



Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

**Evidence Session with Autism NI/Parents
Autism Lobby**

16 December 2010

NORTHERN IRELAND ASSEMBLY

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AND PUBLIC SAFETY**

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Members present for all or part of the proceedings:

Mrs Michelle O'Neill (Deputy Chairperson)

Mr Mickey Brady

Mr Pól Callaghan

Dr Kieran Deeny

Mr Alex Easton

Mr Paul Girvan

Witnesses:

Mrs Arlene Cassidy)

Ms Paula Hanratty) Autism NI

Ms Audrey Mullan)

Mr David Heatley) Parents' Autism Lobby

The Deputy Chairperson (Mrs O'Neill):

Arlene, Paula, Audrey and David, thank you for bearing with us for three hours until you could get to the table. I know that the issue is so dear to your hearts that you do not mind waiting. I am going to have to leave and Alex is going to take over.

(The Acting Chairperson [Mr Easton] in the Chair)

The Acting Chairperson:

I welcome both groups here today. There will be a 10-minute presentation. Would one of your groups, or both, or all four of you, like to make a start?

Mrs Arlene Cassidy (Autism NI):

I will start, and then —

Mr David Heatley (Parents' Autism Lobby):

I will finish; if there is time.

Mrs Cassidy:

An additional set of papers has been presented to the Committee. The first three pages have been tabled already. In the original papers, there is a point 9 — the additional papers expand the headings under point 9. The three pages presented originally are very much about context — the credentials of the charity, Autism NI, and our history. I do not intend to go through them now; I want to prioritise other issues that have not been submitted to the Committee; however, time may run out. At least members have the hard copy, and if there are any points of clarification, please feel free to contact us afterwards.

In addition, before I start, I noted the earlier discussion on the costs of autism. I want to submit a paper that Autism NI prepared as part of its early lobbying work. We can provide other copies. There has been a study carried out already, by Martin Knapp, regarding the cost of autism in the UK, including the hidden costs, the loss to the economy, the whole issue of misdiagnosis and the cost to parents and couples for caring where one person is not able to work and contribute to the economy and the family. So, an analysis is available; and there was one carried out in Australia and Canada. We briefly analysed that work, really just to register that work in that area has already been done which may usefully contribute to the Committee's discussion.

I will make a few key points, the first of which is on the present level of need. I am sure that members have the relevant information, so I will not insult them by going through it in detail. I could quote figures from recent research carried out by the voluntary sector, some of which were quoted in the Bill's Second Stage debate. I could quote prevalence rates from the Department of Education, which show that 5,000 school-age children have been diagnosed recently, compared to

900 in 2002. I could also quote targets set by the DHSS regarding waiting lists, the positives and the negatives. I could remind the Committee of the recent judicial review decision, referred to earlier, regarding autistic spectrum disorder (ASD) service failures. I could refer the Committee to the Autism NI report that catalogues the hours spent on ASD statutory service reviews and strategies. There is a companion document to that, which gives a history of work of health boards and trusts in the past, prior to the departmental action plan. I can encourage the Committee to consider the Assembly Research and Library Service's reports, and, again, members heard a further submission this morning. However, my final point on this is that the conclusion remains the same: there has been more talk than effective action. Prevalence rates have increased by 500%, but funding has risen by just 100%.

The next point that I wish to register concerns the human and financial costs referred to in the first two paragraphs of our submission. The cost of ineffective leadership and engagement on ASD in Northern Ireland is incalculable and shameful. By comparison, Wales is ASD-informed, systematic and professional. It has built on existing expertise and has not thrown the baby out with the bath water or reinvented the wheel, as Northern Ireland is doing under the cloak of service redesign. Families are reporting to us that the re-referral system — as referrals are recycled and targets are met — is one of the negatives in tackling the waiting list for diagnosis.

We will address the human cost by presenting a single case history. If the Committee wishes us to do so, we can elaborate on the detail when answering members' questions later. As regards the current system's capacity to meet needs, there is a family that is happy to share their information with the Committee. Their experience encapsulates the nature of the service breakdown and underlines some points that we will highlight. The family has a child whose school phobia led to a build up in volatile behaviour which culminated in the child presenting as a danger to himself and others. A GP and a consultant were involved in the case. The child locked himself in his room, and an ambulance and the police were called. Ambulance staff admitted a lack of awareness of autism and said: "ASD complicates everything."

