Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Draft Autism Bill: Evidence Session with the All-Party Assembly Group on Autism Secretariat

14 October 2010

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
Dr Kieran Deeny
Mr Alex Easton
Mr Tommy Gallagher
Mr Sam Gardiner
Mr John McCallister
Ms Sue Ramsey

Witnesses:

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

The Chairperson (Mr Wells):

With us today are Dominic and Arlene, both of whom have been before the Committee on several occasions. Although Dominic Bradley needs little introduction to anyone in the room, he is an MLA for Newry and Armagh and chairperson of the all-party Assembly group on autism (APAGA). Arlene Cassidy is a member of the group's secretariat. As is usual, Dominic, you have 10 minutes in which to make an opening presentation, after which I will invite members to ask questions on the draft private Member's Bill.

Mr Dominic Bradley (All-Party Assembly Group on Autism Secretariat): Thank you for the opportunity to present evidence to the Committee on the draft autism Bill for Northern Ireland. We have been before the Committee on one previous occasion, and I am pleased to say that we have advanced the proposed Bill since then. The Committee has a copy of the draft Bill, and we intend to make few further changes to it. A single word or phrase here and there might change, but any further changes will be minimal.

I am the proposer of the draft Bill on behalf of the all-party group on autism. Arlene Cassidy is the chief executive of Autism NI and provides secretarial services to the group. Some members of the Committee, including Michelle O'Neill, are also members of the group. We sent a copy of our presentation to the Committee earlier, and it illustrates the tension between the unprecedented and rapid rise in the prevalence of autistic spectrum disorder (ASD) and the limited resources that are available to meet the resulting needs.

The case that I wish to put to the Committee today is that the historical failure to prioritise autism appropriately is compounded by the failure of existing legislation to recognise the disability. The draft Bill addresses that anomaly. To ensure that ASD is included, it amends the definition of disability in the existing Disability Discrimination Act (DDA) 1995 by inserting: "social (including communication)". The draft Bill, therefore, provides more clarity for the Departments and public bodies that use the DDA definition of disability as guidance when making decisions, for example, on disability living allowance.

The measure will profoundly affect families because it will accord recognition to a challenging condition that has been low in the hierarchy of disability in our society. When implemented across public bodies, it has the potential to improve the public understanding of issues that face individuals with ASD, such as access to services and buildings. Significantly, it will signal the beginning of the end of discrimination against individuals with ASD who have an IQ of above 70.

The draft Bill directs the establishment of a cross-departmental approach to ASD by requiring the development of a cross-departmental or government strategy for autism led by the Health

Department. As I said, the historical failure to recognise ASD has resulted in a legacy of underfunding across Departments, and, as the amendment to the DDA takes effect, all Departments will, inevitably, have to address the impact of legislative change to their policies, practice and provision. Clause 2 creates the requirement to undertake that exercise together in an effort to minimise duplication and maximise effectiveness. I presume that there is consensus on the view that the development of a single departmental ASD strategy by the Health Department and, more recently, by the Education Department stands in sharp contrast to the joined-up realities of life as one transition leads to another across home, education, employment and community.

Given the climate of economic constraint, it is incumbent on all of us to plan smartly for future challenges. A cross-departmental commitment to joint planning for ASD is not only good practice, it also provides an opportunity to look afresh at existing resources and how they could be used or redeployed. It also challenges Departments to work innovatively with the voluntary sector to maximise the accountability, flexibility and creativity of all sectors.

The draft Bill addresses the issue of scrutiny. Just as there is an equality and financial balance to be struck between the entitlement to services and their cost, so there is a balance between the processes of accountability and bureaucracy. That clause recognises that challenge by placing a duty on the Minister of the designated lead Department to report to the Assembly every two years on the progress of the autism strategy.

The proposal to establish an autism advocate has been withdrawn, but it can be introduced in the future should the need arise. The withdrawal of the autism advocate from the Bill is a decision that we made in light of the present pressures on resources. The current accountability mechanisms, including this and other statutory Committees, along with the requirement of the Minister to report to the Assembly biennially will ensure accountability for the strategy. In light of the huge pressures on resources, the decision to withdraw the autism advocate is a responsible one.

