

# COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

# **OFFICIAL REPORT** (Hansard)

**Autism Bill** 

2 December 2010

#### NORTHERN IRELAND ASSEMBLY

## COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

### **Autism Bill**

2 December 2010

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

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Mr Jim Wells (Chairperson) Mr Pól Callaghan Mr Alex Easton Mr Tommy Gallagher Mr Sam Gardiner Mr Paul Girvan Mr John McCallister

#### Witnesses:

Dr Maura Briscoe Mr Peter Deazley Dr Hilary Harrison Dr Ian McMaster

Department of Health, Social Services and Public Safety

#### The Chairperson (Mr Wells):

We have with us representatives of the Department of Health, Social Services and Public Safety. Some of the faces will be familiar to the Committee. Dr Maura Briscoe is the mental health and disability policy director, and has been before us on several occasions to address various issues; Dr Ian McMaster is a medical officer in the Department; Dr Hilary Harrison is a social services officer in the Department; and Peter Deazley is from the Department's learning disability unit. Please give the Committee a 10-minute presentation on the Department's position on the Bill.

#### Dr Maura Briscoe (Department of Health, Social Services and Public Safety):

Thank you very much, Mr Wells. Good afternoon, everyone. We fully recognise the importance of autism. We have, through various mechanisms in the Department, tried to promote and enhance autism services for children and adults, particularly over the past few years, and we will continue to do so. Therefore, on that basis, we believe that legislation is unnecessary at this time. I will drill down into the detail of why we think that it is unnecessary. Before I do that, however, I highlight that there has been substantial investment over the last comprehensive spending review (CSR) period. There have been a number of successes, including the formation of the regional autism spectrum disorder (ASD) network group, a significant reduction in waiting times for children for assessment and diagnosis, and the launch of a children and young people's assessment and diagnostic care pathway. The Committee will have heard the recent announcement about investment in adult autism services.

I do not propose to go into the detail of service provision. Rather, I will concentrate on the legislation and why the Department does not support it at this time. Members will see that the Autism Bill seeks to unilaterally change the Disability Discrimination Act 1995 (DDA) to include terms such as "social interaction (including communication)" and "social relationships". As the Committee knows, England has an Autism Act and a Bill is proceeding through the Scottish Parliament. No other jurisdiction has sought to change the UK/Westminster-enacted legislation to put in place a very broad definition in the Disability Discrimination Act.

Members will have seen the Office of the First Minister and deputy First Minister (OFMDFM) guidance for Northern Ireland on the Disability Discrimination Act. It is quite clear, and there are specific examples under DDA on autism. That is supplemented by recent case law that makes clear that autism is covered by the Disability Discrimination Act. It is unclear why the very broad definition of "significant difficulty" as:

"(i) taking part in normal interaction; or

(j) forming social relationships"

is being proposed to amend UK-wide legislation unilaterally in Northern Ireland. Clearly, there is a cost in doing that in respect of legal opinion, consultation, and reissuing and redeveloping guidance. There may also be challenges from individuals, for example in relation to workplaces or schools, etc, with a resultant potential cost. Given that there is already clear guidance, it is unclear why there is a proposed unilateral change in definition in the DDA. The Bill also seeks to change the definition of autism. Members will note that no other UK jurisdiction has sought to define autism in primary legislation. Indeed, the Committee will have noted that Scotland considered it disadvantageous to do that because research and understanding of autism and the range of the spectrum will change over time. Therefore, that was not put in legislation. In addition, the inclusion of any pervasive disorder that is not otherwise specified in the legislation would have the potential to widen the scope of autism and, therefore, may include individuals who would not generally be considered to have autism. That may, over time, have an impact on prevalence data and the labelling of individuals with autism.

One of the main provisions of the Bill relates to the autism strategy. That is not in any other legislation, it is an indefinite autism strategy, and it is mandatory. That would place the Health Department in the lead position in respect of the future production on an indefinite basis of an autism strategy. Minister McGimpsey made it clear that he does not need legislation to effect change and improve ASD services. Indeed, a new strategy with a new bureaucratic infrastructure to monitor it could slow down progress in moving forward with our enhancements for ASD services.

Members will also note that the Department of Education is producing an autism strategy for consultation in the new year. Therefore, there is potential for confusion with the new autism strategy as defined in legislation.