The child was admitted to hospital eventually. The doctor there phoned eight to 10 psychiatrists. That doctor's impression was that Asperger's syndrome complicates the matter, and said that they felt that the reluctance on the part of psychiatrists to come and see the lad had something to do with his condition. To get psychiatric support, the family had to agree to the 11-year-old boy being sectioned. The psychiatrist arrived 24 hours later. I have been given

permission to read the parent's comments to the Committee. This is how the parent related her story on paper:

"Why did every psychiatrist on call refuse to treat my son? Why is there a bewildering confusion among professionals when it comes to dealing with a child on the spectrum? Why did my only support come from the autism charities? Why did I experience one single moment where I felt nobody would or could help me or my boy? This should not happen ever. A child with ASD should not be in any way discriminated against because of their condition, which is exactly what all those psychiatrists did. This should never happen again. It was, without a doubt, the most traumatic experience of my life, and of Finn's."

I want to address the issue of equality. I will not read through my briefing, because I know that time is not on my side. I met Brice Dickson and representatives of the Human Rights Commission this week and I have detailed their view of the Autism Bill in my briefing. They were profiling the work that OFMDFM will have to do to comply with the UN Convention on the Rights of Persons with a Disability, citing that as the rationale for not going forward with the Bill and waiting for that compliance to take place. However, as we know from history, there is no guarantee that autism will ever sit at the table, but we see the Bill as a guarantee that autism will sit at the table.

I will skip the rest of my briefing and move on to the impact on families. The Committee already possesses some of this information. I want to give a few examples that show why legislation is needed. Others who have given evidence today have referred to the fact that disability living allowance (DLA) guidance uses the current definition of disability in the Disability Discrimination Act 1995, which does not give clarity on autism. Physical markers dominate the DSD regulations on housing adaptations. The case study on the lack of awareness of autism by the ambulance crew showed that they lacked confidence in how to deal with the situation. The emotional impact of the legislation should not be overlooked. Recognition of autism has been a long time coming and the clarity that it brings to existing regulations should not be underestimated.

I want to make a few comments about the DHSSPS action plan and the Department of Education framework. I want to reinforce the comments made earlier that, no matter how effective something is or is not, things can always be made better. We believe that the legislation can only strengthen and empower that which is already happening. At the moment, there is limited buy-in from other Departments. The DHSSPS ASD strategy relies on a medical model, not a social model. The balance of resources has gone into diagnosis and not into early

intervention or family support.

The Department of Education ASD framework does not include an operational partnership role for the voluntary sector. Significantly, the DHSSPS engagement model, with non-mandated carers and individuals with ASD, is reckless, because it is unsupported and unresourced. Leaving parents in that kind of consultation and implementation network unsupported and unresourced risks them ending up spent and burnt out. There is quite a demand. My point is that there was a submission for supporting those parents, but the DHSSPS chose not to accept it.

My final contextual point about the Bill is to do with its implementation. We are concerned about that; leadership is crucial and respect is essential. Later in our briefing, we recommend that there should be a link and partnership and some sort of agreement with what has happened in Wales, looking at examples of best practice across the devolved nations.

We have provided a written response to the Bill. Autism NI supports the changes to the Disability Discrimination Act 1995 in clause 1, mindful that correct criteria in the 1995 Act for key elements, such as those that deal with long-term conditions, will be in place as well as diagnostic evidence.

As regards clause 2, Autism NI supports the critical need for a cross-departmental strategy to establish lifelong services plans that ameliorate the particular challenges experienced by individuals with ASD across life transitions. That is really to say that we recognise that transitions are difficult, but there is a particular poignancy as it hits on one of the core impairments of the condition of autism.

Autism NI is mindful of the need to consult with, integrate and recognise the contribution of the voluntary sector and the families they represent and suggests that that be included as an amendment. If this request will delay the passage of the Bill, Autism NI will defer its request and address the point operationally. The overarching message that we would like to get across is that we would like to put forward amendments to the Committee in this paper, but the overarching and overriding consideration is that we do not want, in any shape or form, to cause any delay to the passage of this Bill, because there are other ways of tackling the issues afterwards.

