Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Autism Bill: Committee Stage: National Autistic Society Northern Ireland

13 January 2011

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Mr Jim Wells (Chairperson)
Mr Pól Callaghan
Mr Alex Easton
Mr Tommy Gallagher
Mr Sam Gardiner
Mr Paul Girvan
Ms Sue Ramsey

Witnesses:

Ms Regina Cox	)	National Autistic Society Northern Ireland
Ms Shirelle Stewart	)	

The Chairperson (Mr Wells):

Ladies, you are well known to many Committee members. You have been here before as witnesses and have met us individually on many occasions. However, I formally introduce Regina Cox, who is a co-director of the National Autistic Society Northern Ireland, and Shirelle Stewart, who is also a co-director. You have plenty of experience of giving evidence and know what is expected. I suggest that you take 10 minutes to make some introductory remarks, after which there will be about 45 minutes for questioning. In case you are wondering why the Public Gallery is packed, it is because of the swine flu update that follows your evidence session. They are not all piling in entirely for your evidence.

Ms Regina Cox (National Autistic Society Northern Ireland):
I thank the Chairperson and the Committee for inviting the National Autistic Society (NAS) Northern Ireland to present evidence on the Autism Bill. I will start by giving members a brief overview of our work, after which Shirelle will talk more specifically about the Bill.

The National Autistic Society Northern Ireland is a charity that works throughout Northern Ireland for everyone who is affected by autism, including children, adults and their families. We provide information, advice and support, and we campaign and lobby for lasting positive change for those who are affected by autism. We also have 12 NAS parent branches that provide local support, and we encourage them to fund-raise to deliver local community services such as playgroups and sports activities.

Our other services include a help! programme that provides training for parents and carers of children or adults with autism, and a befriending scheme, in which we train volunteers to work with a child or adult with autism and families to provide some respite. We have a parent-to-parent confidential telephone support service and an education advice line. That is popular and provides information, advice and support on education provision and entitlements to guide families through education, which many of them find complicated. We run support groups for parents who have adult children with autism and youth groups for adolescent children. We also have social groups for older adults, who are aged 16 or over, with autism. The linchpin of our services is our team of family support workers who work in the west, the north, Belfast and north Down. Each of those family support workers will support 80 to 120 families over the course of a year and will act as advocates for parents, providing emotional support and, more importantly, practical support.

We also have a rolling monthly programme of parent workshops on a range of activities, which are currently free to parents. Furthermore, we provide a range of training for professionals.

Ms Shirelle Stewart (National Autistic Society Northern Ireland):
First, I will set our comments in context and briefly outline the work in which the National Autistic Society has been involved in autism legislation and strategy development across the UK. In England, the NAS was one of the principal proponents of the Autism Bill, which became the

Autism Act 2009. The NAS worked with 13 other autism organisations to take that forward, which resulted in the development of an adult autism strategy in March 2010, and statutory guidance was published in December 2010.

In Scotland, the National Autistic Society pioneered the Autism (Scotland) Bill, which is currently in the Scottish Parliament. In Wales, the NAS is an active member of the autistic spectrum disorder (ASD) strategic action plan, which sets out how services will be delivered in Wales. In Northern Ireland, we play an active part in the regional autistic spectrum disorder network (RASDN), which was formed to take forward the Department of Health, Social Services and Public Safety's (DHSSPS) strategic action plan. The NAS sits on the reference group, the adult subgroup and the Northern Health and Social Care Trust ASD forum. The society is also involved in the transitions, interventions and training work streams.

I will now deal with specific clauses and our views on the Bill. I will focus my comments on the cross-departmental strategy that is proposed. The National Autistic Society Northern Ireland supports the main objective of the Autism Bill, which is to enhance the provision of services and support to people with autistic spectrum disorder. The society supports clause 2, which requires all Departments to co-operate in the development of an autism strategy and implement any part of that strategy for which they are responsible.

Although we welcome the intention for consultation among Departments, we are concerned that the views of people with autism, parents, carers and the voluntary sector will not be adequately considered unless their involvement in that process is outlined in the Bill. With that in mind, we would propose an amendment to the Bill, the wording of which could be along the following lines:

> "that the Department should establish a reference group that comprises people with autism, parents, carers and representatives from the voluntary and statutory sector to develop the autism strategy and to oversee its implementation".

