Northern Ireland
Assembly

COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Autism Bill: Committee Stage: Autism Initiatives Northern Ireland

13 January 2011

NORTHERN IRELAND ASSEMBLY

COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

Autism Bill: Committee Stage: Autism Initiatives Northern Ireland

---

13 January 2011

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

Witnesses:

Ms Grainne Close	)	Autism Initiatives Northern Ireland
Mr Alan Hanna	)	

The Chairperson (Mr Wells):

Mr Hanna and Ms Close, I am sure that you are a little shocked that you have been called so quickly. We dealt with other business much faster than we expected to. You are very welcome to the Committee for Health, Social Services and Public Safety, and you are aware of why we are here, which is to discuss the Autism Bill.

We usually allow witnesses 10 minutes to introduce the topic, after which there is 45 minutes of questioning. You may have watched or listened to previous evidence sessions, so you know the procedure. We are very keen to hear your point of view on this important legislation.

Mr Alan Hanna (Autism Initiatives Northern Ireland):
We will keep our evidence concise, and members already have our submission, which I will summarise.

I often refer to our organisation as being the largest direct service provider for people with autism but the least well known. We provide services to over 200 families across Northern Ireland and employ almost 250 staff, but people often ask what Autism Initiatives Northern Ireland is. We provide a range of services, mainly to adults, particularly in supported living, residential services, community outreach and floating support. We are very much involved in caring for people who need extensive support. Often, those are people who have been resettled from long-stay hospital, but we also help people towards independence. Floating support is about keeping people in their own homes or preparing them to live more independently by providing support where it is needed.

We also provide a range of support programmes to young people. Our youngest service user is around eight years of age, but that is a relatively small part of our work. Our main contacts are with adults. It is striking that much public attention is, understandably, on the areas of diagnosis, young children, families and education. However, all those children grow up and will need support throughout the rest of their lives. That is one of our strengths: we take a more strategic approach to autism because otherwise health could become the provider of last resort. People who could be capable of further and higher education and of competing in the workforce may not get the opportunity to do that, and their services remain largely within health and social care.

That gives members some background on the organisation. I do not propose to read through all our submission because members already have it. I will highlight only some areas.

We have been strong supporters of the move towards an Autism Bill throughout the process, and we acknowledge the strong support and leadership of Autism Northern Ireland. Autism Initiatives Northern Ireland used to share the same office with Autism Northern Ireland. We carried on the direct service work while our colleagues down the corridor looked after the information and campaigning work. We kept a close eye on that work and have seen it develop over a number of years. We hope that it comes to fruition. There is a strong case for both a legislative and a strategic approach to autism in Northern Ireland, not least because of the numbers involved and the relatively sudden increase in diagnosis and an increased recognition that people have the condition.

It is interesting that members referred earlier to the Public Health Agency press statement on swine flu. At this time last year, when we thought that a significant proportion of the population would contract swine flu, we made a number of strategic and operational decisions and actions to prepare for that. In the absence of a legislative process for autism, we have not been able to respond in the same way to a large increase in the number of children and young people coming through the system who will then feed through to adult services in the future. We hold that view strongly.

The Minister of Health, Social Services and Public Safety issued an autism strategy last year, and we have been involved with the regional strategy process. We are also extremely supportive of that and do not believe that the Bill and the strategy are mutually exclusive. We are able to push on with a number of issues that would probably be strengthened with legislative backup.

I will move on to the main issues that are proposed in the Bill. Firstly, there is a proposed amendment to the Disability Discrimination Act 1995. Grainne and I are not legally trained, but it seems to us that the range of ability or impairment associated with autism is so wide that some people are clearly receiving services through either mental health or learning disability provisions, but there are others for whom access to those services is difficult. That is partly down to a misunderstanding of what autism is. Some of it is also down to the way in which we have structured our services.

There is a major challenge for health and social care. If we have a learning disability service for people who have an IQ of a certain level, it is clearly not the service for people with an IQ above that level. If that person does not have a mental health problem, mental health services are not for them. Currently, there is no obvious place for health and social care to respond to those needs. That may be part of the outworkings of either the regional strategy or the Bill.

There is certainly evidence that a key part of employment legislation and disability discrimination cases are concerned with the definition of disability and whether or not a claimant is disabled. We feel that an amendment to the Disability Discrimination Act 1995 may help to clarify that position to someone who is not a legal expert. Certainly, it is clear that many people with autism are often recognised as being disabled for the purposes of the 1995 Act, but that is not the case for some people. We think that the amendment would help that.