As regards clause 2(2), Autism NI is mindful of the need for a time limit on any consultation

between Departments as part of the Bill implementation process. There is no time limit specified in the Bill although there is a requirement to consult. Perhaps that is required. As regards clause 2(3), Autism NI wants to profile the fact that data collection is not just done by the Department of Health. Other Departments have been very effective in data gathering. We have been reliant on the Department of Education's figures for years. It is about sharing data and synchronising it across Departments.

On clause 3, Autism NI is mindful of the critical importance of quality, accredit-intensive, early intervention models such as those profiled by Autism NI through the Parents' Education as Autism Therapists (PEAT) programme, the Keyhole programme and other organisations such as PEAT and Centre for Early Autism Treatment (CEAT). We request the inclusion of recognition of the overwhelming evidence that supports the effectiveness of early years intervention. Once again, it has been suggested that an amendment would be likely to affect the passage of the Bill adversely, so Autism NI will address the issue operationally.

The point of early intensive intervention is critical in view of the previous point made that although diagnosis is an important issue resources have been allocated to the condition disproportionately. For parents who are wondering what they can do when they receive the diagnosis, the resources and the supports available are not in place.

In clause 3, Autism NI regrets the omission of the role of an autism advocate to secure progress, consistency, effective structure and much needed and respected leadership. Autism NI supports the need to explore that omission further, but is mindful of the issue of delay. Autism NI requests the consideration of a memorandum of understanding, particularly with the Welsh Assembly, to secure the required partnership assistance towards establishing effective implementation structures, especially in the oversight of joined-up and planned services across the transitions. What I am saying is that the Welsh strategy crosses three of our Departments. It includes health and social care, education and lifelong learning, so it goes right into adulthood.

Autism NI is proud to be associated with the Autism Bill and is hugely grateful to Dominic Bradley, the all party group members, and all the MLAs who have listened, studied and acted. Before I introduce David, I want, as chairperson of the carer's autism lobby, to record that the principal stand taken by this charity has remained constant to its political lobby dating back to 2001 and to its pledge in 2006 to campaign for ring-fenced funding, a cross-departmental strategy

and legislative recognition for autism. I would like to register that with the Committee. However, since 2008, Autism NI has been subject to threatened investigations, withdrawal of DHSS regional board and health trust funding, as well as expulsion from the Northern Ireland Regional Autistic Spectrum Disorder Network (RASDN) reference group unless we gave up the aspiration to legislation.

In 2010, those threats were directed towards the new chief executive and the director of development. Yet, in comparison, in 2010, Autism NI won recognition of its principled, dignified and professional stand for social change from the voluntary sector, when it was presented with the CO3 Voyager Leadership award in political impact.

Autism NI may pay the ultimate price for its principled stand unless the position is reversed and relationships are actively reconstructed.

I would be grateful if the Committee would accept a brief presentation from David.

Mr David Heatley (Parents' Autism Lobby):

I am chairperson of the Parents' Autism Lobby (PAL), which is the parents' voice in the charity of Autism NI. We represent 30 groups across Northern Ireland and a list of them is at the back of the paper I have given to members. Branches vary in size from having only 10 members to much larger groups of over 50 members and a few have over 100 members affiliated.

Autism NI has approximately 800 registered families and agencies who are members of the charity. However, all branches also have families who have not formally joined the charity but count themselves as members. They may not have paid their £5 or whatever, but they are associated with the charity. Therefore, I can confidently say that PAL represents over 1,000 families across Northern Ireland.

That mandate gives me confidence to back every statement that Arlene has made on behalf of the charity. I have been in regular contact with the branch-support group network by phone and letter over the past year. I have personally visited almost 50% of the groups over the past nine months and I have meetings set up with another five before the end of first week in February. In all my contacts, no parent has said that he or she does not want legislation — not one.

What do I hear? Parents ask me why it has taken so long for legislation to appear. Is it not just common sense to see that autism is being left out and that there is a little gap to be filled; and that we need joined-up government so that we do not have to fight the battle with one Department and then separately with another and then another? Parents tell me that services are terrible and that they get diagnosis and are then avoided. After diagnosis, there is no one to help or explain. Everyone is too busy to help, and some of those parents are on their own. Unless you live with autism, you cannot possibly understand.

The branches I have mentioned vary from some that are very new, only a few weeks or months old, to some that have been established for many years. Do you know the date when the first one was founded, Arlene?