The NAS supports clause 2, which requires the Department to request that every health and social care trust provides data on the prevalence of autism in its area. That is essential for the planning and commissioning of services. The National Autistic Society Northern Ireland outlined the need for the collection of data in its 'I Exist' report, which examines the needs of adults with autism in Northern Ireland and was published a couple of years ago.

In relation to whole-life support for people with autism, the National Autistic Society

Northern Ireland supports the content of the strategy in requiring the lead Department to set out how the needs of people with autistic spectrum disorder are to be addressed throughout their lives. Health and social care has started to address some of what we consider historic deficiencies in that sector on autism.

In June 2009, Minister Michael McGimpsey published the ASD strategic action plan, which arose from the independent review of autism services chaired by Lord Maginnis. The Minister commissioned the regional autistic spectrum disorder network to take forward the implementation of the strategy, and Dr Bergin and Lord Maginnis head up that process. We believe that RASDN has started to produce some results in health and social care, some of which I will outline for the Committee.

The NAS is an active participant of RASDN. RASDN is unique because of the involvement of parents, carers, people with autism, the voluntary sector and the statutory sector, who are all working together to devise services that best meet the need of people with autism and their families. Parents and carers are officially mandated as advisers to that reference group and to each trust. They are involved in all recent investments and in service improvement from the group.

A number of things have happened: there was a financial investment in autism services of around £1·54 million over the 2009-2011 period, and a £100,000 investment was announced in November 2010. Although we welcome the investment, the provision of services for adults with autism is negligible in Northern Ireland, so £100,000 is not enough money. More resources will be needed to provide adequate services for people with autism.

There has been a reduction in waiting lists for assessment to 13 weeks, and four of the five trusts are seemingly meeting that programme. That figure goes up and down and needs to be monitored, but that is quite a dramatic improvement from a number of years ago when people were waiting for two or three years to start the assessment process. There are also recommendations for the adult diagnostic pathway, which should be coming out in January or February, and work streams are ongoing in training, interventions and transitions. The National Autistic Society Northern Ireland supports the work of that group and suggests that any future strategy needs to ensure that the work is continued.

The NAS has proposed an amendment, and we feel that any reference group that is set up should be structured in the same way as RASDN. That is also the policy of the National Autistic Society in that when it devises services or policy initiatives, trustees of the society and board members are elected from parents, carers and people with autism as well as other members of the community. We feel that that is best practice, but it is not common practice in Northern Ireland. We feel that that is very positive and want other strategies being implemented in the same way.

I will deal with education because —

The Chairperson:
We are rapidly running out of time. Is this material in addition to your subamission?

Ms Stewart:
No, but I just have a little more to say. Educational representatives sit on RASDN but are not officially mandated to do so. That is one reason why we need a cross-departmental strategy. The other reason is that employment and learning are also major issues for adults with autism. The Department for Employment and Learning is not involved with RASDN in a strategic way.

I know that the Bill mentions taking cognisance of the health and social care, education and social needs of people with autism; however, I suggest that employment needs to be included, because NAS research shows that only 15% of people with autism are in employment, so that is a major issue that needs to be included in that clause.

The Chairperson:
If you have missed anything, feel free to tag it on to your answers. Nevertheless, as you might expect, I have to ask you about the elephant in the room. You commented on clause 2, but there has been absolutely no comment from your organisation about clause 1. The obvious question is: why?

Ms Stewart:
We are not opposed to any amendments to the Disability Discrimination Act (DDA) 1995, but we feel that it probably covers the majority of people with autism. That view is based on training and advice that we have had from the legal profession. We are not lawyers; we seek training and advice. Indeed, the Committee is probably better placed to ask for specialist legal advice in that

regard.

The Chairperson:
That surprises me, because you are one of the main players in the field — a very disparate field — and I question why so many organisations operating in Northern Ireland are dealing with the same condition.

Ms Stewart:
Look at any other sector. Look, for example, at the environment sector. As you know very well, it involves 14, 15 or 16 organisations. Autism is a spectrum condition, and people are placed at various points on that spectrum. Therefore, the range of interventions that need to be adopted must be child-centred. Another reason why there are so many organisations is that people take different approaches to different interventions, which is right, because a child or adult will need a different intervention depending on his or her need and where he or she is on the spectrum. Furthermore, there should be parental choice so that people can decide what services they need. There will not be a parent in Northern Ireland who feels that the needs of his or her child or adult with autism are being met.

The Chairperson:
It strikes me as unusual that one of the major organisations in the field in Northern Ireland has not made any comment on an absolutely crucial aspect of the Bill.

