panel, for their support and contributions, which have been helpful. I look forward to listening to the session again and digesting what has been said. The suggestions that have been made will be helpful to the Bill's progress. I thank the panel for their answers and my Committee colleagues for their questions.

The Chairperson (Mr Gildernew): I also thank the panel.

One of the things that struck me during discussions on the various issues was the point about pilot projects that demonstrate their worth but are then discontinued. At various times, we have heard that the problem is exacerbated by having one-year budgets. Given that we are moving to three-year budgets, I hope and expect to see a significant improvement in the continuity of programmes of care that clearly work for people. Hopefully, that is one element that will be addressed. Then, with the legislation, there will be other improvements. I agree with all the comments made: this issue impacts a massive number of people, and it impacts on every one of them massively. We need to give our attention to that. It is useful that we are discussing the Bill in that context and applying scrutiny to it.

I thank every member of the panel for their contributions and for providing assistance to the Committee. I wish you all the very best in the time ahead.