Mrs Cassidy:

Yes. The first was established in 1993.

Mr Heatley:

The expertise in those branches is only surpassed by the expertise and professionalism of the Autism NI staff team. Many of the team are also parents of individuals with ASD. The very first diagnostic training in Northern Ireland took place in 1997. It was set in place by Autism NI and funded by the east Antrim branch. Parents paid for it. Since then, there has been training every year, thanks to Autism NI. In recognition of this, Autism NI was made an honorary member of the Independent Northern Ireland Autism Diagnosticians Forum, a group of ASD experts unique within the UK and Ireland. Most diagnosticians and other experts in Northern Ireland have received much of their training through the charity. Therefore, the charity has led the way right from the very start. Parents are very angry that the 20 years of work, expertise and partnerships that Autism NI has had have to a large extent been overlooked over the past year and half or more

Autism NI's lobby campaign started in 2001. It is a founder member of the Celtic Nations Autism Partnership and the Atlantic Autism Alliance. In 2006, Northern Ireland was ahead of Wales in the international autism strategy, but unfortunately politics here got in the way of that progress. Our parents are sadly used to being let down. So much has been promised in the past. Seeds are sown, but the fruit never ripens, it withers on the vine. Please make sure that this is not another blind alley.

The autism community needs this Bill desperately. We are being disadvantaged by a disability that is not recognised in law. Parents are already under unbelievable stress because of the very nature of the condition; and it is not only the parents, but the siblings, grandparents and wider family circle, carers and schools. The Bill needs to do exactly what it says on the tin. It needs to be strong and watertight: it must become law. However, if it should fail, we will be back. We will not let this rest, we will just lobby and lobby.

Thank you for your time.

The Acting Chairperson:

Thank you for your presentation.

First, I can reassure you that, no matter what I heard earlier, I fully support the Bill and I will not change my mind. Nothing has changed for me. Secondly, you spoke of some amendments. If you want us to see them, we will need to have them in writing before 13 January. Bring them to us and we will talk about what we can and cannot do. Thirdly, I was disturbed to hear that problems were being created over funding. I hope I speak for the Committee when I say that we take a very dim view of anyone in the Department or any other area who plays games with funding because of support for the Bill. The Committee will take a very serious view of that. I hope that message is passed back to the Minister from his official at the back of the room. That is my view on that.

I have two questions. Cost is being used as an excuse. Please explain why there will not be a huge increase in cost? Why is the Department so opposed to the Autism Bill? I believe it will complement the strategy that we have already.

Mr Callaghan:

I think we heard enough on that from the Department.

Mrs Cassidy:

All jurisdictions find cost very hard to quantify. The analysis behind this document is very revealing. I will make the obvious points. With an effective cross-departmental strategy, with good strong leadership at the head, the potential for cost saving through reduction of duplication

is incredible.

The issue of training came up quite a bit. There are levels of training, and each Department is accessing training for staff that is very similar and will only increase. A strategic look at training is essential. However, it has already happened. Ironically, Autism NI received funding three or four years ago from the Health Department to look at the development of a training strategy for autism in Northern Ireland. We put that work out to tender, and the University of Ulster completed that document and convened round table discussions across health, education and the voluntary sector. The report was written, but I do not believe that it has been accepted by the Department of Health yet. However, that report sets out an implementation strategy for cost-effective training across Departments, utilising all resources efficiently.

My other point is that people with autism are already out there. That is highlighted in Martin Knapp's study. They already cost the nation a lot of money, not necessarily appropriately. Consider the issue raised earlier; misdiagnosis, which may put adults through psychiatric inpatient services, where they receive inappropriate drug treatment when the condition all along is autism. A lot of inherited mental health issues may have stuck to that person because of unmet need. Such a story is not untypical.

Ms Paula Hanratty (Autism NI):

Cost is a big issue at the moment because of the economy and the cuts. However, there is a massive cost to families, mental health carers and relationships, as well as to the education of an individual with autism, and their ability to work and contribute to the economy. There are massive emotional and physical cost implications for families when parents/carers are unable to work, and they need to be offset against costs that may be incurred.

Mrs Cassidy:

Paula Hanratty is our director of family support. She is also a parent. Audrey Mullan works for the South Eastern Health and Social Care Trust. She is also a parent.