We already have a DHSSPS autism strategy, we already have a multidisciplinary ASD regional network group, we already have a reference group that includes 30 parents, carers and service users, along with 10 voluntary organisations. The implementation of the English strategy is not a million miles away from the infrastructure that we had ahead of them.

The Bill also states that DHSSPS will be the lead Department responsible for monitoring all other Departments that are required to contribute to the implementation of the strategy. No other jurisdiction has that in its potential legislation. Indeed, the recent Scottish legislation mentions Scottish Ministers — plural.

We feel that all of that will involve bureaucracy. The requirement to monitor the rolling indefinite nature of the strategy will cost money that we feel would be better placed in front line

service provision. The Bill also asks us to collect prevalence data, but we have already recognised the need to do that. We do not need legislation for that. Members will note that the recent launch of the children's care pathway on assessment and diagnosis is one step in the general direction to ensure streamlining of those services and enhanced data collection.

Finally, there is no detail on resources in the financial memorandum, but we feel that costs will arise from a cross-departmental strategy, the consultation process, extensive monitoring arrangements to be put in place, unilateral amendment to the DDA and from potential challenges that might ensue from those changes. Clearly, further guidance will need to be developed on the DDA. Costs will also stem from a public information campaign and to rolling out training for front line civil servants in all Departments. There will be a cost to implementing the actions in the new strategy, and that is not addressed. We would far prefer to see costs and finances going to front line services.

In summary, with the combination of the unilateral amendment to the DDA, a wider definition of autism, the costs and bureaucracy associated with the Bill, and the monitoring arrangements that would need to be put in place, we would far prefer to concentrate on areas where we are moving forward in partnership with what has already commenced through the regional ASD network group to improve front line services. Therefore, the Department believes that the legislation is unnecessary.

#### The Chairperson:

Thank you, Dr Briscoe. On a procedural point, I may have to nip out at some point, because there is some interest in the issue of waiting lists. The Deputy Chairperson is not here, so we will have to go through the procedure of nominating an acting Chairperson. Do we have any nominations for acting Chairperson?

#### Mr Gardiner:

Mr Easton.

#### The Chairperson:

Mr Easton will assume that role, as usual.

Dr Briscoe, you made the point that, because the rest of the UK does not have such legislation,

we should not have it. The view that many people would take is that we in Northern Ireland should be trailblazing, leading from the front, and trying to do our best for our autistic children. Others have not had the pioneering spirit to do this, but does that mean that we should automatically or slavishly agree with them?

#### **Dr Briscoe:**

Not at all. We are potentially ahead of other jurisdictions in having had an ASD network group in place and a strategy in 2009, before England put through its legislation or Scotland initiated its legislation. I emphasise that broad definitions such as "social relationships" and "including communication" will have knock-on effects that will be unilateral to Northern Ireland. They may potentially cause significance, perhaps not this year, but further down the line. Do not forget that the wording is not related to autism, but to broad words such as "social interaction" and "communication", so it has the potential to widen the net.

#### The Chairperson:

Autism groups have made the point that, at present, the definition of disability in Northern Ireland, physical and mental, does not necessarily cover every autistic child. The child might be all right physically and be very bright, but have enormous problems.

#### **Dr Briscoe:**

I am happy to accept that point. I refer you to the OFMDFM guidance on the Disability Discrimination Act 1995, which clearly defines disability in the context of impairment. It specifically says that:

"It is important to remember that not all impairments are readily identifiable."

It goes on to list a range of them, including:

"learning or developmental difficulties such as autism spectrum disorders, developmental co-ordination disorders or dyslexia".

If you read through that guidance, you will see that there are at least two specific examples in relation to autism spectrum disorder. There is also case law that does not support the view that autism is not covered by the Disability Discrimination Act 1995.

#### The Chairperson:

I have been familiar with these processes for 30 years, Dr Briscoe. I know that there is a world of difference between a definition in legislation, and one in guidance. In legislation, a definition allows a parent to take a judicial review or court action if he or she feels that a child has not been

properly dealt with. Guidance is simply that. Therefore, it much more powerful to have a specific reference in legislation that defines what is meant by an autistic child.

