Northern Ireland
Assembly

COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Proposed Autism Bill

17 September 2009

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)
Dr Kieran Deeny
Mr Alex Easton
Mr Sam Gardiner
Mrs Carmel Hanna
Mrs Dolores Kelly
Mr John McCallister
Mrs Claire McGill
Ms Sue Ramsey
Mrs Iris Robinson

Witnesses:

Mr Dominic Bradley	) All-Party Assembly Group on Autism
Mrs Arlene Cassidy	) Autism NI

The Chairperson (Mr Wells):

The all-party Assembly group on autism will now brief the Committee about proposals for an autism Bill for Northern Ireland. Members have copies of various briefing documents from the Committee Clerk, Research Services, the all-party group and the Committee for the Office of the First Minister and deputy First Minister. I found Vincent Gribbin's paper particularly useful and fascinating.

I welcome Mr Dominic Bradley and Mrs Arlene Cassidy, who have kindly provided the Committee with an advance copy of their presentations. I invite you to make your presentations, after which members may ask questions on what is, we all agree, an important subject.

Mr Dominic Bradley (All-Party Assembly Group on Autism):
I will formally identify and introduce myself. I am Dominic Bradley, an MLA for the constituency of Newry and Armagh. Some members may know me, but I am sure that all of you know Arlene Cassidy. I am the chairperson of the all-party Assembly group on autism, and Arlene is on the group's secretariat. We will both make presentations today. We have some extra documents that will be useful to members and to which both of us will refer during our presentation.

The all-party Assembly group on autism was formed in 2008 to attempt to inform Assembly Members about autism issues. The group commissioned Research Services to research and investigate Government measures that are needed to implement real change in response to inequalities in services, policy and legislation on autistic spectrum disorder (ASD). Members have a copy of that research paper, and it may be the document that the Chairperson described as being useful; we certainly found it so.

The all-party group's position is based on the findings of that Research Services investigation. We decided that it was of the utmost importance to advocate for a cross-departmental regional strategy for ASD, linked to, and supported by, legislation. I am pleased to present an abstract of a draft autism Bill to the Committee. We have succeeded in securing, not all-party support, but at least cross-party support for the proposed autism Bill.

I will explain why we believe that an autism Bill is needed. Many of the more than 20,000 people in Northern Ireland who have autism do not receive the support that they need, which means that many children and adults with autism are unable to realise their full potential. The Bill proposes to address the barriers that exclude people with autism from accessing services and support. Accessing services often depends on individuals having strong advocates to work on their behalf. I am sure that many MLAs on the Committee have been charged with that duty on behalf of their constituents. Autism legislation would end that inherently unfair situation.

An autism Bill will strengthen the information that is available regarding the number of people with autism and their needs, and that will help to improve the planning of services. At present, accurate statistics are not available, particularly for autism among the adult population. A Bill would improve cross-departmental working to secure effective transition for young people with autism —

The Chairperson:
I am sorry to interrupt, but somebody has left their mobile phone switched on. The Committee is worried that the recording of what is being said may be completely obscured. Has everyone checked whether their phone is on? Leaving phones in silent or vibrate modes may seem OK; unfortunately, doing so simply wipes out a recording of what is being said for the purposes of the Hansard report. What is being said is incredibly important, and we do not want to lose it. I am sorry to have interrupted, but I must draw that to people's attention.

Mr D Bradley:
I have pressed a button on my phone and switched it back on again. *[Laughter.]*

The Chairperson:
Whoever is responsible is obviously a very busy, hard-working MLA or autism worker, but it would be best to turn off phones.

Mr D Bradley:
We believe that autism legislation would also secure an effective transition for young people with autism from child to adult services. At present, that transition can be extremely problematic, and adult services are often not available.

Legislation would ensure access to appropriate support and services for adults with autism and their families. The Bill would address equality issues through the appointment of an autism advocate. Legislation could recognise autism as a social and communication disability.

One of the Bill's proposals is to address the need for up-to-date statistics about the prevalence of autism across the entire age range. The transition from school to adulthood is a particularly difficult time for many young people with autism because bridging services are often not available. Effective support through early planning is vital to a successful transition from school life to adulthood.

The services that are available to adults are far from being fully developed. Adults with autism are often unable to access the right support and, consequently, often become dependent on their families: 61% of adults with autism rely on their families for financial support, and more than 40% live at home with their parents. The Bill will seek to address key structural barriers that prevent adults with autism from accessing the support that they desperately need. I will not go into the detail of those at the moment, because time is at a premium.