Mr Heatley:

I was a school principal, but I had to give up that job because of autism. I could not come home, work with Christopher until bedtime, then work for school and go back next day and cope with the job. My doctor told me that I had to give the job up.

My wife ended up with anorexia and spent five months in hospital last year. I was left looking after Christopher. I was also holding down a shop job at the time, but had to give that up. My family's income has disappeared, and I am, therefore, not paying the taxes that I was paying before. Mine is a simple example, but some are much more complex.

Ms Audrey Mullan (Autism NI):

I did not work for 10 years. Nobody would have employed me because of the number of appointments I had for my son. He has co-morbid difficulties as well as Asperger's syndrome. I had to go to so many appointments, so I understand why parents' incomes are reduced, because they have to look after their children.

A lot of money is spent on going to appointments, especially when there are co-morbid difficulties. Therefore, a family's income is drastically reduced, because both parents cannot go out to work, or can maybe work only part time. Single parents find it very difficult to make ends meet, and, depending on the difficulties, find it difficult to go to appointments at hospitals or with paediatricians. There are huge costs.

Mr Heatley:

If there is intervention and support, there is a chance that those families could be effective and able to support the community.

Mrs Cassidy:

It is a huge puzzle to us also why the Department is opposed to the Bill. We are able to multitask as an organisation. We are a very active member of the DHSS action plan and have attended in excess of 40 meetings in the past year. The model is complex.

We are also a member of the training and communication subgroups, the reference group, the Western Health and Social Care Trust forum, and the Western Health and Social Care Trust forum subgroup on children. We are not without investment in the process, and we contribute what resources we have. However, we do not believe in a one-Department strategy. Autism requires a whole-life approach; it is a holistic issue. So, we are puzzled by the Department's attitude. I believe that it is a reflection of the silo situation: they are making honest comments about how they see things in their Department but are not able to see that this is about life.

Mr Heatley:

The key issue when they kept talking about the DDA was that they did not look at it that way. However, they could not see that other Departments do depend on the criteria in the DDA. It is impossible to get supported housing unless one has a learning disability or mental health issue.

Mrs Cassidy:

We have an active member from west Belfast who has 10 children. If she were here, she would argue the point that a number of her children are on the spectrum, and some have a learning disability and some do not.

Children with a learning disability access services through learning disability services. Those with autism, who do not have a learning disability, do not have access to services unless they inherit a mental health problem because of unmet need or if there is a co-morbid condition. One of our other chairpersons has a letter from her trust stating that it does not provide services for individuals with an IQ of over 70. There is evidence.

Mr Girvan:

Thank you for your presentation. I put on record my congratulations to the group for its tenacity in driving forward and keeping at this. Mention was made of a few clauses in the Bill over which there is some concern. I caution the group against raising some issues, in case that might delay the Bill. The Bill will be of some benefit.

During the presentation, there was mention of the bullying tactics of the Department, which is the only way I can describe them. This is not the first time I have heard of that, and not only in relation to autism. The Department is arrogant, and it seems to use the process. Mickey and I attended an event this night last week at which the arrogance of some members of the panel was only too evident. They showed a lack of understanding about their responsibilities. We do not claim to be clinicians or to know the ins and outs of detail, but we know how to manage certain things and make sure that things happen.

You talked about how the referral system was used to meet targets. Please explain that to me. However, before we come to that, will you address the issue of cost? Had one listened to the Department's presentation, which was given prior to this one, one would think that it was doing

everything and that therefore there would be no cost to the Department at all. I am saying that we are trying to look at the overall picture. It is not necessarily only the pounds, shillings and pence cost that is involved. The quality of life for families is a cost that is suffered and has to be addressed.

Perhaps you will give us an insight into the case study you referred to and the testimony you gave of one family and a young chap who had to be sectioned. Was that a recent occurrence? If it has occurred while the Department's strategy is supposedly in place and shows how this is being dealt with, that creates a bigger problem for me.

Mrs Cassidy:

Audrey will answer one of your queries, Paula the other.

Ms Hanratty:

I will talk about the issue of children being reviewed and referred for assessment.

