Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Autism Bill: Committee Stage: Regional Autistic Spectrum Disorder Network Reference Group

20 January 2011

NORTHERN IRELAND ASSEMBLY

COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

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Members present for all or part of the proceedings:
Mr Jim Wells (Chairperson)
Mrs Michelle O'Neill (Deputy Chairperson)
Mr Mickey Brady
Mr Pól Callaghan
Dr Kieran Deeny
Mr Alex Easton
Mr Tommy Gallagher
Mr Sam Gardiner
Mr Paul Girvan
Mr John McCallister
Ms Sue Ramsey

Witnesses:

Ms Laura Collins	)	
Lord Maginnis	)	Regional Autistic Spectrum Disorder Network Reference Group
Ms Nuala White	)	

The Chairperson (Mr Wells);

The witnesses are led by Lord Maginnis of Drumglass and are from the Regional Autistic Spectrum Disorder Network (RASDN) reference group. Once again, I remind members of the public and Committee members to turn off all mobile phones. It is particularly difficult for witnesses when mobile phones ring. Please allow the witnesses to make their presentation without interruption. Lord Maginnis, who is known to most of us, is the chairperson of the RASDN reference group. Laura Collins is a parent care representative, and Nuala White is a parent.

Lord Maginnis (Regional Autistic Spectrum Disorder Network Reference Group):
Do you mind if I take my jacket off?

The Chairperson:
No problem, Ken. You are back to your old stomping ground of 1982 to 1986, so you should know the routine here very well. Normally, we ask witnesses to make a brief opening presentation of around 10 minutes, and there will be questions for around an hour. You are very welcome, Ken, and I am sure that you will have no problem handling this session.

Lord Maginnis:
Thank you, Mr Chairman and members of the Committee, for having us here. After a long wait, a sudden summons came that we should arrive with you, and we are pleased to be here. With your permission, I intend to outline briefly my involvement, and then Laura and Nuala will tell you about themselves. Similarly, so that we know the extent to which we have to go into detail, I would like members to indicate whether they have read the independent review of autism services. I know that they have had a multitude of papers.

The Chairperson:
The majority of members have probably not had the time to read it all. All that we have had is summaries and press reports on it.

Lord Maginnis:
Indeed. We will keep that in mind. As you know, I have been involved in public life for around 30 years. Around 16 years ago, under direct rule, I began to take an interest and to talk to Ministers in the Northern Ireland Office about autism problems. It was not something that I knew a great deal about, but I did that simply in response to parents explaining the situation to me. I learned that there was no formal structure and no one with overall responsibility for autism in the Northern Ireland Office. Later on, about nine years ago, I discovered that a member of my family

was on the spectrum, so I have had nine years of living cheek by jowl with that.

When the current Assembly was formed and sitting, I spoke to the Minister of Health, Social Services and Public Safety and suggested that he should take an interest. I am grateful to say that he responded very positively. I finished up, for my interference or for whatever other reason, chairing the independent review of autism services, during which we took a great deal of evidence, sitting around the table with half a dozen experts. The Department of Health, Social Services and Public Safety (DHSSPS) subsequently asked me to chair the regional reference group. It is difficult but necessary to have a comprehensive group, given that we have five health trusts. It is important that we have groups that can interface with each of the health trusts and co-ordinate a programme so that people who live in Castlederg have the same opportunities as those who live in Newtownards or Coleraine. That has taken time.

There is a group of 30 people, consisting of parents, carers and users, who work together and who have addressed the issues as they know and experience them. They interface with the health trusts. I will now let my two colleagues tell you who they are and what their experience is.

The Chairperson:

We are particularly interested in the Bill. We have had copious evidence on the concerns of those who care for autistic children and adults. That is a major issue in itself, but we are particularly interested in the relevance of those concerns to the Bill.

Lord Maginnis:

I fully understand that. The group wants to give the Committee an idea of where it is coming from and of our hands-on experience. We will certainly address the issues in the Bill.