Equality issues that are related to autism are based on a lack of understanding of ASD as a social and communication disability. Autism is neither a learning disability nor a mental-health condition. Consequently, the unique needs of people with autism are not addressed or recognised in disability legislation. The word “autism” is not mentioned in the resultant guidelines and good practice handbooks. The rare references are often misleading — for example, in disability living allowance (DLA) regulations. The only legislative mention of autism is in the UK’s Chronically Sick and Disabled Persons Act 1970. Therefore, families are forced to use case law, which is costly in human and financial terms.

We would include a clause on recognition in the Bill. An understanding of ASD is lacking throughout all layers of public services. That is not to single ASD out for special treatment; it is about addressing a significant and fundamental inequality in understanding. In an Assembly debate on autism earlier this year, the Minister of Health, Social Services and Public Safety misquoted a report by Sir Jonathan Michael as evidence that legislation was not required. That report was about learning disability, not autism, and was the result of years of lobbying by Mencap on the need to improve acute health provision.

In Northern Ireland, many people with autism and their families have experienced a postcode lottery with health trust services. We wish to establish equality of service throughout Northern Ireland. Members may ask how the autism action plan that was drawn up by the Department of Health, Social Services and Public Safety fits in with an autism Bill. We welcome the autism action plan and do not envisage the Bill negating that plan in any way. We are glad that the Department is committed to produce that plan; however, it is not a holistic, cross-departmental or cross-sectoral initiative. A regional cross-departmental response within a legislative context is required.

In the present deep economic recession, members may wonder whether the resources are there to finance an autism Bill. We believe that disability does not recognise recessions, and a proportionate response would be the just course of action. We can give some more detailed figures later.

Legislation on autism does exist. In England, the Autism Bill has reached its Committee Stage in the House of Lords. The Bill was initiated by the Conservative Party, and it has now garnered the support of all the parties at Westminster. In Scotland, there is a cross-departmental strategy; in Wales, there is a cross-departmental action plan; in Sweden, there is ASD legislation; and, in the US, there is a raft of legislation that is awaiting funding. There is also legislation or holistic national strategies in Australia, Canada and Denmark.

We do not believe that other disability groups will resent the proposed autism Bill. ASD is a disability that displays a number of unique features, so it requires legal recognition. The perception of others does not invalidate the statement. Other disability groups are already involved with the issue of autism; autism is associated with a wide range of co-morbid conditions such as ADHD, ADD, dyslexia, and so on. An autism Bill will enable the entire disability community to address the needs of people with autism.

I am aware that time is at a premium, so I will draw my remarks to a close. I also want Arlene to have time to make her presentation. On behalf of the all-party Assembly group on autism, I thank the Committee for affording us the opportunity to make our presentations today. When Arlene is finished, we will be happy to take questions and discuss any issues that arise from our presentations.

Mrs Arlene Cassidy (Autism NI):
Thank you for affording us the opportunity to present to you today. I have some information to contribute, which, I hope, will put today's request and submission from the all-party Assembly group on autism into context.

When Baroness Pitkeathley introduced the English Autism Bill for its Second Reading in the House of Lords, she stated:

> "This Bill is an excellent example of how relatively small changes in legislation can make huge changes in the lives of

people with disabilities and their families".

The English Bill will amend children's and young person's plans, place new duties on local authorities and confirm ASD as a specific category. It is also tied in to a national strategy for adults with autism.

If one tracks the English Bill's journey through Westminster, the way in which the legislative mechanism has initiated change through negotiation is immediately evident. Consequently, existing and impending legislation has been enhanced, and the English Autism Bill has morphed into legislation that is fit for purpose and which has the support of the Labour Party, the Conservative Party and the Liberal Democrats. Initially, it was opposed by the Labour Party, and it was introduced by the Conservative Party.

In Wales, a cross-departmental action plan that was initiated by the Welsh Assembly Government is proving an effective holistic response because of the deliberate investment in infrastructure and accountability. Even so, the need for legislative change has not been ruled out if, in time, it is required. In Scotland, plans are well under way to underpin the existing national training initiative with a cross-departmental national strategy.

In Northern Ireland, the case for legislation has been detailed and documented independently at considerable length. There is a small minority opposition to legislation, and that remains uninformed, unproven, undocumented and unvalidated independently. In addition to that, the report commissioned by the Committee for Health, Social Services and Public Safety, 'Autism Spectrum Disorder Services', categorises current single departmental initiatives as not holistic. Lord Maginnis of Drumglass, in his evidence to this Committee in his capacity as chair of the independent review of autism services, recorded the serious impediments that his review experienced and the future implications of the lack of co-operation among Departments.