Autism is a spectrum condition, and the range is very wide. In the regional strategy group, a son or daughter could receive a service from an organisation and the staff ratio is 2:1 for that service. Other families in the regional strategy group can describe how their son or daughter is making presentations to their grammar-school class. The range is very wide, and the types of need that arise from that are diverse.

We support the autism strategy approach that is recommended in the Bill. We already have the regional ASD strategy. The strongest elements of the Bill will bring other Departments into that. There is a level of co-operation, but, particularly at a time of acute financial difficulty, it is much easier for other Departments to prioritise other areas or reduce services in some areas. A legislative commitment would make it more difficult for that to happen. That is one of the main reasons why we support that approach.

As part of the regional strategy, I pay tribute to the work that has already been done, particularly by Stephen Bergin and Lord Maginnis, some of which has been quite controversial publicly. The view that we have taken — and that I have taken partly as the parent of a child with autism, and Lord Maginnis is a grandfather, as well as everything else — is that we recognise the support from other people in the family.

As I said earlier, in the absence of a legislative imprimatur, health becomes the provider of last resort. People can find themselves getting into trouble with the law, leaving themselves lost between different services, lacking the support that they need or developing all types of other ancillary problems because there has not been a joined-up approach to meet their needs.

Finally, I want to say a little on the collation of data. As I said in relation to swine flu earlier, when we had an estimate of the numbers of people that we thought would get swine flu, we took action. The absence of reliable figures for the actual number of people with autism and their likely future needs means that we have not been as efficient and effective in our planning as we could have been in forecasting the need for employment and training schemes and supported living schemes in the future. There is a disconnect between the time when young people leave school and when they move into adult services. It seems to us that legislation is probably the best way to help that situation at this time.

Given the number of people with autism who are coming through the system, and the need to promote even greater joint working between Departments, a legislative approach is probably the best way to supplement and strengthen the work that is under way.

The Chairperson:

Thank you, Mr Hanna. Ms Close, I presume that you are happy with that.

Ms Grainne Close (Autism Initiatives Northern Ireland):

Yes, I am.

The Chairperson:

Many bodies represent autism in Northern Ireland. In fact, it seems that every conceivable angle of the spectrum is covered by a separate charity. It strikes me as extraordinary that so many groups are dealing with the condition in a little place such as Northern Ireland. There is not unity. We had a strong representation from the Aspergers Network, which is totally opposed to the Bill and has great concerns. Why is there a splintering of opinion on the Bill within the sector?

Mr Hanna:

The range in autism and the service responses are so wide that it is almost not the same condition. Take Asperger’s syndrome, for instance: the level of support that we provide to individuals is extremely intensive and is a different experience for many people with the condition. It almost does not feel like the same condition. That is part of it. People become involved in different organisations for different reasons.

There are similar disagreements within other disability groups. In a previous life, I worked for another learning disability organisation, and there were divisions within that. People become involved and set up different organisations for different reasons. I am sorry, Chairman; I know that that sounds like a waffly answer. People take different views on issues.

The Chairperson:

Autism Initiatives Northern Ireland is one of the main providers of care in this field. I am very aware of your work in Newcastle. At a practical level, should the Bill became law in the morning, what difference would it make to the service that you provide? What would you be able to provide tomorrow that you could not have provided yesterday?

Ms Close:

Alan said that it is a hidden condition for many people on the spectrum. We feel that the Bill would help to identify facts. You mentioned the Aspergers Network. Many of the groups and people with Asperger's syndrome with whom we work do not like to be labelled as having a disability, but the Bill would help us to acknowledge that hidden condition and to be able to support more people with Asperger's syndrome.

The Chairperson:

Why can that not be done now? The Minister would argue that he has the power to provide funds for any form of treatment or care that is required for anyone on the spectrum.

Ms Close:

There is an issue about benefits. Some people on the spectrum who would identify themselves as having Asperger's syndrome have difficulty accessing certain benefits such as disability living allowance (DLA), which is a big issue. However, the Bill would help in recognising that there are people with a hidden or invisible condition and that they need help in accessing benefits.

The Chairperson:

We get lots of letters and cards from folks urging the Assembly to support the Bill. Is there a danger of building up a false sense of hope for those who are treating and caring for people with Asperger's syndrome and all sorts of autistic conditions? They think that there is going to be a revolutionary change, that there will be vast new resources and that many of their problems are going to be solved. However, the Bill is minimalist; it does not promise a lot. Is there a false sense of hope that cannot be sustained?