Ms Laura Collins (Regional Autistic Spectrum Disorder Network Reference Group):

I am a registered adult nurse and a registered sick children’s nurse. I have a BA from Queen’s University Belfast in business and management. I have been a family carer for 30 years. I have cared for five members of my family: learning disability, autism — my son is approaching 30 — mental ill health, dementia, brain injury and cancer. I have been a carer–activist over that period, championing the support needs of disabled people and their carers.

I have 40 years’ experience in the voluntary and community sector and have been involved in more than 30 organisations. I have been involved with nearly every one of the autism charities in Northern Ireland and was a founding member of the original one. I have represented carers' views in an official capacity: I sat as a carer representative on the disability living allowance (DLA) advisory board from 2001 to 2005; I was a regional counsellor with the National Autistic Society between 1993 and 1997; I was a carer representative on Crossroads Care management committee between 1990 and 1996; and I was a Carers UK trustee with 18 years' active engagement with Carers Northern Ireland. I am a member of several strategy groups in my local trust. I am the facilitator for the Belfast area of the reference group.

Ms Nuala White (Regional Autistic Spectrum Disorder Network Reference Group): Hi, guys; I am glad to be here. I am nervous, so you will have to bear that in mind. We will give the Committee summary documents when we have covered all the areas that we intend to speak about so that you do not have to take copious notes. We will talk about the handout that we gave you in advance in just a second.

I have been an ASD parent carer for the past 16 years: my son turns 16 tomorrow. As a parent carer, I am in family crisis at present, but I am still here working from a different angle. I live with autism, so I speak with some authority, although I do not intend to major in it.

I have a masters in autistic spectrum disorders from Queen's University Belfast. The particular experience that I bring to the Committee's meeting, to the reference group and to the whole debate on legislation is that I am a fellow of the Chartered Institute of Personnel and Development. I specialise in organisational and whole-systems change around what it takes to make successful transformation happen. I have significant experience in the Scottish Government and with Irish health. I am a practising psychotherapist counsellor, and I provide support to autism families. I am a reference group member with the South Eastern Health and Social Care Trust, one of the 30 to which Ken referred. We are happy to answer questions later about any of our roles and our experience. That puts us in context.

I am aware that you have probably been swamped with submissions and written documents: we do not intend to add much to that. I would like to cover a few issues before we talk in detail.

We are members of the reference group for RASDN. Among the 30 parents and 10 voluntary organisations, there are diverse views, ideas and experiences. We have never had a vote or debate specifically about who is for or against a Bill. We do the "roll up your sleeves" work in the field with all professional bodies and interested parties. We hold and can tolerate all those different points of view. We do not come here with a "for" or "against" stance; our purpose is to engage with you in dialogue about what will improve services for ASD parents, carers and service users; to explore with you in shared questions and answers the negative and positive effects that legislation might have on living out that strategy; and to inform the real living of the strategy in service provision. Are you with me?

The Chairperson:
I re-emphasise: we are talking about the Bill.

Ms White:
Absolutely, but we do not come with a "for" or "against" view. We want to put the issues in the context of some of the real work that is going on. We invite you to test us on the Bill around that, if you so wish.

I will hand over to Laura to outline some of the input of our work.

Ms Collins:
The two main clauses of the Bill concern amendments to the Disability Discrimination Act (DDA) 1995 and the proposed strategy. I will address the strategy.

In the RASDN reference group, we have been working extremely hard in response to the framework set up by government. I will quickly outline the achievements so that you can understand what the strategy looks like in action and what has been delivered. As parents, carers and users, we are at the very heart of the work. It is exceptionally new work.