In the end, legislation requires us all to deliver, and legislation informs the regulations that guide us on how to deliver. That imperative is currently missing with regard to autism because autism does not exist in legislation. Consequently, people with autism have to fight for recognition, assessment, diagnosis and to receive informed support to address their very different learning style. The ultimate resort of case law is an unrealistic mechanism for exhausted parents to access services.

Generic approaches do not work for autism. It was only when specialist diagnostic ASD clinics and ASD classrooms were set up that we began to see progress for children with autism in Northern Ireland, and it was only when the Department of Education published a series of ASD-specific regulations that we saw the gaps in special education regulations being addressed.

An autism Bill is about the creation of equality. What is the cost of that equality, and can we put a price on doing the right thing? In Northern Ireland, we are used to challenges, to making ends meet and to cutting our coats according to our cloth. It is surely not beyond us to ensure that we prioritise and incrementally and holistically improve the lives of all children and adults with autism through the proposed Bill.

Autism has waited 20 years for this day, and the political lobby has taken eight years to reach this stage. Please break the cycle of ignorance and give the social and communication disability equality and the right to inclusion.

Today, we are being observed by those to whom the proposed Bill matters most, those whose patience has been tested to the point of frustration, anxiety, hurt and anger, but who still want to support us all in making the situation better for future generations and for the children with autism who have yet to be born. It is not about reputations, organisations, egos, interventions or therapeutic or scientific approaches. It is about doing the right thing for people with autism at last.

The Chairperson:
As expected, there is much interest from members. I will lead off the questions before bringing other Committee members in.

The Committee has received a letter from Parents' Education as Autism Therapists (PEAT), which, as you will know, is another autism charity. That letter has prompted me to ask how representative of the autism sector the all-party Assembly group on autism is. I also had a meeting with the National Autistic Society (NAS), and it appears that neither PEAT nor the NAS has been directly involved in the all-party group. Those organisations are aware of the existence of the all-party group, but Autism NI is playing the lead role. Therefore, how representative is your view of a need for a Bill, given that only one charity has been involved with the all-party group?

Mr D Bradley:

The all-party Assembly group on autism is made up, not of a range of charities, but of a range of MLAs representing the various parties in the Assembly, and Autism NI provides useful secretarial backup to the group. The NAS made a presentation to the group, and I attended the PEAT conference in the Europa Hotel in early July to explain the workings of the all-party Assembly group on autism. Both charities are welcome to attend further meetings of the all-party group if they wish to do so.

The all-party group has been established only for one year, and we hope that, in the coming year, meetings will be organised on the basis of Committee meetings. That would mean that members of the public could come along, sit in the Public Gallery, listen to proceedings and apply to make presentations. Any charity that is prepared to take on the onerous task of helping to provide secretariat support is welcome to apply to do so.

The Chairperson:

In your presentation, you said that, if you were able to obtain legislation, the wider disability community might be jealous and might cry "inequality". Is it not more likely that that community would congratulate you and ask where their Bill was?

The argument that has been made by the Minister is that there is a danger that, if autism secures a Bill and that Bill delivers the sort of services for which you have asked, other charities with equally pressing needs would immediately join a queue to ask for their own legislation. I am not here to argue the Minister's case, but we should consider that issue. What is particular about autism that means that it justifies its own legislation?

Mr D Bradley:

In my presentation, I pointed out that there is a lack of understanding about autism throughout Departments and providers of Government services, and that there is a need for a much better understanding. I also pointed out that autism can be co-morbid with other conditions that are considered to be disabilities. To address the difficulties faced by people with autism, we will address several other conditions that are co-morbid with autism. I will ask Arlene to add to my comments.

Mrs Cassidy:

I want to emphasise that the issue is about addressing inequalities. I do not think that other disability groups are uninformed about the inequality in autism, and, therefore, I reinforce Dominic's point.

We have supplied members with an information pack, in which a coloured graph vividly points out the difficulties of autism. It is only one piece of research into parental stress levels. It shows that stress levels among parents who have children and adults with autism are higher than those for any other disability group. Autism has a unique developmental profile. It is not about one-upmanship; it is about practicalities and realities.

We have been in touch with Disability Action and the Equality Commission, and they acknowledge the lack of awareness of autism in the decision-making process and in Government regulations. They are already involved in an ASD equality network, which aims to address the problem from within. Sometimes, housework has to be done, and the Disability Discrimination Act 1995 has recently been changed to include HIV, multiple sclerosis and cancer. Change happens.

Mrs D Kelly:

Your comments, and those of other autism representatives, suggest that the need for differential treatment occurs because, in legislation, autism does not fall neatly into the category of learning disability, mental illness or disability.