The phrase used is "watchful waiting". A child may go through an initial assessment process in which there may not be sufficient evidence for him to be diagnosed or his condition may tick some boxes, but not all. The normal process is to review in six or twelve months to see whether, as the child gets older, things change, become more obvious, or improve. At the moment, the difficulty is with the number of calls we are getting from parents whose children are being placed in "watchful waiting", yet seem to have a very classic presentation of autism. We are concerned about the numbers. Minister McGimpsey talked about an increase of 40% this year. The numbers going through to try to meet that target are possibly being placed in the "watchful waiting" category, rather than in a more thorough process. So, there are concerns about the quality of placing someone in the "watchful waiting" category.

Ms Mullan:

You wanted to know about the particular family. It happened very recently. I first met them in April and went out to visit them. I was subsequently contacted through our helpline around four weeks ago. The mother had my name, and I took the call. I referred her to her GP and told her that she needed to follow this up because the child was not well, and that she needed to get a referral back to the GP and get the child's anxiety levels down. She came back to me last week. I spoke to her on the Friday and the events happened on the Monday, but there was a build up as

recently as three weeks ago.

Mr Girvan:

It worries me that we have been told that the strategy is in place and that the programme is working and has been implemented.

Ms Mullan:

It is also about the process in the hospital. The mother, when she spoke to me last week, said she could not believe that eight psychiatrists had been asked to come and help her by the doctor in A&E, and none came. They had to spend a night in the hospital, which was very distressing for the child because he was in a new environment. He was on the floor crying and they had to spend the whole night there before a psychiatrist eventually came. Even after the child's being sectioned, the psychiatrist still did not come. They hoped that the child being sectioned meant that a psychiatrist would come, but that did not happen.

Dr Deeny:

Thank you, ladies and gentleman. David, I could not agree with you more. I have seen a number of conditions in all practices. This is a family disease, almost, because it affects everybody, and you have my support. Paul touched on this point, but, one thing that shocked me is the huge increase in the number of sufferers that we are seeing from a clinical perspective. You said that there are 5,000 school-aged children with autism now as opposed to 900 in 2002, and that the ratio has changed from one in one hundred being affected to one in sixty in the past three years. Why is that the case? Is it because of under-diagnosis in the past?

Secondly, I will get this in now and then shut up. I think that autism has fallen into the same trap that we talked about before; the whole nonsense of targets. I have had suspicions about targets from the start, both as a clinician and as a doctor. This is all to do with people getting their first appointment. That had to be done within a certain period, and after that, it was a case of to hell with you.

I will quote one incidence. However, it is not about autism. Yesterday, I saw a young man whom I know. He is a very pleasant young man in his 30s and has multiple sclerosis. It was the first time I had seen him in months, and I was shocked to see his deterioration. He can no longer manage to climb stairs, and has lost some of the power in his left leg; not completely, but he is

walking with a stick. I checked, and his case has not been reviewed by a neurologist for a year and nine months.

The same thing is happening here. The phrase “watchful waiting” is a very fancy term that they have given you, Paula. It is a very polite term. It means they have put people on a waiting list, and to hell with them. That is what happens in the Health Service — as long as the first appointment meets the target, they are happy. However, for the review, diagnosis, follow up and care, people are being put on the long finger. Had I not I phoned this morning, God knows when that fellow would have been seen. He will be seen until shortly after Christmas. There were all sorts of apologies and excuses, but I think it is the same thing with autism. You mentioned the re-referral system.

Mrs Cassidy:

That is really the watchful waiting.

Dr Deeny:

Do GPs have to re-refer or expedite cases? That happens sometimes. Usually, a phone call asking why my patient is waiting to be seen does the trick. Even in some cases as serious as potential cancers; the first appointment has been on time and then, suddenly, the patient does not know when he or she will be reviewed. It is as bad as that.

We have mentioned it before. The Department needs to sort the situation out quickly, because a lot of people with serious conditions, including autism, are waiting for review appointments now. I have been told that the Department is going to look at that, but I do not know how long it is going to take.

Mrs Cassidy:

As regards prevalence rates; the rate of one in sixty has been quoted by the Belfast Education and Library Board, and we are awaiting confirmation of that. The fact that people such as that are mentioning such figures is worrying. We are no wiser about the cause of the increase in the prevalence rate. As we have always thought, there is a combination of factors such as slightly better awareness and better diagnosis.

Mr Heatley:

There are more people with it as well.