Mr Hanna:

The Bill does not specify what individual organisations should do in response to it. However, it strikes me that those people who, with some support, may avoid falling into other services in the future — I am sorry, I am not putting that very well. People with autism who have a learning disability can, in theory, access learning disability services, and many do so. People with autism who also develop a mental health problem can access the services that are run by mental health teams. Our structures do not currently allow for the people who are in the middle, whose IQ is assessed as being over 70 and who do not have a diagnosable mental health problem.

I think that the view of those opposed to legislation is that we can simply have a trust reorganisation; that is not a problem. That point — whether we need a law or reorganisation — could be argued for almost anything that comes before the Assembly. We feel that, by giving the issue an impetus through the Bill, structural changes in the trusts could be progressed to provide a service to the people who have neither a learning disability nor a diagnosable mental health problem.

If we knew the number of people with autism, that would lead to a more accurate assessment of need. There has to be more detail than simply claiming that there are X number of people with autism in Northern Ireland. The range of need is so wide that it would also be useful to have a notion of how many people are likely to require supported living, will need help to access education and further education in the future, and so on. That is an issue because it is possible to provide services to many people with a relatively small amount of money, at least to those who do not need much support but need some help with co-ordination and activity.

We have a staff ratio of 2:1 with some of the people with whom we work. With such people, a staff member has to stay awake with them in their households for 24 hours a day. The collation of numbers and the assessment of need would enable trusts, the Department of Health, Social Services and Public Safety (DHSSPS) and other Departments to plan more thoroughly and cost accordingly for the future.

Mr Callaghan:

Witnesses have put it to the Committee that, should the Bill be enacted, one potential benefit would be that it would help to reduce the overlap that some people complain about in the provision of services. It seems that there may be disjointed provision between the health side of the house and even various teams working on the trust side, as well as the education provision. The point has been raised that sometimes if a child — or, for that matter, an adult, but I generally hear people talking about children — is in one team, it may temporarily or indefinitely be removed from the influence of another team where it could benefit from certain service provisions or taking up support**.** What is your assessment of the potential benefits of streamlining service provision to families and people with autism and the wider benefit to the public service generally in efficiency terms?

Mr Hanna:

A number of years ago, pioneering programmes were set up that brought together further education, education and health, particularly in the area of learning disability. Professionals and parents' groups came together to provide opportunities for people with a learning disability. They were also able to lever European social fund support for that. That would probably not have been possible without bringing those various groups together, otherwise we would have had a disjointed approach that involved someone undertaking an activity that was run by one service on one day and undertaking a different activity on another day. He or she may not have had the opportunity to progress from one to the other. That scenario probably applies more to adult day services.

The problem has something to do with the nature of public administration. Some time ago, a special school in Belfast had an issue in that it crossed two health trust areas. The school had therapy support, but one therapist was paid for, for the sake of argument, by the South and East Belfast Trust and the other therapist was paid for by the North and West Belfast Trust. The therapists were not supposed to work with children who lived in the other trust area. A way was found to make that happen. It was not done at a strategic level but at an operational level, and people made it work. The Bill will provide the impetus for such issues to be considered in a more strategic, joined-up way.

It is certainly the case that there are some excellent pockets of service in Northern Ireland, but there are some areas in which not much is happening. It is often down to individuals who have made a major commitment and made things happen. It is not a criticism of people in those other areas, but the same set of circumstances has not arisen. There are good services in one place and not-so-good services in others because there is no, or little, strategic approach. The innovation of individuals and family groups made things happen. The potential to spread that across the region would be valuable.

Mr Gallagher:

I want to ask about the residential facilities that you provide, and particularly the level of demand for those kinds of facilities. What other Departments or agencies are involved with you in that provision?

Ms Close:

We currently have 92 referrals from the five trust areas. In the Belfast Trust, there are 30 referrals for supported living; in the Northern Trust area, there are 15; in the South Eastern Trust area, there are 45; in the Southern Trust area, there are three; and in the Western Trust area, there are 19. When we receive a referral, we go through an assessment of need with the individual and the family. There is currently a backlog because we do not have the resources to house 92 people, so we will have to set up a priority list. Those are the current numbers for supported living accommodation-based services in the trust areas.

Mr Gallagher:

Are other Departments involved in that?