Mrs Cassidy:

It is a social and communication disability. Not everybody with autism has a learning disability. In fact, the figures have moved from 50:50 to narrower than that. Therefore, if we include autism in the learning disability programme of care, we will exclude everybody with, for example, Asperger syndrome.

There is much debate about the relevance for autism of mental-health services in Northern Ireland. People argue that, if we strip away unmet need and the effect of lack of recognition and lack of support on people with autism and their parents, we may strip away much of the need for mental-health services. People with autism are, first and foremost, people. They are as subject to illness as the rest of us.

The information pack contains a more detailed case, from which I have extracted some points. It goes into more detail on the difficulties in accessing services and specifically zeroes in on disability living allowance. That comprehensive checklist vividly points out autism's uniqueness. People with autism have a unique learning style, and, frequently, they do not fit with existing treatment regimes. That is why new teaching strategies had to be introduced and why teachers had to receive top-up training on how to work specifically with children with autism. It did not form part of their original teacher training.

Mrs O'Neill:

I declare an interest as a member of the all-party Assembly group on autism. Moreover, I voted in favour of a proposed Bill in the Assembly. I, and most people, would support any legislation or strategy that improves the lives of those with a disability. We need to examine this legislation very carefully.

The Chairperson already referred to the fact that some people are asking why autism should be prioritised. I will play devil's advocate: this week, I received an e-mail from a parent of a disabled child who, on the basis of not understanding what day-to-day difference it would make on the ground for families, asked MLAs not to support the proposed autism Bill. Therefore, this is a brilliant opportunity for the all-party group and Autism NI to highlight the differences that the Bill would make. It is great that you have welcomed the action plan; that is a step forward.

I also welcome Dominic's remarks about not wanting any autism charities or groups to feel excluded. We want the process to be inclusive and everyone to be on board. Therefore, any suggested changes about how we work as a group would be welcomed.

The Welsh strategy, which does not involve legislation, was launched two years ago, so it might already be possible to identify some benefits. Perhaps you will point out the differences between the Welsh autism strategy and the action plan that has been launched by the Department of Health, Social Services and Public Safety. I understand that the Welsh Government have a different set-up and that the Education and Health Departments work together. I would appreciate some more information about that.

I understand the pressures and stresses that parents of children with disabilities are under. As legislators in the Assembly, we have an obligation to do everything that we can to change the law to improve the lives of everybody with a disability.

Mrs Cassidy:
There are a number of unique features in the Welsh strategy, which was a Welsh Assembly Government initiative, so it was joined up from the get-go. It is a joint national strategy from the Health and Education Departments with Executive approval. Our action plan emanates from the Department of Health, Social Services and Public Safety.

The Welsh system is infrastructure-led. In its first year, people were heavily involved in implementation and action; they went straight into implementation at the end of the consultation period. Funding was set aside to employ full-time co-ordinators in each local authority area; they were mentored by three regional co-ordinators, who link in to Government. In addition, the strategy majors on the importance of the voluntary sector, and the action plan was seen as a high Government priority. Interestingly, they considered high-cost, low-incidence services. In other words, because services had to be provided out of state for individuals with autism and challenging needs, part of the job was to bring those people home. Those are the aspects of the Welsh system that stand out in my mind.

Mrs O'Neill:
Am I right to say that the Welsh system has not ruled out legislation?

Mrs Cassidy:
Wales is at the implementation stage of its strategy, and the implementation manager told me that, should legislation be required, that has not been completely ruled out. However, given the strategy's cross-Government emphasis, at the moment, implementation is the driver.

Mr Easton:
I support what you are trying to do, and my colleague Mrs Robinson asked me to say that she will also support you.

I also received an e-mail, which, I suggest, is probably from the same person who wants us to oppose the Bill. However, I will not oppose the Bill because it is good legislation. However, I reiterate that some people feel somewhat left out, so perhaps that issue should be addressed. The e-mail stated that there does not seem to be anything in the proposed Bill to help carers. I have not examined that in great depth, and it is probably not true, but perhaps you will dispel that misconception and tell us whether that is the case.

Mr D Bradley:

I think that there is a provision in the Bill for support services for families, which obviously also includes carers.

Mrs Cassidy:

The autism advocate is the parents' voice in Government. It is an independent agency or individual, and that is the most tangible feature of the proposed Bill. It should greatly reassure carers that there is a direct route in and that there is an autism advocate to consider cross-departmental working.