After the all-party group’s previous evidence session to the Committee on 17 September 2009, representatives from the Department of Health, Social Services and Public Safety raised concerns about the proposed legislation when they gave evidence on 1 October 2009. Their concerns focused on the perceived cost of the implementation of an autism Bill and on the impact that such legislation would have on other disability groups. It is our duty to listen to all views, as has been the policy of the all-party group since its inception in 2008, which was in response to the campaign led by families committed to change.

More recently, the consultation on the proposed legislation was conducted across a wide range of statutory and voluntary agencies and resulted in a positive rating of between 70% and 80%. Follow-up meetings were held with the Equality Commission, the Children's Commissioner and Disability Action. Those meetings resulted in agreed positions on the potential benefits attached to the introduction of the legislation in providing and enhancing clarity. In addition, the Northern Ireland Local Government Association (NILGA) and most of the 26 local councils passed unanimous motions in support of the draft Bill.

It is our position that the all-party group has, therefore, addressed the concerns expressed by the Department of Health, Social Services and Public safety and that the proposed autism Bill is deserving of support. We welcome the opportunity to present to you, and we would also welcome feedback from Committee members. I will finish there, and, once again, thank you for the opportunity to present our case.

The Chairperson:

Thank you, Dominic, for your extremely helpful presentation. I would like clarification on a few points. Initially, there was a discussion about ring-fencing funding for those who have autism and those who care for them. That does not seem to feature in this draft. Was that an idea that was floated but did not come to anything? What is the position on funding?

Mr D Bradley:

I will ask Arlene to respond to that.

Mrs Arlene Cassidy (All-Party Assembly Group on Autism Secretariat):

Thank you. I remember the issue of ring-fenced funding as one of the three key messages of the political lobby that was led by Autism NI. In 2006, the three key aspirations of the political lobby were ring-fenced funding for autism, a cross-departmental strategy and an impact on legislation. Those were the aspirational goals of a political lobby; they were not signed up to per se by the all-party group.

The Chairperson:

Does this draft Bill still leave it in the Minister's power to allocate funding for autism services as he deems appropriate?

Mr D Bradley:

It will be the Minister's duty to co-ordinate the strategy across several Departments. Naturally, the Minister would not have power over any Department other than his own, but there would be a duty on him to provide the best possible services through the strategy and to meet the needs of those services with appropriate resources.

The Chairperson:

Does any provision enable the Minister to do something that he cannot do currently should he so wish?

Mr D Bradley:

Yes. At present, the Minister would probably find it difficult to formulate a cross-departmental strategy, as it would depend on the willingness of other Ministers to participate in and agree to it. From that perspective, the draft Bill gives the Minister added strength. It means that he does not have to depend on the goodwill of other Ministers, but that other Ministers are obliged to co-operate with him in formulating the strategy. From the point of view of the Health Minister, the draft Bill adds something to his armoury in relation to co-operation and linkages with other Departments.

Mr McCallister:

Welcome, Dominic and Arlene. The Chairperson made a point about co-operation between Departments, and it will be no great surprise to the two of you, or to anyone around the table, to hear of my concerns about Middletown. How do you envisage the Minister linking into such a situation? It could almost be said that there is a divergence between the health and education policies on an autism strategy. This draft Bill does not give the Minister the power to intervene or to obtain resources from another Department. That concern is linked to some of the Chairperson's concerns about what the legislation will enable the Minister to do that he cannot do now. Even under the provisions of the draft Bill, he could not develop a strategy or demand resources if his plan was at odds with what the Minister of Education wanted to do.

Mr D Bradley:

The Minister will outline what he believes to be an effective strategy, and the onus will be on other Departments to provide the resources to implement it.

Mrs Cassidy:

If it is to be a cross-departmental strategy with a required sign-up by the other Ministers, all resources and plans would have to be reconciled. The other Ministers would be accountable to the Assembly should they not progress that strategy.

Mr McCallister:

There could be potential difficulties with that because the structure of government means that all the Ministers might change next May. However, there the divergence in policy may remain, which could result in a worse position in which nothing happened. If the consensus that is required between Departments cannot be achieved, we could be left with a situation in which little or nothing happens, or, indeed, with a strategy that is weaker than what exists at present.

