



Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

**Autism Bill: Parents' Education as
Autism Therapists**

13 January 2011

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Members present for all or part of the proceedings:

Mr Jim Wells (Chairperson)
Mrs Michelle O'Neill (Deputy Chairperson)
Mr Mickey Brady
Mr Pól Callaghan
Mr Alex Easton
Mr Tommy Gallagher
Mr Sam Gardiner
Mr Paul Girvan
Mr John McCallister
Ms Sue Ramsey

Witnesses:

Dr Tony Byrne) Parents' Education as Autism Therapists
Ms Karen Gallagher)

The Committee Chairperson (Mr Wells):

I hope I have not caught the witnesses unaware, they are very welcome. I am sure that they have been following the Autism Bill evidence session and are aware of what has been going on. We normally invite witnesses to give a 10-minute introduction on their paper and then allow members an opportunity to ask questions. That normally lasts for 45 minutes.

Dr Tony Byrne (Parents' Education as Autism Therapists):

Good afternoon. I am Tony Byrne, a father of two boys diagnosed with autism and chairperson of the Parents' Education as Autism Therapy charity, or PEAT for short. With me is Ms Karen Gallagher, the mother of two young boys diagnosed with autism. She is treasurer of the PEAT charity.

I first wish to thank the Committee for inviting us to present evidence on the Autism Bill for Northern Ireland. Autism is a terrible disability, and it has a devastating effect on the whole family. My personal position is that my son Conor was diagnosed at the age of two, but with non-intensive applied behavioural analysis (ABA) intervention, he made substantial gains. Conor is now 15, and I am happy to say that he is a normal teenager, although he has teenage problems as all teenagers do, but that makes me happy because he is normal.

My son Mikey is a different story. He was diagnosed with severe autism, also when he was two. Mikey needed early intensive ABA intervention, but that was not provided by statutory services. We did what we could for him within our resources, and he made some gains. Mikey is now 13 years old. He still has severe autism. He will never make friends, play football or argue about what time he can stay out to at night with his friends. He will never fall in love or get married. However, we still teach Mikey at home every day, and he continues to make small gains. We love him and we care for him as best we can, but my wife and I always wonder what his life would be like had he received the intensive early intervention that he needed when he was diagnosed.

PEAT is the parent-led charity for autism in Northern Ireland, and it was established in December 1997 in response to the non-existent support for families who had taken an informed choice to use applied behaviour analysis to help their children with autism. Our mission is to help such children achieve their full potential by providing parent and care training in applied behaviour analysis.

In principle, PEAT agrees there is a need for legislation to protect the rights and interests of persons diagnosed with autistic spectrum disorder (ASD) and their families or carers. PEAT is aware that the health and social care sector already has an ASD strategy, which came about following its review of autism provision, chaired by Lord Ken Maginness. However, PEAT was

not consulted in that review, and it raised its concerns about its content when it responded to the autism spectrum disorder strategic action plan produced in 2008.

Indeed, PEAT, in collaboration with Queen's University Belfast and the University of Ulster, published a research report in late 2007 entitled 'Meeting the needs of families living with children diagnosed with Autism Spectrum Disorder'. The report focused on families who lived in Northern Ireland, and 100 children, their parents and 67 professionals were subjects of that research. That report was made readily available but was ignored by the Maginnis review and by the strategic action forum.

The priority for ASD in Northern Ireland should be effective treatment and intervention. The Health Committee should consider implementing a truly independent review of ASD services that is open, transparent and takes account of international best practice. As a start, I will point out some things that are happening internationally. The Health Committee should look at recent developments in ASD provision in the USA and Canada. For example, Ontario will expand services for children with autism spectrum disorder. Starting next spring, the province will spend an additional \$25 million a year to provide applied behaviour analysis services and support in community agencies and centres, schools and homes.

In the USA to date, 31 states have passed autism insurance legislation that will require health insurance policies to cover the diagnosis and treatment of autism spectrum disorders. That will also require health insurance companies to pay for evidence-based early intervention, which is widely recognised as applied behaviour analysis.

In 2007, the US Department of Defense altered its policy to expand the availability of ABA services to extended care health option beneficiaries with autism. That means if the child of anyone who works for the Department of Defense is diagnosed with autism, they are entitled to early intensive ABA.

Applied behaviour analysis intervention is not a statutory right for children with ASD in Northern Ireland. Families must pay privately for such intervention, so it is not regulated. Given the investment and legislation in the USA and Canada, there is a strong economic argument for effective intervention that is based on ABA. Several cost-based analyses have reported on the use of early intervention based on ABA, and all of them conclude that there would be significant cost

savings in the long term. For example, Motiwala et al reported that the use of early intensive ABA would reduce the total costs of care for autistic individuals and increase the gains in dependency-free life. Chasson et al, in 2007, reported estimated cost savings in the region of \$2 billion for the state of Texas alone if early intensive ABA were funded for existing children with ASD. That is opposed to eclectic provision.