It is also proposed that the role will examine the need to update existing legislation. The best current example is that the Disability Discrimination Act 1995 should include issues of access to public buildings for individuals with autism. There are many creative solutions that are not high cost. That kind of housekeeping could be done, so there are definitely actions that could be taken.

Mr D Bradley:

The Bill is not even at a draft stage; it is currently at abstract stage. There is still ample opportunity for the Bill to be improved in many ways through consultation with outside groups. We would be more than delighted if the Committee were to adopt the Bill, sponsor it and bring it forward. We are open to approaches from the Committee on that front.

Ms S Ramsey:

You just took away one of my questions.

Mr D Bradley:

I am sorry, Sue.

Ms S Ramsey:

The Department of Health, Social Services and Public Safety has a moral and statutory duty to provide services. We talk about healthcare being free at the point of delivery from the cradle to the grave, and although there is a moral and statutory duty, we all know that Cinderella services are not the services that we see. That is why we need to put a legal duty on the Department.

I welcome the effort that you, parents, carers and even the all-party Assembly group on autism have put behind this process to bring it to this point. You may not have the answer to some of my questions, but please put them in writing. I am interested in your opening remark about a Conservative Member who brought forward the Autism Bill that was supported by all the parties. There seems to be a bit of a difference of opinion with the Minister, who is associated with the Conservative Party. It was supported by all the parties, but some individuals who are seen as Conservative and Unionist are now rubbishing the idea of the Bill.

In your promotional leaflet, there are some great photographs of people signing up to the legislative campaign. Are you saying that all the parties support the campaign? Are you also saying that all Ministers supported the idea of the Celtic Nations Autism Partnership?

There is a ministerial subcommittee on children and young people. Autism does not only affect young people but adults as well. That could be another avenue for consideration. You say that the Bill needs to be cross-departmental. If one Minister rubbishes it or has other ideas, there are other Ministers.

Have you had any formal meetings or response from the Office of the First Minister and deputy First Minister (OFMDFM)? It is about the First Minister and deputy First Minister being the leaders and progressing the issue across Departments. In the first year, how much will it cost to bring the Bill to the Floor of the House? I ask my next question because departmental officials are present: how much did it cost to set up the so-called independent review, which was set up last year?

Mr D Bradley:

The Conservative Party introduced the Autism Bill. Initially, the Government did not support the Bill, but a process of negotiation, discussion and debate changed that, and all parties eventually supported it. We hope that there will be a similar process here and that all parties will eventually support the proposed autism Bill.

All the Assembly parties have attended Celtic Nations Autism Partnership events and were present at the setting up of the organisation, the Northern Ireland leg of which was held in the Long Gallery. The then First Minister, Dr Paisley, was there, as was the Minister of Health, Social Services and Public Safety.

Arlene has made a presentation to the Committee for the Office of the First Minister and deputy First Minister, so I will ask her to speak about that. She will also deal with the two questions regarding finances: how much it would cost to implement the Bill and the cost of the independent review.

Mrs Cassidy:

At the meeting of the Committee for the Office of the First Minister and deputy First Minister, I supported Kieran McCarthy MLA, who spoke on behalf of the all-party Assembly group on autism. Further papers were requested at that hearing, just before the summer recess, and they were sent earlier this month. I understand that that Committee decided to consult other Committees. That is all the information that I have. The all-party group is also due to make a presentation to the Committee for Education shortly.

Ms S Ramsey:

My question related to contact with Ministers' offices rather than Committees.

Mrs Cassidy:

There have been meetings under the auspices of OFMDFM with the deputy First Minister and with the then junior Minister Jeffrey Donaldson. Both meetings were positive and extremely supportive, and requests were made of OFMDFM to sponsor the Bill. However, the abstract was not even at its present stage so revisiting the issue may be in order.

Ms S Ramsey:

What about costs?

Mrs Cassidy:

I am sorry, but I do not have a clue about the cost of the independent review.

The Chairperson:
I can sense a question for written answer coming from somebody; it seems the obvious way to get that information.

Mrs Cassidy:
Unfortunately, I cannot answer that.

The potential cost of implementing the Bill involves guesstimates. My initial costing exercise examines the component parts of the Bill. Rather than giving the Committee the punchline, I will quickly go through those component parts.

The services of an autism advocate, including administrative support, might cost about £100,000. I have generously estimated that a cross-departmental structure that buys in staff time from at least four Departments that are concerned with autism will cost £40,000 a Department, making a total of £160,000.

The current stated annual budget for the Department of Health, Social Services and Public Safety's action plan is £750,000, which I have rounded up to £1 million. I would look for the Department of Education to match that funding, possibly by integrating some of the functions from the Middletown Centre for Autism and by adding incremental budgets from other Departments that become involved on a year-on incremental basis.