The Chairperson:
The Committee has already heard that evidence from Stephen Bergin. Our problem is that a series of groups has come forward. Each has taken the opportunity to emphasise what it is doing on the needs of autistic children: that is fine. Our difficulty is that we are not reviewing autism services in Northern Ireland; we are looking at specific legislation. A recent set of witnesses never got to the point. It is vital that you move rapidly to your view on the Bill rather than giving an overall view of what is being delivered for autistic children. That is relevant but not to what

we are currently undertaking.

Lord Maginnis:

Let me see whether I can help the Chairman and the Committee. As Laura and Nuala said, because we are involved, I suppose that we want to talk about what we are doing and how that has a practical impact and is an empowering exercise. We believe — I believe — that the Bill would disempower parents, carers and, obviously, users.

I will turn to clause 1 and consider the two amendments to the DDA. The first states that, along with physical and mental impairment, we should insert the words “social (including communication)”. I have already heard Tim Moore from the Assembly’s Research and Library Services express his concern on that issue. It could — I believe that it will — be a constraining addition. It would constrain the definition that is already covered by “physical and mental impairment”.

There is another small amendment to paragraph 4(1) of schedule 1 to the DDA, which has a list running from (a) to (h). I then find that this Bill will insert:

> “(i) taking part in normal social interaction; or
> (j) forming social relationships.”

Those are not in the same grammatical form as the first eight points, which list:

> “activities only if it affects one of the following —
> (a) mobility;
> (b) manual dexterity;
> (c) physical co-ordination;
> (d) continence;”

and so on. Those are nouns. Tagged on the bottom will be something that is not a noun:

> “taking part in normal social interaction;”.

I suppose that that could be changed simply to “social interaction”, and “forming social relationships” could be changed to “social relationships”.

The point is simply that if we were all the same, nobody would be different. You will do things that I will not do, and I will do things that you will not do. If I am different from my peers or the rest of my family, am I somehow to be queried for having the wrong social reaction? Many people here may be teetotal, but if I do not go to pubs to drink, and my colleagues do, is there something wrong with me? If I am shy, is there something wrong with me? When defining autism, we must use much less generic terms than the Bill suggests.

One of my biggest criticisms is that I read the Bill twice before I caught on that I was reading "the Department will" over and over, and it was only when I read the supplementary element that I discovered that "the Department" is the Department of Health, Social Services and Public Safety. Ladies and gentlemen, you know that the Department of Education will not be dictated to by the DHSSPS.

The Chairperson:
Ken, have you finished your objections to the Bill's amendments to the DDA?

Lord Maginnis:
Yes, I have. That will be taken up by Nuala.

The Chairperson:
We propose to split the questions. You have gone on past your 15 minutes already, and I must give members an opportunity to question you.

Lord Maginnis:
That is fine.

The Chairperson:
If that completes your evidence on clause 1, I will ask members whether they have questions on clause 1, and we will then move on to the strategy, which you were about to talk about, and we will ask questions on that.

Ms White:
Will we have an opportunity to give you some information to ground our debate?

The Chairperson:
Some of the information that you gave is not relevant to what we are doing. We are examining a Bill. All the witnesses have had the same problem; they have used the opportunity as a platform on which to bring up other issues about the care of autistic folk. That is relevant, but we specifically want to examine the Bill. That is why I am splitting the evidence in this way.

Ms White:

I am really sorry to come back on that. I would really like to have the opportunity to put to this body the question that we, as an organisation, are struggling with. It is an open question: how will the Bill help or not help, given what is going on at present and some of the cost realities. Will we have a chance to do that?

The Chairperson:

Yes, you will. However, this is about the Bill; it is not a review of general autism services.

Ms White:

Absolutely; we know that.

Lord Maginnis:

At the end of the day, Chairman, we want a result. We want a result that benefits the community and that meets the needs of those on the autistic spectrum. We cannot find — at least, I have not found — a methodology that allows us to examine that in limbo. We have to put it in context. We will leave it to you.

The Chairperson:

Alex is the first person who wants to question you on clause 1.

Mr Easton:

I am not sure that I want to now.