There are a number of reports concerning the cost of provision over the lifetime of a child who is diagnosed with autism. For example, Knapp et al, in 2007, reported on the cost of ASD in the UK. The aggregate national costs of supporting children with ASD were estimated to be £2.7 billion each year in the UK alone. Most of that cost is accounted for by services used. For adults, the aggregate costs amount to £25 billion each year, 59% of which is accounted for by services used. That means that, over the lifetime of a child who is diagnosed with severe autism, the total cost of support and provision over their lifetime can add up to around £3 million. However, the cost of an early intensive intervention programme, which will change the life of that child, may cost in the region of £90,000.

The recognition of high support costs for ASD is important. Investment in early intensive ABA would reduce high support costs in adulthood. Furthermore, greater availability of effective early interventions may reduce the impact of ASD on the UK and Northern Ireland economies, as well as improving the quality of life for people with ASD and their families.

In conclusion, if the proposed Autism Bill will ensure that effective treatment and intervention for children and adults with ASD is delivered in Northern Ireland, it will have the full support of PEAT. Karen, do you have anything to add?

Ms Karen Gallagher (Parents' Education as Autism Therapists):

Not really. Tony has presented all the points.

The Chairperson:

Thank you for your evidence. You dealt at length with ABA, which we would expect given the history of PEAT. We are specifically looking at the Autism Bill. Is there anything in the Bill that you believe would mean that children with autism would be more likely to receive ABA than not?

Dr Byrne:

I do not see anything in the Bill that would mean that children with autism in Northern Ireland will receive ABA intervention as a statutory right.

The Chairperson:

Do you not see anything in the amendment to the Disability Discrimination Act 1995 (DDA)?

Dr Byrne:

A case for ABA intervention cannot be taken on the basis of the discrimination legislation as it stands.

The Chairperson:

That begs the question: why has your group come out strongly in favour of the legislation, if you do not see it making any difference to what you want to do?

Dr Byrne:

When did we say that we were in favour?

The Chairperson:

I got the impression from the last paragraph of your presentation that you were supporting the legislation.

Dr Byrne:

I said "if the Bill would ensure", and that would mean the amendment of the Bill to ensure.

The Chairperson:

So, you are neutral on the Bill itself?

Dr Byrne:

We see the issues that are dealt with in the Bill in relation to the Departments of Education and Health, or the statutory services, co-operating as secondary issues. We see the other aspects of the Bill as secondary issues. The priority and real need in Northern Ireland is effective intervention to change lives and make a difference for children and their families.

The Chairperson:

At the moment, there is nothing to stop the Minister from taking a policy decision that that type of behavioural analysis brings results, and I am sure that we have all seen many examples of such results. You do not require a Bill to do that. That is a resources policy issue rather than a legislative one. There is nothing to stop Michael McGimpsey announcing in the morning what you want.

Dr Byrne:

No, and there is nothing to stop the strategy in the Bill to help to make those policy changes, is there?

The Chairperson:

This is not a general inquiry into the level of treatment and care for those with autism; it is about whether this Bill should proceed past the Consideration Stage and become legislation. I am trying to tie down what advantages or otherwise you see in the Bill from your perspective, which is well known because you have been the lead group in advocating that type of early intervention. Many of us would agree that that does produce outstanding results at times.

Ms K Gallagher:

Surely, when you are formulating a Bill such as this, you have to take in results. It is like a child going to hospital with cancer and somebody saying, "Well, there are good results for chemotherapy, but a bit of this and a bit of that might work, so let's go ahead and try it". When parents are taking an informed decision to go down the route of ABA, which is the only scientifically validated treatment with good results for autism, why should that not be included in Northern Ireland legislation?

The Chairperson:

That would require an amendment to the Bill, because the Bill does not have any prescriptive care packages. The Bill will be asking for a cross-departmental strategy to be developed for the care of those with autism. It does not, at the moment, say that ABA must be compulsory and given to all who ask for it. The inclusion of that would be quite a radical change to the Bill.

Dr Byrne:

I agree that the Bill does not say that. We have already had two reviews of autism provision. The

Department of Education's review of autism was published, I think, in 2002. There were misconceptions, and evidence on ABA, as the evidence-based intervention that it is, was left out. The Maginnis review, undertaken by the health and social care sector published its findings in 2008. Again, it got it wrong. So, are we going to put two strategies into one that will not address the real issues?

The Chairperson:

There is a resource issue here. Do we know what it would cost a parent to put their child through a full course of ABA?

Dr Byrne:

It is estimated at £30,000 a year.