#### **Dr Briscoe:**

"Social interaction" and "communication" do not define what is meant by an autistic child. I draw your attention to the fact that there is case law that clearly identifies that ASD is recognised as a disability under the Disability Discrimination Act 1995.

#### The Chairperson:

Parents tell me that inclusion of the word "social" will guarantee that every child in the autistic spectrum will be covered. It is unusual condition: a child could be like Linford Christie with respect to his physical attributes. Some of those children are incredibly intelligent, and the ability of some of those people in maths and drawing is phenomenal but, because of their social abilities, they are different and they have problems in interacting with other children and their peers. That word guarantees that they will be covered. It ensures that no child will fall between two stools. That is what the parents are looking for.

#### **Dr Briscoe:**

If you look at the categories in the Disability Discrimination Act 1995, under schedule 2(4), it includes mobility, manual dexterity, physical co-ordination, constant ability to lift, carry or otherwise move everyday objects, speech, hearing, eyesight, memory or ability to concentrate, learn or understand, or perception of the risk of physical danger. This Bill will add underneath that the words in regard to social relationships, and so on. Therefore, only one of those categories needs to pertain, and that opens up the Disability Discrimination Act 1995 potentially much wider than was intended in the Autism Bill.

#### The Chairperson:

Some children will tick all of those boxes, but they will still have incredible difficulty interacting with their peers.

#### **Dr Briscoe:**

I draw attention to the fact that that is already covered in the guidance under:

"memory or ability to concentrate, learn or understand".

It gives as an example:

"significant difficulty taking part in normal social interaction or forming social relationships".

If there is case law and, within the definition of DDA, not only here, but across the water ----

#### The Chairperson:

It is in the guidance and the case law. Why not beef it up and make it perfectly clear by enshrining it in legislation?

#### **Dr Briscoe:**

That would expand the category much wider than autism and would have potential knock-on effects with regard to protections under the DDA for a range of conditions. There are lots of conditions beyond autism that involve social impairment and social interaction. Can you imagine what that could mean in the workplace if somebody said that his or her difficulties with social interaction and social relationships impaired his or her day-to-day activities?

#### The Chairperson:

It could mean that those people's difficulties might be covered by the DDA. I am merely putting the points that have been made to me. Alex Easton will take over the Chair; I will be back in five minutes. I know that members are keen to ask questions on this issue.

(The Acting Chairperson [Mr Easton] in the Chair)

#### The Acting Chairperson (Mr Easton):

Does any member wish to ask a question?

#### Mr McCallister:

I have a continuing concern about the Bill as it is drafted. We know that the Department of Health, Social Services and Public Safety has a strategy up and running, and you have said that this Bill could slow down the implementation of that strategy. How far along the track are you with the strategy? How much will it be slowed down? The Department of Education is going to take forward a strategy. There is a Department of Health, Social Services and Public Safety strategy and a Department of Education strategy, a plank of which is the centre at Middletown. There is a fair divergence of opinion between the Departments. How will the Bill overcome and deal with the differing strategies of the two Departments?

There is a good working relationship in the regional ASD network group between the two Departments. At local level, the regional group comprises people involved in education, and the chairperson of the ASD network, Dr Stephen Bergin, is a member of the education and library boards' inter-board ASD group. There is a good working relationship. I am not here to talk about the Department of Education's ASD strategy; I have no idea what is in it. I cannot talk about that. Our prevalence data on children and the sharing of information will be checked against any prevalence data held in the Department of Education.

Therefore we see, again, that on the ground there is already partnership working between health and education at all levels, so having a strategy in legislation is not going to make any difference.

What I mean by slowing it down is that we are well advanced in our strategy. There is an annual report on our strategy, which is one of the things that would be required by the Bill — we are already doing it. Our quarterly monitoring reports against the trusts' performances as part of our ASD action plan are also well advanced. The children's care pathway is a major piece of work that has the potential to streamline assessment and diagnosis — the tools that will make the collation of data and services much more effective.

We do not wish to see a dismantling of the regional ASD network group, which new bureaucratic monitoring systems that involve all Departments would clearly bring about. We are holding workshops in the new year to start evaluating our ASD strategy, which will then be rolled forward. Anything that cuts across that is going to slow us down.