I am a bit baffled, but I will set that aside. If the strategy is working so well, why do so many groups that are involved with the wide spectrum of autism want the Bill? Why do they feel that they need the Bill and that the strategy is not giving them what they want?

The Chairperson:

Alex, is your question about the DDA or the strategy?

Mr Easton:

It is a bit of both really.

The Chairperson:

As regards the DDA specifically, why do you think that so many groups said that they want the amendments?

Ms White:

That is a live question for us in the RASDN reference group. I can answer it only by telling you about the real work that is being done on the ground. No one has had the opportunity to tell you guys about that intense and thorough work. I can tell you about it in two minutes.

The Chairperson:

Is it relevant to the Disability Discrimination Act 1995?

Ms White:

It is relevant to the Bill. You asked a good question: why would a Bill be introduced? That is our working question too: what will a Bill add? We do not have the answer to that, given that we are living through very real change. We are living off an action strategy, which I believe clauses 2 and 3 deal with. The ongoing question is: how will a Bill add to, or interfere with, that strategy? May I give information on that?

The Chairperson:

Is it relevant to clause 1?

Ms White:

I do not know. I do not speak in clauses.

Lord Maginnis:

I will bring in Laura in a minute.

Mrs O’Neill:

Perhaps you are coming at this from the wrong angle. We are not here to attack the work of the group. Dr Stephen Bergin has been before the Committee. We are very much aware of the work of the network and the parents, users and voluntary groups involved. We have to look at it in clauses — that is our job as a scrutiny Committee. There are members of the network who support the legislation and feel that the DDA should be amended. Perhaps you can approach it from that angle. We do not dispute the good work that is done. Why do you think that members of the network feel that we should support the amendments to the DDA despite the good work that is done?

Lord Maginnis:

I heard Mr Easton's leading question. He mentioned the fact that groups support the Bill, but there has been no public consultation. Groups tend to do what they are told. There are some very domineering people in some groups. I have heard groups say that they represent 20,000 or 200,000 people with autism, which is absolute bunkum. Those groups are misrepresenting themselves, because they do not interface with anything like that number of people. Some of the groups work locally. Some are more concerned with whether their group will receive money from the DHSSPS to supply services than —

Mr Easton:

On a point of order, Mr Chairperson. This is not about attacking community groups or any other groups.

Lord Maginnis:

Indeed it is not.

Mr Easton:

I think that we need to stick to the DDA.

Lord Maginnis:

You were the one who said that you had a difficulty in understanding. I was trying to explain it to you.

Mr Easton:

You were being a wee bit all over the place, if you do not mind me saying so. Perhaps you could stick to the DDA question.

Lord Maginnis:

Would you like to ask your question again?

The Chairperson:

The question was: why are so many groups that represent the needs of autistic families and children so keen for the DDA to be amended to include a social —

Lord Maginnis:

Individuals want service, and I believe that that will slow it down. The wording of your Bill suggests that, if you agree to this, it will be two years before we implement a strategy. We are ahead of you by a year in implementing a strategy.

The Chairperson:

The “you”, Mr Maginnis, is Dominic Bradley. We are scrutinising a private Member’s Bill, and we have not come to a decision on it. It is important that you realise that this is not the Committee’s legislation.

Lord Maginnis:

Sorry.

The Chairperson:

However, that was a relevant answer. Ms White, do you to come in to support that answer?

Ms White:

I want to answer the question. I do not deal with technical issues —I know that others do — but the clause in question expands the legislation to include “social (including communication)” alongside physical and mental disabilities. Families find it impossible to achieve service provision and to get the diagnoses and the interventions that they need. Naturally, they want the might of the law to support them in any way that it can to ensure that their young people or adults have the diagnoses that they require and can force the hand of service providers to meet those needs.