Mr D Bradley:

That is probably the worst-case scenario. I do not choose to look at it that way. If that is an issue that needs to be addressed, we will certainly consider it. The Bill is still in draft form, and if there is a mechanism to overcome that scenario, we would welcome your views on it. All legislation must take account of the worst-case scenario and ensure that all possible loopholes are closed. I welcome the fact that you have apprised us of the issue.

The Chairperson:

You have deleted the reference to an autism advocate, but left the door slightly ajar in the sense that it could be reconsidered. Would that require primary legislation, or does any provision in the draft Bill enable that to happen by way of a statutory rule or subordinate legislation?

Mr D Bradley:

There is no such provision in this draft. You raised a good point; perhaps we need to consider including a reference to the autism advocate in the draft Bill. We did not do so because we considered that the accountability mechanisms in the Assembly should be strong enough to ensure the implementation of the strategy. Nevertheless, I note your point, which is useful, and we will consider it further.

Mrs O'Neill:

I declare an interest as a member of the all-party group on autism. Another possibility is that there would be nothing to stop the Department, as part of the overarching strategy, proposing an advocate to oversee that strategy.

The Chairperson:

However, for that person to be at the level of, for example, a commissioner would require primary legislation. We cannot simply decide that there will be an older people's commissioner or a children's commissioner; we have to go through all the required legal procedures. Bills were required to establish both of those posts.

Mr D Bradley:

That is one reason why we have not included the advocacy role at this stage. The start-up costs would be considerable, and it would probably take a year or more to establish the office of advocate and its operation. As I said, we have not ruled out completely the role of advocate, and I take your point, Chairperson, that if consider it to be a future possibility, it may be judicious to include some opening in the draft Bill to facilitate it.

The Chairperson:

That is a double-edged sword, because some people are keen on the idea of an advocate, and others are concerned about it. Its inclusion in the draft Bill as a potential option for the future may cause difficulties for some people, particularly given the current economic situation.

Mr Easton:

As you know, I support a Bill for autism. I am not having a go at you, but I am a wee bit disappointed that it has been watered down, although, to an extent, I understand why. Was it watered down to heal the relationship with the Department, which was unhappy at the prospect of an autism Bill?

I am pleased that the Departments will be forced to work together to come up with strategies. However, I am disappointed that extra funding may not be forthcoming from those Departments, because I believed that we would force them to contribute. Therefore, although I am happy that the Departments will work together, I am disappointed that there will be no additional funding and that the advocate idea will not be progressed. Nevertheless, I will continue to support you.

Mr D Bradley:

To a large extent, I share your disappointment. The dilution or watering down of the draft Bill was not a result of interaction with or feedback from the Department. We took the temperature of some of the parties, and the feedback was that resource implications might make it difficult to move the legislation through the Assembly should it include the position of advocate or commissioner. We thought that such an inclusion would, perhaps, lead to the proposed Bill's not becoming an Act. Although we regretted doing so, we had to balance one element against another, and, with the support of the all-party group, we decided that it would be better to progress the key elements of the legislation and that the advocate's position should be held in reserve for the future.

Mr Easton:

I suppose that it is better to bank what we can now and work towards achieving more later.

Mrs O'Neill:

As you know, I strongly support an autism Bill. When the Committee wrote to the Office of the First Minister and deputy First Minister (OFMDFM) about changing the DDA to include social communication disability, its response was that there was no need to do so. Looking ahead to the Committee's scrutiny of the legislation, I assume that officials of OFMDFM and the Health Department will attend as witnesses. Will you explain why the DDA needs to be changed and why people with a social communication disability are not protected by it at present?

Mr D Bradley:

One practical reason is that Departments use the DDA as guidance when, for example, awarding disability living allowance. Consequently, people with autism have not benefited from the guidance. Arlene will expand on that point.

Mrs Cassidy:

I have a list of issues that may be useful in helping people to get their heads round the implications of amending the DDA. The systematic education of the public that would flow from the adaptations to public spaces and facilities; the emotional hook of ASD being recognised in law would bring a level of validity regarding a condition that is still treated with suspicion and ignorance by some professionals and agencies; and clarity in law is a practical benefit that would guide decision-making on benefit entitlement. I will elaborate on the third point: some DLA adjudicators have disallowed benefits because a child's condition of autism did not fit with the definition of disability that appears in the DDA. We can present such decisions as evidence in support of our case. Such legal clarification will also lead to the updating of disability action plans for public bodies and an improvement in access to equality legislation. Families will have a reference point for entitlement to services, such as those for people with autism whose IQ has been assessed as 70 or above. Finally, the physical adaptations to public buildings will assist not only those with ASD but the wider disabled community.