Ms Close:

If 100 referrals have been received by us, some would be from the Probation Board and some from the University of Ulster in relation to helping someone in the college with Asperger's syndrome. However, our referrals mainly come from the health and social care trusts.

Mr Hanna:

What you may have been looking for is the typical way in which a supported living scheme is set up. We do not run big services. A fairly large ordinary four-bedroom house might house two or three people with autism. The way that that is made to happen is that the house may be owned by a housing association, supporting people through the Northern Ireland Housing Executive, and the Department for Social Development (DSD) would be involved in the funding support for the rent. The Supporting People scheme helps individuals with their support and care costs, and the health and social care trusts are increasingly involved. Essentially, our role is to help all that to stay together by providing support to an individual, but an individual is a tenant in a house, so he or she has a legal tenancy. That has worked very well, but it is clearly coming under severe funding pressures. We have no shortage of potential service users, nor, indeed, does any other service provider out there. There are plenty of people to go around, but perhaps not quite the resources that we would like.

Mr Easton:

I support having a Bill for autism, and I have yet to hear an argument from anyone about why we should not have it. Why do you suppose that the DHSSPS seems to be so opposed to it? Can you fathom that, especially when the joined-up approach with other Departments that will come from the Bill is fundamental? The strategy for autism is good, but what weaknesses in the strategy could the Bill help to make more effective?

Mr Hanna:

I can say more about the strengths of the strategy. The number of parents who are involved is important. We found that, when levels of public accountability are raised, standards often rise as well. That applies in this case. When families hear strategic presentations about how things work, they can say that that is not how it works in practice and can challenge that quite strongly. That is something powerful that the strategy groups have been able to bring forward.

With regard to weaknesses, the range of disability is so wide that coming up with a service response is quite difficult, because what works for some people with autism probably does not work for others. I am not aware that any assessment was made of the circumstances of the people on the reference group and the regional strategy group. Therefore, there could be many people in that group whose children have very high support needs, which means that they would advocate high support services. However, the opposite could be the case. There still needs to be an assessment of need to understand exactly what the service response needs to be for people with the condition.

Our submission states that the practical and direct service issue is of most concern to us. It is because of the practical approach that we have taken that we have not really tried to fathom why other people have taken the views that they have taken. Given that the DHSSPS has had responsibility for this area, it might feel that it will be asked to foot the bill, so it is not quite so keen on legislation. Although the Bill is funding neutral, the result could be an increase in services for people with autism, which is what we want to see. That is also part of the issue.

With regard to other — I will not call them weaknesses — areas that could be strengthened, it is still early days for the strategy. Although it has been going for a long time, the meetings can go on for quite a while and people are doing a lot of work, there is much work still to be done. Although the Department of Education is also considering a strategy for its response for people with autism and its relationship to places such as the Middletown Centre for Autism, much more work could be done. There is probably work to be done in further education and training. Although there has certainly been goodwill from other Departments, when they are under pressure for other funding, they can de-prioritise certain areas. Legislation would not allow them to do that.

The Chairperson:

One point that the Minister might make is that if there is specific legislation for autism, how can it be said to groups that represent people with Down's syndrome or attention deficit hyperactivity disorder (ADHD) that they should not have the same entitlement?

Mr Hanna:

Part of me would say that that is an issue for those other groups. I do not mean that to sound as facetious as it does. The difference that I see — this is anecdotal — but in a special school classroom 10 or 15 years ago, it would not have been unusual for there to be six out of 10 kids with Down's syndrome. In a special school classroom today, there will be seven out of 10 kids with autism. The change in numbers and in the profile of pupils is such that we would benefit from an approach that allows us to concentrate on autism. That does not deny the needs of those other groups, it is simply that the circumstances have changed and the service response that is required is very different.

As an autism-specific service, we have found that, because we try to cater for the specific needs of people with autism, we have service users who have come to us after being placed in other settings with perfectly reputable and good organisations that had not been working in an autism-specific way. Those placements have broken down because of that, and the people have come to us. Although we are far from being a perfect organisation, we feel that by taking that autism-specific approach we have been able to — touch wood — facilitate that and work with those people. What we are suggesting, therefore, is that part of the legislation would be to take that more strategic approach to make those changes for people with autism.

The Chairperson:

We have received quite a bit of evidence already on the Bill, so many questions have already been asked, which you may be glad to know. In the absence of any other questions from members, I thank you for your time and for your written submission, which has been very useful.