The next component is a training strategy to address the issue of workforce capacity. I believe that considerable savings can be made here. If all Departments were to have one training strategy as opposed to having individual strategies and a budget for each, I think that an overall cost of between £100,000 and £200,000 could be incurred. That estimation is probably on the generous side.

Another component is the issue of an autism awareness campaign. I have put down £60,000 for that, which is a guesstimate. We are looking for a £2·5 million contribution from all the Departments concerned. This morning, I received figures from the NOW Project, a supported employment service in west Belfast. NOW's social return on investment (SROI) results for 2008-09 show that, for every pound that was invested in its supported employment schemes, £13 was returned to the local community. There is a need for rationalisation and common sense.

That is all the information that I have at the moment.

Mr McCallister:
I am also a member of the all-party Assembly group on autism, and I have travelled with the group to various locations, including the USA.

I wish to point out that the private Member's Bill that is making its way through the legislative stages at Westminster was introduced by a Conservative Party member rather than by the Conservative Party.

We have a different health and social care structure from England in that our system is integrated. I thank Sue for her conversion to being so pro-Union.

Ms S Ramsey:
I was actually talking about the Swedish model.

Mr McCallister:
I wish to tease out some of the equality issues. Our equality laws are also different from those in other parts of the UK. If those laws are not — as you believe — strong enough, how will section 75 tie in with your proposed changes? During the debate on autism, one of the Minister's key messages was that he did not feel that he needed any more legislation because his Department has all the powers that it needs for its response. What do you think that the Department of Health, Social Services and Public Safety needs to change specifically?

The Welsh Assembly Government's strategy seems to be bedding down very well. However, the Department of Health, Social Services and Public Safety has already produced its action plan. I think that it is up to other Departments to put in place an action plan, too. What further powers do you want to be given to the Department of Health, Social Services and Public Safety to help it to deal with the issue of autism?

Mr D Bradley:
You mentioned the issue of section 75; an equality impact assessment is conducted on all legislation. I do not think that what we are proposing will, in any way, contravene the rights of any of the groups that appear under section 75, but do not take my word on it. An equality impact

assessment will have to be conducted.

We welcome the Minister's action plan. Although aspects of it may need to be improved and strengthened, it is to be welcomed, by and large. The plan, however, refers mostly to the Department of Health, Social Services and Public Safety and to health services. We aim to bind autism services across the relevant Departments and ensure that a streamlined service is provided across all age groups. I mentioned the particular difficulties with the transition from school to adulthood and employment. That transition would involve services provided by the Department for Employment and Learning, the Department of Education and, in some cases, the Department of Culture, Arts and Leisure. The Department of Health, Social Services and Public Safety cannot do everything; there are several Departments that need to provide services, and those services need to be properly co-ordinated and streamlined. That is one of the main planks of the Bill.

Mr McCallister:

I counted about six or seven Departments that should be involved, including OFMDFM, DHSSPS, DE, DEL, the NIO because of the criminal justice element, DSD and DCAL. Like all good things, one Department will take the lead. What Department do you see as the lead Department?

Mr D Bradley:

We have proposed an autism advocate to help to ensure the required level of interdepartmental co-operation. Instead of a lead Department, a major Department may provide the majority of the services. That may be the Department of Health, Social Services and Public Safety, but the Department of Education would also have an input. Instead of depending on a lead Department, the autism advocate's role would be to ensure, on behalf of people with autism and their parents, that the services provided by Government are properly streamlined and co-ordinated.

Mr McCallister:

I accept your point about the transition into adulthood, and the I Exist campaign highlighted many of the issues associated with that.

What will happen when there is a policy difference between the autism advocate and a Minister? For example, the Health and Education Departments put a different emphasis on the policy for autism. How would you deal with that? You have only to look at the Middletown Centre for Autism to see that there is a huge difference in policy between Departments.

Mr D Bradley:

The autism advocate would be useful to all Ministers because he or she would be in touch with families who require services and would receive feedback from them. The advocate could pass that feedback to the Departments to ensure that they respond appropriately to the needs of families. I do not see the autism advocate as someone who would work in opposition to any Minister. Instead, he or she would work in co-operation with the families and the Departments, and he or she would form a conduit through which families could communicate their needs to the various Departments. That would help to ensure that the services provided are the ones that are really needed. I hope that that would not be a cause of disagreement or conflict between a Minister and the advocate.