You have discussed whether or not the expansion to mental and physical needs to be made. We do not have a collective view on that. However, I can support the notion that pinning the definition down further will make it more difficult, as somebody said earlier, for the likes of high-functioning people with autism or people with Asperger’s syndrome to have their diagnosis held up. As Tim said earlier, expanding it makes it narrower, not broader. Therefore, people want the complete Bill to have some weight and to include a horse of Troy with which they can get diagnostic and intervention services to meet their needs.

The Chairperson:

I will not make any comment on your answer; it has hit the target 100%. That is the sort of answer that we require. You dealt with the issue very succinctly.

Ms White:

As a representative and given my experience, our response is that, when we consider a Bill, we determine whether the ongoing work is doing enough. With more support and joined-up government — I am sorry; I cannot separate it into different clauses — and if the Department of Health, Social Services and Public Safety, the Department of Education, the Department for Employment and Learning and other parties were to work together in support of the provision of autism diagnosis and intervention and the active joined-up work that is being lived out, there would, possibly, be no need for a Bill. I use the word “possibly”, and I do not say that on behalf of 30 people in the reference group. I speak from my experience and knowledge.

Dr Deeny:

Do a significant number of carers and parents who look after people with ASD across the spectrum feel that clause 1 will make the situation worse and should not go ahead? Perhaps you do not know; I am not asking for figures. Secondly, as I said to Tim, I am concerned that, if we extend the clause and include the words “social (including communication)” it may apply to many groups of people. For example, I work with blind and deaf people. They do not consider themselves to be mentally ill but sensory-impaired. They may well say that those conditions should be added, but are we opening up a can of worms for the definition to apply to a whole list of conditions? Is your reference group happy that “physical or mental” — I dispute that it covers everything — is all-encompassing? Are you happy that it fulfils the needs of the carers of those with autism?

Lord Maginnis:

Not only are we reasonably happy with that but we have conducted research and know that the Equality Commission believes that, so far, cases that involve people with autism have been satisfactorily dealt with under the Disability Discrimination Act 1995. It appears to be the commission’s view that autism is already embraced by the existing words. Tim Moore cited the

Hewett case. Does that case stand alone and, as Tim suggested, not create a precedent? Is the Act adequate to his case? On that basis, the Equality Commission believes that clause 1 is flawed.

Ms Collins:

As far as I am aware, the Autism Act 2009 in England did not require the Disability Discrimination Act 1995 to be amended. Scotland's Bill has fallen, and Wales is delivering extremely well on its action plan. Wales has £7·1 million and, therefore, effectively twice our per capita investment.

Therefore, strategic plans are enacted and working. There is sufficient legislation. The DDA is strong because it is broad. My concern is that we should not narrow it down, or the people whom we are trying to protect will lose out. Even the definition given in it is not the clinical definition in the International Classification of Diseases (ICD) 10 that is normally used for autism, and other syndromes are included. As was said earlier, we could end up legislating for absolutely everyone. The DDA already covers people who have autism, and there is no need to amend it.

The Committee has received many presentations. Not every autism-specific charity supports the Bill, and the Committee may not have heard evidence from them all. The disability sector's position is neutral. It will not be championing something that could split it, in that one disability may have pre-eminence over another.

My other comments are to do with the disability aspect, which is extremely important. If we reach a point at which everything is about a medical diagnosis, that could be a retrograde step. We have moved so far into a social model, whereby we see the person first. It is retrograde to revert to labelling people, so that people without labels will not get what they want.

The Bill does not address the issue of dual diagnosis — co-morbidity or co-occurring conditions. It is rare for someone to have pure autism. Some 50% of people with autism will have a learning disability, and similar numbers will have mental health problems, attention deficit hyperactivity disorder (ADHD), epilepsy and some 30 co-occurring conditions. Those people will not be supported. That is the complexity of autism with which we struggle. We are not dealing with just one condition but with many, which is why the regional strategy is pulling all the groups together. We have 10 voluntary agencies, which are not just autism voluntaries.