Mrs O'Neill:

I am on board with the change to the DDA. I thought that it would be useful for the Committee also to be aware of the implications, because we will have to deal with the counter-arguments. The fact that a commissioner, or whoever was involved in the tribunal process, refused someone a benefit because autism did not fit is a powerful argument and just what we need to drive through the legislation. You mentioned that you have evidence of such cases. It would be great if you could provide that to the Committee.

Another issue is that the Health Department might say that it already has a strategy in place. Will you comment on how your strategy will differ?

Mr D Bradley:

The Department of Health, Social Services and Public Safety has an action plan on autism, and the Department of Education is formulating a strategy on autism. In a way, that illustrates the need for strategies to be streamlined between Departments. Indeed, some Departments that need such a strategy do not have one at all.

We welcome the Health Department's action plan. It can fit into and become part of the legislation. The draft Bill does not negate that action plan, but encourages its integration with strategies in other Departments. In that way, the services that people with autism receive can be streamlined between Departments and between the various transitional stages of their lives.

Mrs Cassidy:

I noted a few points that might be helpful to the Committee. By recognising in law the requirement for cross-departmental planning, buy-in and synchronicity, an autism Bill will make a real difference to families. As Dominic indicated, the strategy will assure families that government recognise the lifelong and whole-life reality of autism. Through shared funding initiatives across Departments, it also assures the potential for service development during harsh economic times. The strategy identifies autism is a shared responsibility in our community. It means that duplication and confusion can be addressed and transitions, which are uniquely distressing for individuals with autism, can be better planned and resourced.

The Chairperson:

I may be playing devil's advocate again, but why do other conditions, which are sometimes complex and have implications that cross several Department, not demand a similar Bill and treatment?

Mr D Bradley:

Perhaps some of them do. The Department of Health, Social Services and Public Safety considers that autism requires an action plan. Indeed, it has formulated such an action plan and set up original reference groups to deal with that. That Department agrees that there is a need to focus on autism and to undo its history of neglect. The Department of Education also set up a task force on autism, yet it did not establish a task force on any other disorder or disability. It is also formulating a strategy on autism and agrees that action must be taken to tackle the ignorance that surrounds autism and to undo its historical neglect.

The Health Department and others argued that it was wrong to focus on one particular disorder or disability. However, both the Health and Education Departments have adopted a focus on autism.

Mr McCallister:

My question about the potential risk was on the same lines as that of the Chairperson. Given your reply to the Chairperson, is there any risk involved in having an autism Bill? The Health Department has, for example a stroke strategy, but we do not legislate for that. I also have concerns about autism and any sort of special need that is difficult to identify in young children. I have dealt with some statementing issues in my constituency. Will legislation take autism to a level at which it is almost advantageous for a child to have had the condition diagnosed when attempting to acquire a statement of educational need? Do you regard that as a risk inherent in setting autism on a different level from other conditions or needs?

Mr D Bradley:

No. You described a scenario in which parents might regard a diagnosis of autism as a means of obtaining a statement of educational need. I do not consider that to be a danger connected to the legislation. Most parents to whom I have spoken, and I am sure that you have spoken to many in your constituency office, do not rejoice when their child receive a diagnosis of autism. In fact, some of them go into denial. Parents say that they wish that their child did not have autism and had been diagnosed with a less challenging condition. No parent wants a child to receive an inaccurate or irrelevant diagnosis of autism. Based on our evidence of parents' reaction to such a diagnosis, that is not the case.

Mrs Cassidy:

That goes back to the core issue of an autism Bill, which is the amendment to the Disability Discrimination Act. The current definition refers to disability as physical or mental, and, under the latter, to learning disability and mental illness. As autism is none of the above per se, but can be any of the above, it is not included. As I said earlier, much flows from its non-inclusion. That is a fundamental flaw in our system, and we hope that other equalities will flow from its redress to afford autism equality with other disabilities. We want equality for autism, not for it to be regarded as something special or above other conditions.

Mr McCallister:

If I may widen the scope, autism is a developmental illness that does not fit neatly into any category.