Ms Stewart:
I have just commented. My answer is that we feel that the majority of people with autism are covered under the Disability Discrimination Act 1995. There are also ongoing changes to the Equality Act 2010, which was introduced in GB, and we are out of line with some of those provisions. That is where the Committee probably needs to seek expert legal opinion, because we need to bear in mind the changes that we need to implement to bring us into line with the Equality Act 2010.

The Chairperson:
That is a very valid point. Nevertheless, it is a bit strange that your organisation, which has many members and is in constant touch with people on the ground who care for people with autism, has not found it necessary to support the change to the definition of the DDA. That indicates that the

driving need that others suggest is not there.

Ms Stewart:

I want to make it perfectly clear that people are being discriminated against. We are not saying that that is not happening, and there is ambiguity in the application of the law by people on disability living allowance (DLA) and employment and support allowance (ESA) tribunals. There is definitely discrimination. We are simply stating what our advice and training has always been. However, that involves the people being discriminated against taking a legal case, which, for people with autism, is a very difficult process.

The Chairperson:

You cannot feel that strongly about it, because you did not mention it at all in your written submission, and, indeed, had I not asked the question, you would not have mentioned it in your oral submission.

Ms Stewart:

You cut me short. You told me to finish.

The Chairperson:

I was carefully following the text from which you were reading, and there is no mention whatsoever of clause 1. You went directly from an introduction to talking about clause 2, and I think that it is telling that there is no unity in the sector about the need for an amendment to the DDA. That comes from my simply asking an obvious question that I had to ask.

Ms Stewart:

As I understand it, in the context of the Equality Act 2010 in England, changes will have to be made to the DDA, so there needs to be a conversation based on expert legal opinion.

The Chairperson:

I take it that you have no strong views on the amendments to the DDA and that you are moving on to strategy. Is there anything in the Bill that could not be done without legislation?

Ms Stewart:

Our view is that legislation underpins strategy. The NAS is a strong supporter of the existing health and social care strategy. However, it does not meet the needs of people with autism across the spectrum in every aspect of their life or provide lifelong support. There is a little bit about health and social care. The Department of Education is developing an education autism strategy, but that needs to come together in one strategy. The Department for Employment and Learning is not necessarily producing an employment strategy. Employment issues for adults with autism need to come together. The Assembly has not produced a cross-departmental strategy. The Bill proposes that it does so, and it compels all Departments to take part in the development of that strategy, which is needed to tackle a lifelong disability such as autism.

The Chairperson:

There is nothing to stop the relevant Ministers announcing tomorrow morning that they will develop a cross-departmental strategy. It does not require legislation.

Ms Stewart:

It has not been done, and this is an opportunity to do so. The NAS has been talking about this issue for about four years and has been calling for a cross-departmental strategy since before I joined the society. However, it has not yet been taken forward. The Bill takes it forward, enshrines it in law and gives it teeth to ensure that people co-operate in a meaningful way.

Ms S Ramsey:

You covered my question, but I will take the opportunity to make one point. I agree with the Chairperson that there is nothing to stop Ministers from coming together to develop a strategy. However, it will involve more than three Ministers. You mentioned DLA. There is a need for supported housing. There is a possible need for the involvement of the Department of Culture, Arts and Leisure (DCAL) to make provision for leisure activities, and so on. Even the Office of the First Minister and deputy First Minister (OFMDFM) should be involved.

The Bill puts a strategy into a legal framework. Ministers may introduce a strategy today, but the trusts will not implement it tomorrow. We have seen that it is too easy to cut services for the people who are most in need and most vulnerable. That is a key issue for placing a strategy within a legal framework.

Ms Stewart:

I agree.

In these financial times, it is not popular to say that there has been historic underfunding of autism services in Northern Ireland, and if we want to provide more services, more funding has to go into those areas. From the economic appraisal of the amount of money that it takes to deliver autism services in the UK, it seems that there will be an economic saving as time progresses if we put in place the right interventions and support earlier in a person’s life. That would stop us reaching a crisis situation that is costly for health and social care or whatever agency to resolve.

The Chairperson:

Your group has brought forward parents to individual groups of MLAs and to me as Chairperson of the Health Committee**.** We learned at first hand the incredibly difficult life that many of those carers lead. Many of them are women, physically trapped in their homes because of the need to care for someone with profound autism. We all get many letters and cards from those folks. Everyone has tremendous sympathy for their situation. However, as I asked the previous set of witnesses, are we not building up a false sense of hope? Many of those folk believe that the Bill, in its own right, will deliver a radical change to their situation. Is that true, or is it not a minimalist Bill that will address some issues but will not provide the resources that they so desperately feel that they need?