The Chairperson:

How many children in Northern Ireland do you think would benefit from that type of course?

Dr Byrne:

We do not have the data. I notice that the Department of Health would have to provide data on how many children are diagnosed with ASD. I know that in the Southern Health and Social Services Board area there may be between 100 and 200 diagnoses per annum. So, a substantial number of children would benefit from early intensive intervention.

The window of opportunity is from diagnosis, which should be done by at least two years old, up to seven years old. So, an enormous number of children here could benefit from early intensive intervention. There is also evidence that other children, irrespective of age, will benefit from ABA intervention. In fact, in British Columbia no age limit is set to determine which children can benefit from ABA intervention.

Mr Easton:

The Bill will result in a joined-up approach between all Departments. That approach is not currently taken. Do you think that that is vitally important to help people with the condition?

Dr Byrne:

I agree with having a joined-up approach between the two Departments. We are represented on

the regional autism network, which is run by the Health and Social Care Board under its strategy. I am aware that the Department of Education will take a similar approach to the development of its strategy. Obviously, those overlap and should be run not in parallel but under the same banner, and co-operation between the statutory bodies is required. If they do not get it right in the first instance and there is a fundamental flaw where they are not following international, evidence-based best practice, they will simply be doing more of the same thing only together.

Mr Easton:

Some forms of autism are not currently covered by the DDA. Do you feel that the changes to the DDA will cover a lot more of those?

Dr Byrne:

I agree that some children with Asperger's syndrome fall outside of certain care packages. For example, a person who is diagnosed with Asperger's syndrome may not be entitled to a social worker, and that is totally unfair. I agree that autism is a recognised disability and, whether the person has Asperger's syndrome, another form of ASD — or classic autism, as they call it — it should be dealt with.

Mr Easton:

Based on those two good points, is the Bill not worth supporting?

Dr Byrne:

In principle, PEAT supports the Autism Bill, but you have an opportunity to make a difference for the children. We can continue to ignore the evidence. Why would 31 states of the USA legislate to ensure that their health and insurance companies pay for the intervention? Why would Ontario invest an additional \$25 million a year in an intervention if it were not worthwhile? Why are children here not entitled to that?

Mr Easton:

Do elements of the Health Department's current strategy not work well? Does it need to be improved, and is it letting the side down a bit? Are there any areas in which it could be improved?

Dr Byrne:

Yes, it should go back and look at the so-called independent review, on which it is based. It was certainly independent of any expertise from behaviour analysts, who were not invited to be part of the review. That is surprising as ABA is the intervention that has the overwhelming body of evidence to support it. The strategy should be revisited to ensure that any intervention team that is put in place for a child with autism includes an appropriately qualified behavioural analyst, which it currently does not.

The Chairperson:

We have had quite a few evidence sessions, so quite a few of the issues have been dealt with already. Is ABA suitable for every child, or are there children who cannot benefit from it?

Dr Byrne:

The research has been published, and there have been numerous reports on and independent reviews of autism provision. We can forward those many reports to you. They tend to show that 90% of children who gain access to an early intensive ABA programme will make substantial gains. The research shows that 10% of children will make minimal gains, and the reason for that is not known. Fifty per cent of the children will make such gains that they can move to mainstream school unsupported, and you can imagine the benefits that that has for the child, their family and for economics.

Mr Brady:

So, you are saying that if children do not get the opportunity to have that intervention, you cannot really tell whether they will benefit from it.

Dr Byrne:

Of course not —

Mr Brady:

That may sound simplistic, because you gave the example of your two children, one of whom had that opportunity and benefitted and the other did not.

Dr Byrne:

What I said in relation to my two children was that my older boy's autism is less severe and,

fortunately, the provision that we could give him helped him. For our younger child, we spent half our time battling with education boards or whatever. That time was wasted. He should have been put on an intervention programme when he was diagnosed at two and a half years of age, not when he was four and a half.

Mr Brady:

From my experience of working in the voluntary sector and from talking to parents, I understand that by the time some children are diagnosed, that chance of early intervention has been lost. They might have lost two or three years in which that intervention would have been most beneficial to them. What you are saying makes sense. Is it a resources issue as well?

Dr Byrne:

Yes, very much so. There are very few appropriately trained behaviour analysts in Northern Ireland, and that is because the investment was never put into training them. PEAT campaigned for the teaching of a master's degree in applied behaviour analysis with specific emphasis on autism at the University of Ulster, and that has been running for several years. It is a part-time degree that is designed for professionals who are already working with children with autism to allow them to become fully trained in applied behaviour analysis.

Mr Brady:

May I make one more point, Chair?

The Chairperson:

Is it specifically on the Bill, Mickey? We are drifting away from the Bill towards a wider debate.