#### Mr McCallister:

If the Bill goes through and you are the lead Department, what happens if the other Department disagrees with what you want to do? Who gets priority? If the Department of Education decided to stick with the Middletown centre, for example, and the Department of Health said that it was a white elephant or a waste of money, how would you make those two different opinions meet? It is encouraging that you have outlined a good relationship between the Departments which are both so intricately involved, but I do not know what would happen were policy to go off in two different directions.

#### **Dr Briscoe:**

The Department of Health would be required to monitor the actions of other Departments.

#### Mr McCallister:

So, you would have to monitor ----

#### **Dr Briscoe:**

Any actions in the strategy attributed to other Government Departments, they would have to implement. In Scotland, they talk about Scottish Ministers rather than one lead Department. The implication of monitoring is that we would monitor all other Departments, and the Bill requires other Departments to implement their aspects of the strategy. Therefore, the strategy would follow due process by going out to consultation and so on. That is the basis on which the final strategy would be agreed.

#### Mr McCallister:

Would your Department's monitoring include reporting back on whether it thought that a strategy was wrong or ineffective? Potentially, might you report that back without making any difference to it?

#### **Dr Briscoe:**

We would report as fact what other Departments were doing.

#### Mr McCallister:

But possibly could not do anything about it?

#### **Dr Briscoe:**

The strategy would be consulted on in advance. Therefore, whatever the outcome of that consultation, Executive agreement would be needed to publish the strategy. It would be up to the Executive to publish it. The decision on the content of the strategy would be an Executive decision, not one for one Department. We would have to monitor, post-consultation, once the Executive agreed the final strategy.

#### Mr McCallister:

But that could deadlock the strategy. You might end up with nothing being done.

That is why, as I say, we do not want a new strategy to cut across the good work that the regional ASD group is doing. Through that network group, we will be holding workshops in January and February in relation to rolling forward our 2009-2011 strategy.

I again emphasise that on the ground, at regional and local level, the interface with education is good and there is an interrelationship there that can and is being built on through participation in its ASD group and our ASD group. Given that the final strategy is a cross-departmental strategy, I imagine that it would be for the Executive to agree to its publication.

#### Mr Gallagher:

It seems to me, unless you can convince me otherwise, that you are just concerned with limiting the autism strategy to your Department's view of it. You are not giving consideration to the wider lifetime needs of individuals who suffer from the condition.

We are talking about legislation. While you can be effusive about guidelines, parents are very angry and annoyed about the failure of the system and of those guidelines. The needs of their children are not being met. Parents are very worried that, as their children move into adulthood, their needs are not being met. The Bill is designed to meet those needs. Why would you not agree that:

"The autism strategy must set out how the needs of persons with autism are to be addressed throughout their lives ... the needs to be set out in the autism strategy shall include the health care, educational and social needs of persons with autism ... The autism strategy must set out how the needs of families and carers of persons with autism are to be addressed"? How can you convince me that that is not an improvement on the current situation?

#### **Dr Briscoe:**

I am sure that you have read our autism strategy and strategic action plan. Within that strategy, actions are listed under five key themes: service redesign to improve ASD care; performance improvement in ASD services; training and raising awareness; communication and information for individuals and families; and effective engagement and partnership working. As we move forward with the action plan we will be able to address, through those themes, the issues that you have highlighted. We emphasise again that we do not feel that we need legislation to do that.

The first annual report of the regional ASD network group specifically says that it is taking a life cycle approach. You will have noted that the investment recently announced by Minister

McGimpsey for transitions and adult autism services is in recognition of the fact that autism services are about a lifelong approach. We believe that we have the infrastructure to build on to be able to do that.

As you will appreciate, this is a relatively new arrangement with both the ASD action plan and the regional group. Therefore, yes, our concentration to date has been in our own backyard in trying to reduce waiting times and get a children's care pathway in place. However, that children's care pathway very much identifies family support, the crossover into education and the production of care plans, which include all the aspects that you talked about. We do not feel that legislation is required to do that.

#### Mr Callaghan:

Good evening. In case any of you do not know, I am Pól Callaghan, the new SDLP Member for Foyle replacing Mark Durkan.

A few things came up in what was a very interesting presentation, Dr Briscoe.

#### **Dr Briscoe:**

Thank you.