Ms Cox:

We are involved in the regional ASD network. Many of the parents are very committed and give of their time. I have seen that, as time progressed and we started to see results, how encouraged parents are that they can help themselves and make changes to services and have their voices heard. They feel that the legislation will help them to get those services off the ground. As Shirelle says, one of the major problems is funding and getting services up and running, and if that were placed within a legal context, services would improve — not overnight but in the future. RASDN has really encouraged parents in that regard. They have seen changes.

The Chairperson:

Let us look at the issue practically. You are obviously agnostic on the change to the DDA. However, let us assume that that goes ahead and that, for instance, more children are entitled to DLA. However, the Aspergers Network states that it has been successful in every appeal that it has launched on the issue.

Ms Stewart:

However, people have to go to appeal and —

The Chairperson:

Let us assume that a significant number of children receive DLA. Then there is a strategy, and Departments are forced to get together to develop a strategy, which could be six pages stating that a strategy has been developed.

Ms Stewart:

Legislation is a step on the journey, and any organisation involved in the process understands that. Parents understand that the process takes time. We assume that if a strategy were up and running, there is another job to be done in ensuring that the strategy is fit for purpose. That is the other reason why we suggest an amendment to the Bill in order to involve parents, carers and people with autism as well as the statutory and voluntary sectors in devising a strategy that will be fit for purpose.

The Chairperson:

Have you floated the idea of your amendment with the proposer of the Bill, Dominic Bradley, and other charities in the field? What sort of support do you feel that you have for the amendment?

Ms Stewart:

We have proposed the amendment only in this evidence session.

The Chairperson:

Therefore, you have no idea how the proposer would feel about it.

Ms Stewart:

No, but it is recognised good practice; I cannot imagine that it would be contentious.

Mr Callaghan:

I have a few questions; I know that the Chairperson gets a bit nervous when he hears me saying that.

I want to make a point that I put to the previous witnesses. There are some issues about duplication and also about a vacuum. To be fair to the Minister, there has been a ramping up of investment over the past years. Partly because of that, I heard one family member say there were times when he could hardly keep up with the number of appointments. There was a feeling that not all of them were necessarily productive, because education authorities were undertaking some activities on the children's side of the house, and people were undertaking other activities on the health side, and they were not necessarily joined up at the top. On the other hand, we hear about people, whether children or adults, who fall outside service provision catchment altogether. It would be helpful to hear your perspectives on that day-to-day experience.

Ms Stewart:

There is an issue around joined-up provision. Let us take as an example a child with autism who is in mainstream school. That child with autism, as well as probably needing support in the classroom environment, will require speech and language therapy as quite a lot of their difficulties may stem from language. They may also have profound sensory difficulties. It is difficult to provide that spectrum, because there will not necessarily be a joined-up plan. There is no legal obligation on the DHSSPS to provide in a statement the occupational therapy provision or speech and language provision needed.

The experiences of children in the classroom and how they cope overspills into the home, so there needs to be joined-up provision between parents and school and school and health. When a child is transitioning into adolescence and adulthood, there needs to be a joined-up approach to getting proper work experience, careers guidance, interview skills and social skills, all of which are necessary to gain employment. At present, the system is not working in a joined-up manner.

There is little employment and learning support for people with autism. Many people with autism want to work but do not necessarily have the skills to get through the interview process. Employers do not understand the process of employing people with autism and how to deal with them.

Ms S Ramsey:

Or benefits.

Ms Stewart:

Yes, or benefits. That is going through much change, which will cause more problems. People falling through the system has been a historic problem. People with Asperger's syndrome did not fall into the structures around mental health or learning disabilities because their IQ is above 70, so they did not fit learning disability and they did not fit —

The Chairperson:
The Aspergers Network is the organisation that is most vociferously against the Bill. Does it not strike you as strange that it has put its face totally against it?

Ms Stewart:
I am not sure what the reasoning is behind that. I am sure that you will ask the network.