There is Mencap, which provides learning expertise for the early years of learning disability. There is Barnardo's, which has early years guidance. We need people from many different areas and many different areas of expertise. That is what we struggle with. I do not feel that by being prescriptive that we are helping. It is important for those different groupings to work together, and we are doing that. They all bring their expertise to the table to design the services that families with complex needs require.

The Chairperson:
We are back to the territory that I was keen to get into.

I will open up the session to include the second aspect of the Bill, which is the strategy and co-operation between Departments.

Mrs O'Neill:
May I make a point on the DDA?

You said that the English legislation did not amend the DDA, but in England, the definition of disability under the DDA is being examined, and much work is being done, so it is recognised that we all need to consider that.

The Chairperson:
I can now open the meeting to other aspects of the Bill.

Mr Callaghan:
I would like to stay on the DDA for a moment.

Lord Maginnis mentioned that the Equality Commission is not promoting the change to the DDA. However, it appears to me that the Equality Commission's proposal is for a more fundamental review of the DDA as it applies here generally: founded on a social model rather than on a medical one. That is a question for another day, I suppose.

Tim spoke from the research side. It is important that we all recognise that Tim was putting forward various views for the consideration of the Committee rather than expressing a view, either on his own behalf or on behalf of the Assembly's Research and Library Services. He did not take a position.

The Chairperson:
He took no position. He is neutral.

Mr Callaghan:
The Research and Library paper states that the Equality Act 2010 in England, Scotland and Wales has guidance and that it refers to activities such as normal social interaction and forming social relationships. Therefore, those concepts that are to do with protecting capacity are in place in England as far as the guidance is concerned, rather than at primary legislative level. I am not sure how that rhymes with some of the concerns that you are expressing about the definition being too broad. You talked about what is normal and what is not normal and the rest of it. What is your view on that?

Lord Maginnis:
I am not here to try to explain the medical definition. I am not a medical person, nor have I ever pretended to be. I run things, I chair things —

Mr Callaghan:
I am not asking you to do that, but to be fair, Lord Maginnis, perhaps I mistook you. My interpretation of what you said to the Committee is that you drew particular attention to clause 1(3) of the Bill, which inserts at the end of paragraph 4(1) of schedule 1 to the Disability Discrimination Act 1995 the following:

> "(i) taking part in normal social interaction; or
> (j) forming social relationships."

I distinctly remember your talking about the grammatical construction of the amendment. My understanding of what you were saying is that that was almost going into the realm of the absurd and that it was a case of legislation taking a view of what is normal and what is not normal. I am making the point that in England, since last year, guidance has been in place relating to the Equality Act 2010 that specifically covers those activities. It is also probably useful for us to remember that the threshold for activities to be covered has to be met. It is not the case that any old problem with, for example, social interaction, would be covered. There is a threshold that has to be reached before the test is met. Do you think that the guidance in England has created a problem since it was put in place?

Lord Maginnis:

We all know that there is a difference between guidance and legislation. There is a difference between that which is aspirational and that which is substantive content. There is no answer to your question. We are discovering day in, day out that there are special needs. It is about enabling people not only to be aspirational — to want to treat the needs of all the people on the spectrum — but to get down to the substance of the issue. It is about having links and pathways. We use the word “pathway” quite a lot. You will understand that. We are trying to create pathways that cannot possibly be legislated for. However, if we base what we are doing on the Disability Discrimination Act 1995, we will be continually creating guidance, whether it is for GPs, therapists or whomever, and doing that at the coalface.

I will repeat my criticism of the Bill. It requires the Department of Health, Social Services and Public Safety to:

> “publish the autism strategy not less than two years after the passing of this Act.”

If the Bill is enacted in March 2011, will we be in limbo until 2013? The DHSSPS will have to peddle the Act through a series of groups of civil servants who have to be made aware, first and foremost, of the objective. We have the objective group, and the Bill would stymie everything that we stand for.

Ms White:

May I come in to try to come back to what you are asking? I want to give you an example that tries to answer both clauses.