#### Mr Callaghan:

The topic is obviously very important to not just everybody in the room but to the wider autism community. We all know that that community has a very genuine concern and interest in all of this. I will go step by step through this so that I do not get lost.

You seem to be bringing up the matter of judicial interpretation in relation to clause 1(3), the stuff about:

"taking part in normal social interaction; or ... forming social relationships."

Maybe I am getting the wrong end of the stick, but it seems to me that you are somehow implying that, in a judicial action, that may be interpreted as referring to a '40-Year-Old Virgin', as the film has it, who cannot chat up a girl in a disco. However, if a case went to court, any judge looking at that clause would clearly understand that, in the context of the Bill, certain specific conditions fall within the autistic spectrum definition. Do you not accept that view?

No.

#### Mr Callaghan:

On what basis do you not accept it? Is there any case law to demonstrate that any judge would go beyond the context of a Bill, which, in this case, is specifically cited as an Autism Bill?

#### **Dr Briscoe:**

The amendment is to the DDA and does not specify autism. Therefore, all that will be included in the DDA is "social relationships", with no reference being made to autism.

#### Mr Callaghan:

I am not a lawyer, but, you know, if you read what judges say in case law history, you see that judges give regard to the context of the Bill. This Bill going through this legislature clearly states that it is to be referred to as the Autism Act and specifies autistic conditions. What it is that you are afraid will be trapped within the scope of the Bill? I do not really understand. I am not being flippant or frivolous for a second; I am absolutely serious. Is the Department suggesting that some guy who is too shy to chat up a girl or a guy in a disco could take an action under the DDA using that instrument? Is that what you are seriously suggesting? If not, I do not understand what it is that you are suggesting.

#### **Dr Briscoe:**

As you say, this is not a frivolous matter. You have listed a very extreme example of social relationships. One needs to go back to the definition in the DDA of "impairment" — a definition that would also cover any changes as outlined in this Bill — as something that has a significant adverse effect on a person's ability to carry out normal day-to-day activities. Given that the purpose of the DDA is to give extra protection to those who have impairments that have an adverse effect on normal day-to-day activities, regardless of the cause of those impairments, your example is neither here nor there.

You mentioned the judiciary and case law. I say to you that there is already case law that clearly says that ASD is covered by the Disability Discrimination Act 1995. Therefore, we have to ask why it is necessary, on those grounds, to put in generic wording such as "social relationships" when it covers a broad range of conditions, not just autism. The add-on to the

1995 Act will be about social relationships, but there will be nothing on autism.

#### Mr Callaghan:

I am not sure that that is so. There is a clause in the Bill specifically about interpretation and, clearly, interpretation is what is at issue. If someone comes before a court arguing that their case be included under the DDA on the basis of this Bill, if it were passed by the House, and some condition that is not diagnosed as autism or one of the other specified conditions — Heller's or whatever else — a judge would have to give regard to the interpretative provisions of the Bill. The one does not stand without the other, or perhaps I am missing something.

#### **Dr Briscoe:**

The Bill amends specific clauses and schedules in the DDA. The Bill talks specifically about social interaction and social relationships —

#### Mr Callaghan:

I understand that. However, my point is that there are other provisions in the Bill that are, effectively, statutory interpretive guidelines for the judiciary. It seems to me that the Department's presentation today has no regard to those provisions in the Bill.

#### **Dr Briscoe:**

I am not sure that I understand what it is that you are saying. I reiterate that, from the Department's perspective, it is clear in the official guidance underpinning the DDA and in case law that autism is already included in the DDA. Given that that is the case, we ask the Committee why it is that one would need to include that broader definition.

I want to move on, because you asked quite important questions about the definition of "autism". We have other concerns about the definition, and my colleague Dr Ian McMaster will talk about that important definition and its potential consequences.

#### Mr Callaghan:

I am happy for Mr McMaster to come in on that point, but I do have further questions for the Department.

#### The Acting Chairperson:

How many questions?

#### Mr Callaghan:

Probably four.

#### The Acting Chairperson:

Can you do them all in one go?

#### Mr Callaghan:

That depends on the response from the Department.

#### The Acting Chairperson:

Try it; go for it.

#### Mr Callaghan:

OK.