Mr Callaghan:
As the Chairperson rightly points out, the Bill is not a panacea. However, there are advantages to the Bill not being overly specific, because things may change over time. It is ironic that we heard evidence stating that the Department and the statutory bodies want to be flexible in order to respond to changes over time, but, on the other hand, some of the complaints about the Bill are that it is overly prescriptive and constrains people. Somebody must be wrong — I do not know who it is — or is perhaps not anticipating how things go down the line in the correct way. I do not want to jump too far ahead of the Bill, but there is a possible outworking in relation to on-the-ground provision. If there were a unified strategy as prescribed in the Bill, do you think that it would be helpful if there were single assessment points and united service delivery teams? We would then no longer have people working in, for example, an education silo and seeing the educational psychology side. Some of the trusts have dedicated ASD teams, and there is speech and language and whatever else. Do you think that it would make more sense for families who receive services? My examples are more related to children than adults. Is the NAS view that it would make more sense to have cross-cutting teams?

Ms Stewart:
Yes, without doubt. In order to meet the needs of children or adults with autism we need a multidisciplinary approach. We need to involve people, because the care required to meet the needs of people with autism is extremely complex and involves several Departments as those people progress through their life from birth until death. The only way in which to meet that adequately is through a joined-up approach.

Ms Cox:

We push for person-centred planning for an individual with autism, so that we are not putting a prescriptive service in place but dealing with each individual child and adult and putting in a service that meets their needs.

Ms Stewart:

That is extremely important, because one size does not fit all. That needs to be built into any process. A strategy is not written in stone. The legislation compels people to put that strategy together, but it can be reviewed and revised.

Mr Callaghan:

Over the weekend, I had some conversations with people who knew that the Bill was in Committee. They mentioned the fact, which may not be a disjoin, that certain people deal with children in the school environment and then, when those children go home, they are supported by different statutory officials. It can be difficult for them to provide a properly tailored approach to all of a child’s needs, because a school environment can be very different from a family environment, especially for families who might be struggling. Across society, there are some families who struggle and some who have more capacity. It is almost as if a child is dealing with two entirely different environments, which must in itself be quite disconcerting for a child, regardless of whether he or she has autism. Do you have any views on how that type of difficulty could be better addressed?

Ms Stewart:

One problem that we find is that, when a child goes into the school environment, there is much more routine, but a child with autism often struggles within the environment if he or she is not receiving the right type of support. The anxiety reaches boiling point and, by home time, that child is so full of anxiety that it overspills into the home environment. We also suggest that the right type of support in school would help with the difficulties that a child might experience in the home. There needs to be a plan for a child with autism that looks at the school environment, the home environment and leisure activities, because that child is entitled to the same aspects of life as every other child.

The Chairperson:

None of the other sets of witnesses really addressed the need to gather statistics on the prevalence of autism. The departmental officials said that they are gathering statistics already. They can improve on that, but their mantra is that we do not need legislation to do that. Where does your organisation perceive deficiencies in the statistics?

Ms Stewart:

This is probably a new initiative, whereby people are starting to count the numbers of people with autism. In a school environment, one has a better idea of the numbers of children with autism because they have, perhaps, been through the statementing process. As for adults, we have no data to tell us how many adults with autism are in the system. As I said earlier, many of them have fallen through the system. An individual might be registered under mental health services but not necessarily as having autism. Those who have autism and a learning disability will be registered under learning disability services. Those with Asperger’s syndrome who do not have either a learning disability or a mental health difficulty have, in the past, not existed. There are many such people out there whose existence the two services do not acknowledge. Many older adults with autism are not known to the services and do not get the services that they need.

Ms Cox:

Misdiagnosis is also a problem. Adults in their 30s and 40s will have been diagnosed for something else. We must also take that problem into consideration.

Mr Callaghan:

I will flag an issue. In gathering data, a current difficulty may be that because a co-ordinated approach from departmental level is not cascading down, different data sets are sought. On the health side of the house, clinically diagnosed criteria may be applied, whereas on the education side, criteria may be more based on observed behaviour. We are not necessarily comparing like with like, and that could be a problem.

Ms Stewart:

You are correct. That data will follow the person from one Department to another. For example, there is no data in the Department for Employment and Learning about how many people with autism receive which benefit or how many people are benefiting. The data is not collected. If someone with autism goes through one of the work programmes in that Department, data is not collected about whether it is successful for that person or whether that programme got him or her into work. Therefore, data is extremely important for the planning and commissioning of services and evaluating which services are the right ones and which support programmes work for people with autism. Data is extremely important.

The Chairperson:

Thank you very much for your evidence and your answers. Members have all had a chance to ask questions, and we have your written submission.