Mr Brady:

A point was brought up about legislation that will affect adults with autism, where it is now recommended that there should be champions or mentors available for interviews and that sort of thing. It is an issue that ties in.

The Chairperson:

The Vice-Chair will ask a question, which, I hope, will relate directly to the Bill.

Mrs O'Neill:

Thank you for your presentation. For clarification, are you asking that the Bill should be amended to include the provision that all children with autism should receive ABA?

Dr Byrne:

Yes.

Mrs O'Neill:

OK.

Ms K Gallagher:

That is if the parents wish to go down that route.

Dr Byrne:

Every child should have the statutory right to access early intensive, effective intervention.

Mr Callaghan:

My question is very specifically on the first clause of the Bill, on the amendment of the Disability Discrimination Act. There has been quite a bit of consideration of that, and various views have been expressed. Effectively, it boils down to whether the definition of disability under the DDA, as it stands, is wide enough to cover people presenting with autism, so that they get the benefits of protection under that Act. Does PEAT have a view on that one way or the other?

Dr Byrne:

I really cannot comment. I have experience of the Special Educational Needs and Disability Tribunal (SENDIST), legislation, whereby my child has a diagnosis of autism and, therefore, has a recognised disability. Possibly there are cases where a child has a diagnosis of Asperger's syndrome and is not recognised as having a disability. I do not know. Do you know of any cases where that has happened?

Mr Callaghan:

To be fair, Dr Byrne, it is not for me to present evidence to the Committee; we are here to gather evidence from people who have direct experience. We are trying to extract as much information as possible from people. A question such as that is designed to decipher whether people can give

us practical examples.

Dr Byrne:

I am not aware of any case of any discrimination case, under SENDIST legislation, where a child has a diagnosis of autism, and that has not been recognised as a disability.

Mr Callaghan:

Just for the record, the SEN-based legislation is different from the DDA. One is for special educational needs and the other is about disability. The Bill does not seek to amend any of the SEN-based legislation. It is important that that is clear in our minds.

Mr McCallister:

The Chairperson has told me that I have to mention the Bill.

The Chairperson:

No, you must “deal” with the Bill.

Mr McCallister:

All right, I must deal with the Bill. I was going to mention the Bill and then go off on a tangent. If the Bill were to be amended — and you indicated to the Deputy Chairperson that you would be in favour of such a move — do you know what the cost would be? Are we talking about a year’s ABA treatment, or longer?

Ms K Gallagher:

It depends on the child. My son needed a year’s treatment, which cost us £30,000, and he sailed straight into mainstream school. It was predicted that he would go into a learning support unit, because his IQ was 75, one point below the learning disability limit. Within five months, his IQ reached 100. He is now nine years old and he has the IQ of a child of 11 years and 6 months. He is coping well at school.

Mr McCallister:

Therefore, you are saying that if the Bill were amended to include that intervention, there would be an obvious payback.

Ms K Gallagher:

The payback is there, but, unfortunately, the people of Northern Ireland are remortgaging their homes to provide what they feel are the best pathways for their children.

Mr McCallister:

In your evidence to the Committee you mentioned an evidence base. Does the NHS provide this treatment in other parts of the United Kingdom? I assume that if this were in the Bill, or if it were provided by the NHS, then those who opt out could be covered, as in the American model, through private health insurance.

Ms K Gallagher:

The onus is on the Department of Education to provide.

Dr Byrne.

Unfortunately, in the UK, this is like a postcode lottery. By the time a child receives a diagnosis, he or she is in the education system. Typically, parents will go to their local authority to fund this treatment. In the US and Canada, it falls under health insurance, which is where it is funded. That being said, when children are diagnosed at two years old and younger, it should fall to the Health Department to provide early intervention. Obviously, providing that intervention benefits both Departments, and the average is three years early intensive intervention and anywhere between two and five.

Professor Gina Green and Dr Bill Ahern were at Queen's University Belfast on Monday. We were looking at the establishment of an autism research centre, and they are going to help with that. Unfortunately, although representatives from the Health and Education Departments were invited, they declined to attend. Gina has an honorary doctorate with Queen's University and Bill works alongside us. Those people are world renowned experts, and they can give you all the information you want on cost savings and implementation.

Mr McCallister:

Am I right in saying that unless this is in the Bill you see no huge value —

Dr Byrne:

I am saying that the priority for children in Northern Ireland lies in effective intervention. The

issues being dealt with by the Bill are secondary. Do we want to do the best for our children, or do we want to deal with fallout afterwards, which is what we are doing. The problems arise when we do not intervene effectively, and we have to deal with them. We have to deal with those problems throughout the person's lifetime; not just when they are young.

The Chairperson:

Thank you for your time, Dr Byrne and Ms Gallagher. We value the fact that you have come along to give evidence and answer questions.