I will give an example of how this affects young people with autism in an education scenario. Cases in which parents are trying to have the educational needs of their autistic young person met often end up at a tribunal or judicial review because of the legislation, which results in high legal costs for the Department of Education, the parents concerned or the health trusts involved. Cases, tribunals or judicial reviews that involve a dispute about the definition of a young person’s problem in order to determine how his or her educational needs should be met take away from the ordinary good work of people acting on behalf of that young person in the school and the effective way in which that person’s needs are met by their family and school.

An awful lot of time and money are wasted in the education setting today, thereby adding to families' problems and costs all round. We are getting tied up with legislative language rather than working with need on the ground. I know from personal experience and from speaking to many of the parents and families with whom I work on behalf of the South Eastern Trust that whether or not the definition is changed is almost a red herring because the same issues will apply regardless of whether or not the Bill is enacted.

Ken spoke about a strategy being put forward if the Bill is passed. However, there is a strategy right now. It is on the ground and is working. It is working in Belfast and is being emulated, with struggles, in the other trust areas. Nevertheless, it is working and happening. Therefore, we do not need a Bill to put a strategy in place.

Mr Callaghan:
At the risk of continuing to get the same answer, it is difficult for us to understand why witnesses — I am not saying that all witnesses do this — say that there is no need for the Bill because it is happening anyway. That raises an inevitable question: why should we not implement the Bill and statutory duties to compel things to happen rather than leave it to the discretion of various Departments or agencies? The Committee will have to address that issue once it has heard all the evidence.

I was interested in something that you said, Nuala. I think that Hansard will show that you said that — this was when we were trying to deal with the DDA, but it is relevant to clauses 2 and 3 — if health, education and others worked in support of the work that is going on, there would be no need for a Bill.

We all accept that there have been improvements. However, the issue is how to maximise future development and maximum delivery for people who need better services. Your statement seems to imply that there is an acceptance that we could do with better co-ordination. Therefore, what is the problem with having a statutory duty to co-operate, which clause 2 states?

Lord Maginnis:
From a purely political view — as an elected representative, you will know this —

Mr Callaghan:
I was not elected. *[Laughter.]*

Ms S Ramsey:

He was co-opted.

Lord Maginnis:

We will not have that diversion.

We have a responsibility. There are things that we should do, and those things that we attempt to do are less constraining than the things that we must do. If the Bill were enacted tomorrow, would you sit on your hands for the rest of your elected time? How do you control, interface and subscribe to the work that we are doing? For example, clause 2(2) states:

> "Before preparing the autism strategy, the Department must consult the Northern Ireland departments on it."

How long do you think that it takes — I ask you this question again — to get together groups of civil servants from the 13 Departments? How would you do it? On Saturday, I talked to a Minister — I will not say who it was — who promised to ring-fence a sum of money and to work with part of my group and a new group that will work with and inform his civil servants so that we can create yet another pathway. If I told you that there was a pathway, you would know who the Minister was. Do you know what I mean?

Ms S Ramsey:

It has to be the Health Minister because the Minister of Education is female. You said "his". *[Laughter.]*

Lord Maginnis:

Yes. Well, you would not want to distract me with Middletown and such diversions.

Ms S Ramsey:

The phrase "poacher becomes gamekeeper" springs to mind.

Lord Maginnis:

Clause 2(3) states:

> "The Department must request every HSC trust to provide data on the prevalence of autism in its area in order –
> (a) that it can publish and update the strategy".

It goes on to give a list of time-consuming nonsense that must be carried out under clause 2. The Bill would take power out of people's hands. It would disempower parents, carers and service users who are fully involved at present.

Mr McCallister:

I do not doubt the commitment of anybody in the room to want to help. I agree with Ken that frustration with the service has probably driven much of that. I want to raise a couple of points that the Chairperson and others have put to almost every group from whom we have heard evidence. In your work to date, have you felt inhibited by legislation? Have you hit any barriers? Has anyone said that the law needs to be changed because something does not happen, or is it more a matter of resources?