#### **Dr Briscoe:**

Let me just say that the top bit — clause 1 — is an amendment to the DDA, as opposed to what is labelled the autism strategy, in which the definitions of "autism" are included. We see the top bit, which relates to the DDA, as potentially different from the autism strategy.

#### Mr Callaghan:

I am not sure that I accept that. However, we will move on, because we have exhausted the issue.

#### Mr Peter Deazley (Department of Health, Social Services and Public Safety):

Once the first amendment has been passed, the impact of the Bill will cease to exist. The DDA will then stand on its own, as amended.

#### Mr Callaghan:

Yes, but it seems to me that the Department is blind to all the clauses in the Bill beyond the first clause.

#### Mr Deazley:

No, but at the minute we are talking only about the clause that amends the DDA.

#### Mr Callaghan:

The Committee is talking about the whole Bill.

#### **Dr Briscoe:**

That is why we want to get on to the definition of "autism".

#### Mr Gallagher:

We are talking about the definition of "autism".

#### **Dr Briscoe:**

We are not. We are talking about the first clause, which amends the Disability Discrimination Act 1995.

#### Dr Hilary Harrison (Department of Health, Social Services and Public Safety):

When the amendment to the 1995 Act is made, the fact that it has been amended as a consequence of the Autism Bill will have no bearing whatsoever on the interpretation of "disability" within the 1995 Act. For example, it would not mean that an employment tribunal looking at the social relationship aspect of discrimination would link that back to autism; it would link that back to any condition that involves poor social relationships.

#### Mr Callaghan:

I am not sure whether that is a commonly held view; however, I understand your point.

#### **Dr Harrison:**

Once the 1995 Act is amended, it will be completely divorced from the Autism Bill.

#### **Dr Briscoe:**

Your other point about the definition of "autism" is also important, not in the context of the DDA but in the context of the broader Bill.

#### Dr Ian McMaster (Department of Health, Social Services and Public Safety):

Effectively, although it is defined under clear syndromes that are recognised in the International Classification of Diseases, there is, nevertheless, a risk that diagnosis is not accurate in all cases. The classification shows a significant number of similar conditions that could be differential diagnoses for autism — Asperger's, in particular, and some of the other pervasive developmental disorders. Therefore, we have some concerns that people who are not intended to be picked up by the legislation, but who may have similar conditions, will be included. As this is a very emotive area and diagnosis, for parents in particular, there is an issue that people who do not fit the category could be labelled with the disorder.

#### (The Chairperson [Mr Wells] in the Chair)

The other concern relates to a point that was raised by Maura. As time goes on it is likely that autistic spectrum disorder will evolve and that there will perhaps be a change in view as to what is and is not included. Conversely, a tight definition might exclude some people with very similar needs who should be included in that.

The final point is that, as the Chairperson pointed out, it is the needs of the children or adults with autism that we should be focusing on, rather than spending time trying to assess and attach a specific category or diagnosis. Clinicians focus more on that, and the care pathway that has been developed for children and young people focuses very much on the initial triage and on the use of a standardised, approved, accredited method of assessment and diagnosis before taking parents and carers through that diagnostic labelling.

#### The Chairperson:

Pól, are you happy with that?

#### Mr Callaghan:

Sorry, Chairperson, I was not sure whether I was still asking questions.

You may have lost me on that point, Mr McMaster. In my view, the fact that clause 4(1) extends the scope of the Bill to include "any pervasive developmental disorder" means that, in the spirit of the Bill, the particular definitions of one condition or another are not really the issue. The focus of the Bill is not on determining whether or not someone is trapped like a mouse by the

definition of "autism". The purpose of the Bill is to be fairly broad in scope, as long as a condition is comparable to an autistic spectrum disorder. I do not follow the point that you are trying to make.

#### **Dr McMaster:**

The definition is:

"any pervasive developmental disorder not otherwise specified".

That definition is a catch-all to pick up people who do not quite fit the pigeonhole but who perhaps have three of the four necessary criteria, and you are quite right to differentiate them. That is probably the best pigeonhole for those people to fit in. However, other people with emotional behavioural problems — I am thinking of people with moderate to severe learning disabilities — would fit criteria very similar to those of a pervasive development disorder and yet are a separate entity. People with Asperger's syndrome can have schizoid personality disorders and have considerable difficulties with social interaction, but their cognition and language may be reasonable. Unfortunately, those people could be incorporated under that diagnosis. Diagnosis is not always accurate, particularly in this field where there are no specific tests that can be done.