Mr Gardiner:

I thank Mr Bradley and Mrs Cassidy for their presentation. I am pleased to see the many supporters whom they have brought with them. I thank those people because, in many ways, they are carers and have to live with people with autism.

I do not want to throw in a damp squib, but everything hinges on finance. Mr Bradley, as an MLA, I thought that you would have asked the Minister of Finance and Personnel, Mr Sammy Wilson, to make finances available. Before we went into recess in July, I asked whether the Minister of Finance and Personnel would provide funds to the Department of Health, Social Services and Public Safety to help with the costs of swine flu. The Minister was non-committal. He said that he would examine the situation and report back. It is now September.

I think that you should go to the Minister of Finance and Personnel to find out whether the funding is available. I am sure that the Department of Health, Social Services and Public Safety would be prepared to examine the issue, but if we sponsor the Bill, there are other health problems such as spina bifida, cerebral palsy and cystic fibrosis: there is a range of conditions, so where do we stop?

That is the problem as I see it. I do not want to build hopes up when they could be dashed, but if you get funding from the Minister of Finance and Personnel, the doors will begin to open. We could all say that we want the Bill and that we need it, but the funding is not there. We cannot blame the Minister of Health, Social Services and Public Safety for that. You must go back to the Minister of Finance and Personnel. I am sorry about that. All the best, and thank you for all that you do.

Mr D Bradley:
Thank you very much for that advice, Mr Gardiner. We have done some initial work on the costings, but the Bill is at a very early stage. All that we are required to do at the moment is to work out an estimated cost with the resources that are available to us from the point of view of establishing accurate costs.

I agree that money is needed to provide services. Some of the money is already in the system, even within the health system. If certain realignments are undertaken, that money could be better used along the lines that we suggest in the Bill. I admit that not all the finances and resources that would be needed to support our proposals are readily available in the Department of Health, Social Services and Public Safety, and that extra funding would be needed, but that would be across a number of Departments. The Minister of Finance and Personnel may have to provide an uplift or extra funding. We are not averse to requesting that of him when the time comes. At the moment, we have done as much as we can to provide costings to go with the Bill.

Mr Gardiner:
I think that you would be ill-advised to run with the Bill if the finances are not there to meet it, to be quite honest. I do not want you to waste your time and build up your hopes. I would prefer that you sort that out with the Minister of Finance and Personnel first before you start to go down that avenue.

Mr D Bradley:
Thank you very much. We will follow the process that the Bill Office advises us to take the Bill forward. We are obliged to do that, and we will.

The Chairperson:
I remind members that this is a time for questions not statements. Members can phrase their opinions with “Is it the case?” or “Is the honourable Member aware?”, but it must be couched in the form of a question.

Dr Deeny:

I am used to calling the previous Chairperson "Madam Chair", and "Mr Chair" sounds ridiculous, so I will just call you "Chair". Thank you, Chair.

The Chairperson:

If that is the worst that you will call me, I will be happy.

Dr Deeny:

I examined a very autistic child yesterday in my health centre and saw the extreme pressure that the mother was under for that 10 or 15 minutes. Cost is always thought of in financial terms, but we never seem to think of the cost of quality of life.

Thank you both very much for your presentation. I think that it was Baroness Keighley in Westminster —

Mrs Cassidy:

It was Baroness Pitkeathley.

Dr Deeny:

I am sorry; it was Baroness Pitkeathley who said that the Bill is an example of how small changes in legislation can make huge changes in the quality of the lives of those with autism. "Why not"; those are my thoughts.

It has already been stated that autism and ASD fall between different parts. That has been a major problem for some time. I ask my question as a health professional: do you feel that you are not getting enough support from the professionals in health and education, never mind the politicians? Dominic, you mentioned various Departments. I am also thinking about the Northern Ireland General Practitioners Committee (NIGPC) and the Royal College of Nursing. Perhaps they do support you, but they should be doing so in writing. Professional teaching bodies should also support the Bill, as opposed to relying on charities such as Autism NI.

Dominic talked about getting the support of the Committee, and I would like to think that he will get that; he will certainly have my support as a member of the Committee and as a GP. I know many front-line families who are dealing with children with autism. The fellow whom I saw yesterday is 12 years old, and he is now as strong as his mother. It is a very difficult situation. Should this Committee and the Committee for Education not use their combined voices to support the issue?

Mr D Bradley:

As Arlene said, we have spoken to the Committee for the Office of the First Minister and deputy First Minister. We made a presentation to that Committee through Kieran McCarthy MLA, accompanied by Arlene. We hope to make a presentation to the Committee for Education on 7 October. I cannot agree more: the more professional voices that we hear in support of the Bill, the more helpful that will be. We hope that, if the Bill is moved forward through the Committee, there will be an opportunity for a wide range of groups to express their views on its content and on the services that they would like to see provided. It would be an excellent opportunity for people to inform the Committee and change things for the better.