Mrs Cassidy:

As you know, autism involves social and communication impairment, and the intention is to include wording to reflect that in the amendment to the DDA. There is a precedent for the DDA being amended, as it was to include conditions such as cancer and HIV. We are bringing the DDA up to date to make it relevant to today and to what we know about autism.

Dr Deeny:

I have a couple of questions, the answers to which might not be a simple yes or no. Does autism require a specific Bill? The Chairperson asked why we should not have specific Bills for other conditions. Is legislation for autism required because of the problems that have arisen from it not falling directly under a single remit but crossing the remits of health and education?

Arlene, GPs see a wide range of ASD in their practices. A couple of patients in my practice are highly autistic, and it would take a specialist to tell that others are autistic at all. Is the width of the spectrum a problem?

You mentioned that people with autism who have a high IQ are excluded from gateway services.

Mrs Cassidy:

The issue of the IQ level is a current one. The situation is that a child with autism who has a co-existing learning disability can access services through the learning disability services. Children with autism who do not have a learning disability cannot access child and adolescent mental health services (CAMHS) if their IQ is 70 or above, unless they have a co-existing mental illness. The Southern Trust has made some strides in that respect, but I know from parents' experiences in many other trusts, an IQ of 70 or below was required to access the gateway to services.

Dr Deeny:

Does an IQ of above 70 exclude children from access to those services?

Mrs Cassidy:

Yes.

Dr Deeny:

Does that tie in with the severity of ASD? Some people with autism are severely affected, and, in many cases, their IQ cannot even be assessed.

Mrs Cassidy:

I can give only my perspective. As recently as 15 years ago, many people believed that someone with autism also had a learning disability. The statistics were that 75% of people with autism had a learning disability and 25% did not. We now know that the true position is exactly the reverse, and we have a better understanding of what life is like for those individuals who have an IQ of above 70. Many people consider that those with an IQ of above 70 cope better, but their families have to deal with a different set of severe difficulties.

In answer to your other question, the width of the autistic spectrum has become an issue as our understanding has grown over the years. An autism Bill aims to bring us up to speed. Our knowledge of autism and its prevalence have shot through the roof. The current system is creaking in an attempt to meet the accelerating need. The legislation aims to create a foundation on which we can build.

Mr Gallagher:

I support the draft Bill and acknowledge the work that has gone into it. We are trying to achieve a seven-year strategy that will be published by the Department. The idea is that the trusts will feed into the strategy and provide the resulting data to the Department. Arlene, you said that autism rates are rising and rising. Do you envisage the trust providing that data every seven years or annually? Have you decided on that yet? Everyone agrees that the rate of autism is rising? Have you considered whether that data should be collected by the trusts every seven years, or should that be done every year so that the Department has the up-to-date data on its desk?

Mrs Cassidy:

Data collection for planning purposes has to be done annually. The education and library boards collect data on school-age children with autism. A couple of weeks ago, at an event here, a colleague from the Belfast Education and Library Board told me that the prevalence rates that Autism NI was quoting, of one in a hundred, were out of date. I said that I knew that they were conservative but that we did not want to send out the message that the condition is more prevalent than it is. He quoted a rate of one in fifty in Northern Ireland, and we are now seeking to confirm that.

The cross-departmental issue of data collection in the draft Bill focuses more on synchronising the data collection of the Health and Education Departments. The Department of Education has a track record in data collection, but the Department of Health, Social Services and Public Safety has not and is addressing that in its action plan. I cannot report to the Committee on how far that work has progressed, but data collection has been flagged as an issue. The aim is to synchronise such effort to improve cross-departmental planning.

Mr D Bradley:

If Tommy was suggesting that it would be useful for information to be updated much more regularly, I agree. It is hoped that the strategy will not remain static over the seven years, but that it will be sensitive and adjusted in response to information fed back from the statistical report.

The Chairperson:

Any autism Bill will undergo a Committee Stage, so we will have plenty of opportunity to scrutinise it then.

Thank you very much, Dominic and Arlene, for your evidence. The Committee will probably see a great deal of you in connection with the legislation over the next few weeks and months.

Mr D Bradley:

I thank the Chairperson and Committee members for engaging with us today. Although some of the points raised were quite challenging, they were useful and constructive. They will be helpful to us as our work on the draft Bill continues.