#### **Dr Briscoe:**

That is why, in Scotland, they specifically did not include a definition of "autism" on the face of the primary legislation. Over time, as Ian said, having a definition on the face of primary legislation might impact on the collection of prevalence data down the line. You can see that there are relatively small numbers. Nonetheless, that might, depending on what way you look at it, impact on the data collection and the prevalence data.

#### Mr Callaghan:

That last point is probably more an observation than a basis for objection, is it?

#### **Dr Briscoe:**

I am just saying that the Bill asks us to collect prevalence data on autism.

#### Mr Callaghan:

It does.

Clearly, we would have to link that to the definition of "autism" in the Bill.

#### Mr Callaghan:

Absolutely. OK.

#### The Chairperson:

Pól, you have had a very fair crack of the whip.

#### Mr Callaghan:

To be fair, Chairperson, I am not sure whether that is the case. The Department took up much more of the time than I did.

#### The Chairperson:

I think it was a case of when the cat was away, the mouse was playing a bit. I will let you back in at the end, but John has been waiting, and he is very sore.

#### Mr McCallister:

I was in. It was related to Pól's point —

#### The Chairperson:

Do you want to come in on this particular point, then?

#### Mr McCallister:

If there is a rush to get in, I can wait until the end, but it was on that point. I put this point to the Bill's sponsor: if we define "autism" too tightly, will we have people with complex needs who will fall on one side of the line or the other? As Ian said, the diagnosis is not always very accurate. If families with complex needs have an autism diagnosis, that could open up a pathway to more than they have. Will that cause problems, or add to the problems of diagnosis in that if you get the diagnosis, you fall inside the scope of the Bill, and if you do not get the diagnosis, you fall outside it? In addition, will the prevalence lead to significant problems with the diagnosis? I am concerned that falling inside the scope of the Bill will create more of a problem.

#### **Dr McMaster:**

It could change the emphasis from addressing the needs that you see in front of you to doing more extensive assessments to provide a diagnosis so that you can place people inside or outside the category. That in itself will divert clinical time and resources away from working on the needs of people.

#### Mr McCallister:

How will that change over time if the definition is trapped in primary legislation, and there are developments over a five- or 10-year period? A strategy can obviously respond to that pretty much with a stroke of the Minister's pen, but you cannot do that with this Bill.

#### **Dr Briscoe:**

You would have to amend the primary legislation to encompass it as research and development goes ahead and the definition of ASD potentially widens or narrows, depending on the direction of travel. Given that it is in the primary legislation, you would have to amend the primary legislation.

#### Mr McCallister:

If the definition widened, for example, we could potentially end up excluding people six years from now.

#### **Dr Briscoe:**

If research, the evidence base, and authoritative things such as the National Institute for Health and Clinical Excellence produced a definition of "autism" that was very different from that in the Bill, you would have to go back and amend the legislation.

#### Mr Gallagher:

Do you accept that the Bill is enabling legislation?

#### **Dr Briscoe:**

Just define what you mean by "enabling".

#### Mr Gallagher:

That there are fine details that will be worked out once the Bill is passed.

That is beyond the viewpoints that are in the legislation on the strategy. A lot of detail in respect of the strategy will have to be worked out. However, the Bill is not enabling in the sense that where we are going at the moment without legislation is also enabling.

#### Mr Gallagher:

Ian reflected your concern that the legislation would be too inclusive and that people might be stigmatised as a result.

#### **Dr Briscoe:**

It could be too broad.

#### Mr Gallagher:

In other words, it is too broad and too wide.

Our view is that the existing legislation is too narrow. If it is accepted that it is enabling legislation, is it not the case that that can be worked out after the legislation is passed?

#### **Dr Briscoe:**

No; not the definition. The definition is very clear. As I said, if the definition through, say, research —

#### Mr Gallagher:

Will you give me an example of what you mean by "very clear"?

#### **Dr Briscoe:**

The definition of autism is very specific within the strategy. If, for example, in three, five or seven years' time, new research evidence states that the cause of autism is X, and, therefore, the definition moves, clearly one would have to look at the primary legislation because there would need to be a link between the requirement to collect prevalence data and the definition of autism in the Bill.