Mrs Cassidy:

There is the issue of added support. The all-party Assembly group on autism has tried to share information, but Assembly protocol must be followed, and that has inhibited any wide consultation. It is pivotal that, under Assembly procedure, once the Bill receives Committee sponsorship, it goes to the wider community. I have no doubt that very welcome letters of support will come in as the information becomes available.

Mrs Hanna:

Good afternoon, Arlene and Dominic; you are very welcome. Congratulations on all the hard work that you have done, particularly Arlene, who has chased us all around the place for the past few years.

I support the legislation, and I think that it would be a good idea if there were more hands-on involvement, so that we are all aware of the wording of the Bill. It is very much at a draft stage. It would also be a learning curve for many of us, because we have not been involved in hands-on legislation.

I want to tease out a couple of the issues that John raised about the lead Department. There are concerns about the Department of Health, Social Services and Public Safety and potential resource implications. There is a lot of unmet need, and the legislation will address that. It would be helpful if costs were shared with the Department of Education, and there have been huge arguments about the fact that autism is as much about education as it is about health. It would be helpful if that matter were considered.

I was a Minister for a short time, and it did not matter how passionate I was about the biggest issues that came across my desk, because I always had to see where I could get the funds. I support the Bill, but we should try to find out whether two Departments could be involved, rather than having the costs fall to one lead Department. The two obvious Departments would be the Department of Education and the Department of Health, Social Services and Public Safety. Perhaps you should examine that, because it may be helpful. Many people view autism as the responsibility of the Department of Education, while others see it as the responsibility of the Department of Health, Social Services and Public Safety. Other Departments are involved, but if those two Departments were to take the lead, it may be helpful.

Mr D Bradley:

To put the issue into context: the estimated cost of providing vaccine for swine flu could be as high as £80 million. I hope that that will be a relatively short-lived situation, whereas autism is with people from birth to the grave and could not be considered to be short term. Therefore, we are willing to pay £80 million to eradicate swine flu, which many would argue has not properly arrived yet, but it could be difficult to find £1 million for this initial response to autism.

A prevalent problem is that people are not receiving the services that they require at the moment, and anyone who has spoken to the parent of a child with autism — I am sure that Dr Deeny will agree with me — will attest to the fact that it is extremely difficult to get a diagnosis of autism. There are often long waiting lists to see a specialist, with the length of time varying from trust to trust.

We are at the stage when we must be prepared to put the resources into providing services for people with autism, because they face unique difficulties that are very different than those with other disabilities. Furthermore, countries that have already introduced autism legislation have not had a huge backlash from other charities. Other charities in those countries have been pleased that those with such a complex condition as autism were being properly catered for by their Governments, and that they are being supported through legislation.

Mrs Hanna:

I agree with you. All of us know parents who are distraught, because it takes so long to see a paediatrician and to get a diagnosis. I am very supportive of what you are doing.

As education plays such a large role in autism, it might help to move the proposed legislation on if that Department had a more hands-on involvement.

Mr D Bradley:

I agree with you, Carmel, and we will make a similar presentation to the Committee for Education. We have also received briefings from the Department of Education on what it sees as its contribution to autism through schools and the education and library boards.

The Chairperson:

Claire McGill wishes to come in but, after that, we will have to call it a day on this topic. Everyone has had a fair crack.

Mrs McGill:

I also feel that it is important that the Department of Education plays its part. As an MLA, parents of children with autism have come to me, fearful of what will happen to their children, particularly when they move from primary to secondary school. It seems to be a very grey area and parents often have to find out the information themselves. There have been some improvements in the Western Education and Library Board area — and I declare an interest because I am a member of that board. However, despite those improvements, parents still feel that they have to do a lot of the work themselves.

Dominic has said that he will make a presentation to the Committee for Education, and it would be helpful if this Committee were to receive a short briefing paper from the all-party Assembly group on autism after that meeting to allow it to see what happened.

I wish you all well, and I fully support the parents and carers of those with autism whether they are young, or not so young.

The Chairperson:

Thank you very much for giving evidence. You have kept to time well, which is helpful for the Committee. You are welcome to stay in the Public Gallery and listen to our deliberations on your evidence.

Mr D Bradley:

On behalf of the all-party Assembly group on autism, I thank you and the Committee members for affording us the opportunity to make a presentation today and for the useful comments and questions. Thank you very much.