Ms White:

That is a great question. In our experience, whether something is legislated for simply does not come into the picture. We meet the normal resistance of the health and education systems, where an "us and them" history and culture prevails. A medical model is in place. Resistance is met when someone attempts to be an equal player and to have input in his or her family's care or required interventions. That is where inhibitors have arisen. Great movement has taken place on that. Pól's question about whether it will make a positive or negative difference relates to that area. We grapple with exactly that: what difference will it make when work is being done? It feels, genuinely, like a red herring unless a family's only recourse to help is to take the might of the law against the system. There is another way. That reinforces the "us and them" culture. One person might get a result. However, you know better than I do that there is very little money out there, guys. Very little money is available.

Mr McCallister:

Earlier today, we heard evidence from the Department of Education. Although it obviously supports the Bill in principle, it is clearly concerned that it could create a hierarchy of conditions and that, rather than targeting need, it would end up targeting autism. I refer to Laura's earlier point about someone having complex needs. Depending on the nature of conditions, can there, in some cases, be great difficulty in identifying how to address need and in determining whether someone gets help? Do you see all those issues coming into play?

Ms White:

Absolutely; those issues come into play. What difference will legislation make to that — definition or no definition? I cannot for the life of me see what difference it will make except, perhaps, to set parent against parent. It may, perhaps, exacerbate the “us and them” culture, which we are trying to move away from and towards participation and problem-solving together. For goodness sake; the current London Government are giving out to the UK about changing the way in which we work and community empowerment. Legislation would take us backwards.

Mr McCallister:
The Bill states that the DHSSPS will take the lead on the establishment of a cross-departmental strategy. Ken, you mentioned Middletown. I have always used that example, because one could say that the strategies of the Health and Education Departments diverge completely from each other. One says that it is a great idea while the other says that it has severe reservations. I have asked that question of other groups. How would the Health Department, in a lead role, handle that?

Lord Maginnis:
As a legislator, I can answer that. You have heard about the different types of autism. You cannot use the Bill, which is hugely flawed, to create a panacea that will cover every Department and meld them together. That will not work. Any Department that finds that it should do something but is prevented from doing so by legislation can amend existing legislation. They can consult, and so on, but that is a practical way to deal with legislation. That has been my experience over the past 28 years.

The Chairperson:
Thank you very much, Lord Maginnis, and your team. We are very grateful that you have given evidence on this matter. Particularly towards the end, you certainly hammered home some very strong points from your perspective. That is appreciated.

Dr Deeny:
I was going to —

The Chairperson:
You did get in earlier.

Dr Deeny:
Fair enough.

The Chairperson:

The difficulty is that departmental officials are coming at 3.30 pm to brief us on the Budget. It is important that we move on to another very pressing issue.

Ms White:

Being a thorn in your side, I beg to raise one more point before we finish.

The Chairperson:

Can you do it in one sentence, Ms White?

Ms White:

No, I cannot do it in one sentence. I can do it in three sentences. I am a carer; I have a 16-year-old crisis going on in my family, and I have given much of my time to put a case before you. I beg you for the opportunity to add a further significant point.

The Chairperson:

Let us be frank: unfortunately, although the end of your submission was very much to the point, some the early part was not relevant at all. That is, unfortunately, why we are short of time. You put some very strong points across when we got to the core issues.

Ms White:

I will do it in one sentence.

The Chairperson:

Unfortunately, much time was wasted at the start. The other difficulty is that departmental officials are coming to brief us on a crucial issue, which is our £4·3 billion budget for next year. We have to deal with that as well.

Ms White:

I will give it in one sentence.

The Chairperson:

Put it in writing, Ms White. I guarantee that the entire Committee will get it.

Ms White:

OK.

Lord Maginnis:

Thank you very much.