#### Mr Gallagher:

That applies to everything in life. That is why we change and amend legislation.

That is why the other jurisdictions did not include a definition in legislation. They were happy to put that in potential guidance that could be easily changed but not in the legislation.

#### Mr Callaghan:

We all appreciate that this is a complex matter. The Department of Health, Social Services and Public Safety would be, more or less, designated as the lead Department, with a co-ordinating role between Departments in implementing the strategy. I found it interesting, Dr Briscoe, that you said that you have no idea what is in the Department of Education's strategy.

#### **Dr Briscoe:**

That Department has not yet published its strategy for consultation.

#### Mr Callaghan:

That is not a criticism of you personally. However, I would have thought that one purpose of the Bill is to ensure that Departments are working together from the off to provide an overarching strategy that meets all the needs of people with autism and their families and that every Department is, therefore, held to account for its actions.

John asked what you could do if your reports showed that one Department or another was not fulfilling its obligations under the strategy or whether that would make no difference. The difference in respect of the Bill is that those Departments will be judicially reviewable for their failure. With respect, you keep referring to guidance and the existing strategy, but that is not a judicially reviewable sphere of operations, and that is absolutely core to the Bill.

My final point is about the wider purpose of the Bill. Unfortunately, we all know that when budgets are tight and financial pressures are hard, statutory agencies and Departments often first target matters that are not protected by statute. I support the Bill because it will provide statutory protection for autistic services in the future. Although the current Minister says that he is committed to an autism strategy, that is entirely at the discretion of the Minister of the day, whereas the law is not. The Department did not address that in its presentation.

The Bill's explanatory and financial memorandum refers to the production of an autism strategy. It does not detail resources, and so forth, for that, so it would be for the Executive to approve a strategy.

The Department's role is about more than co-ordination. There is a role to monitor other Departments. It is quite unusual in legislation to have one Department monitoring other Departments. There is no detail in the explanatory and financial memorandum about an autism strategy because there is no cost attached to the strategy. Although in statute there would be an ASD strategy, there is, as I understand it, no protection in statute for the resources attached to that strategy.

#### Mr Callaghan:

However, the Bill implements statutory duties, Dr Briscoe.

#### **Dr Briscoe:**

There is a requirement to participate in a cross-governmental strategy, but —

#### Mr Callaghan:

There are statutory duties on your Department, regardless of the explanatory and financial memorandum.

#### **Dr Briscoe:**

Indeed, and we are working on our services for adults and children without any requirement for further legislation. In fact, we think that we have done considerably more than is potentially in the Bill.

#### Mr Deazley:

The legislation makes it a statutory requirement to develop a strategy with co-operation and input from other Departments. Other Departments will develop a strategy for their services. We cannot tell them what improvements they have to make to their services. Eight or 10 component parts will be brought to the Executive for approval. Our role will be to monitor what other Departments say that they are going to do, not what we instruct them to do. We are legally obliged to have the strategy in place. The strategy must address how we are going to meet people's needs; it does not place any statutory obligation on us to actually meet those needs any more so than we do at present. We have a statutory requirement to meet needs as they emerge and to wrap those needs around a diagnosis. The money has to come from somewhere. If it is protected for one group of people, it must come from another group.

#### **Dr Briscoe:**

I want to make it clear that the Bill does not require resources to be made available. It requires a strategy. The implications of that are, of course, that there is an expectation of resourcing, but there has been no analysis, and there is no statutory duty in that regard.

#### The Chairperson:

I am conscious that if the Bill passes its Second Stage, we will be back here anyway, perhaps many times. We will have an opportunity to deal with anything that has been missed. This evidence session has been useful. At least you have set out clearly the Department's view, which is useful for folk who are considering which way to vote next week. Thank you very much.

#### **Dr Briscoe:**

May I say one more thing, Mr Wells? I think that this dialogue has been very helpful, but I would like to end by reassuring the Committee, individuals, parents, carers and service users that the Department is absolutely committed to recognising the needs of people with autism and to doing its level best to promote and enhance services for autism for children and adults. We do not need legislation to do that.

#### The Chairperson:

Thank you.