Mrs Cassidy:

Yes, absolutely. People feel that the rate of increase cannot be explained solely by better diagnosis, because the resources are not so widely available for it to be the sole cause. We do not know whether the increase is down to environmental factors. Obviously, a lot of work is being done on genetics, so we know that there is a genetic factor in play.

Ms Hanratty:

I would like to respond to Kieran's point about review after diagnosis. My son will be 18 in February. He was diagnosed in the child and family clinic at the Royal when he was six. He has never been reviewed.

Dr Deeny:

That is shocking.

Mr Heatley:

Likewise, my son is 16. He was diagnosed when he was four and has never been reviewed.

Dr Deeny:

The point that you made, of which we see evidence, is that the first-time appointment target culture that has come into the Health Service means that even the initial assessment is not done thoroughly.

Mrs Cassidy:

That is the point that I would like to make. I know the diagnosticians involved in this field. A number of them were the pioneers who really linked-in with our branches in the early days and made sure that they got the training and the specialist assessment tools that they needed, such as the Diagnostic Interview for Social and Communication Disorders (DISCO), the Autism Diagnostic Observational Schedule (ADOS), the Adult Diagnostic Interview (ADI), et cetera. They made presentations to their trusts to get resources dedicated to set up the small ASD diagnostic clinics. I know that there is disquiet among them about the quality of the assessment. The informed nature of the assessment is suffering as a result of the target culture.

Ms Hanratty:

A multi-disciplinary approach is good standard practice. This is becoming less so in the case of autism, as the child may be seeing only one or two professionals rather than the whole gamut.

Mrs Cassidy:

A diagnostic scoping study was carried out between 1998 and 2002 by the University of Ulster, which laid out examples of best practice. Those examples are being eaten away. The point that I was trying to get across is that a lot of work has been done by us and the health and social care trusts. However, instead of being built upon, that work is being reshaped and redesigned.

Mr Heatley:

It is such a waste.

Ms Mullan:

Recently, I received two calls about children who were diagnosed at two-and-a-half years old. Clinicians are extremely good at being able to diagnose now, but the point is that those children will not receive any early intervention until they are three. At that point, they will go on a waiting list, which is six months long. So, people have to wait a year after a diagnosis before they get the early intervention that they require. The child might get sent to speech and language therapy or to occupational therapy, but it is the early intervention that is important in helping the child to learn how to socialise and play. In one case, a mother was told that it will be a year before her child receives any services.

Mrs Cassidy:

Autism NI has done a lot of work on early intervention, and we are linked in with other groups who are mainly interested in that area as well. There was a particular project on how to get information to parents who are on the waiting list for a diagnosis. It is all there, but it is not being implemented because it has been caught up in the service redesign and the “let’s talk about it” attitude.

We were already in partnership with Early Years, formerly NIPPA, and Barnardo’s in rolling out training to preschools. Instead of grasping that, evaluating it, and, if it is fit for purpose, rolling it out, we have the frustration of planning. I am not saying that planning is not needed: it

is needed, absolutely. However, this is about identifying areas of good practice that can be built on while reshaping things.

Dr Deeny:

We have talked about the need to do something about targets, which are impacting on many issues — and here we go again with autism. It is the same thing. A couple of weeks ago, I said that two patients who came to me had been put off the waiting list. One had phoned to say that he was going to a family funeral, and the other was in the hospital casualty unit at the time, suffering from the very condition for which he was referred. However, because he did not show up for his appointment, he was put off the waiting list. So, the first appointment targets are having an impact across the Health Service, including in the treatment of autism. I should declare an interest as a doctor. Management are pushing clinicians to see people within 13 weeks. If reviews are not seen, management’s attitude is “so what”, so long as targets are met.

Mrs Cassidy:

That is it. Multidisciplinary assessment was best practice and it was —

Dr Deeny:

This is certainly not good clinical practice, at all.

Ms Hanratty:

As regards the target; if a child is already at school and the family or teachers recognise that he or she has difficulties but do not recognise that the problems may be caused by autism, and that child is waiting see an educational psychologist, the 13-week target does not apply. Because of schools’ priorities and the limited access to educational psychologists, it may be several years before the child gets to see an educational psychologist. Therefore, if the difficulties are not recognised as autism, the child’s education pathway will become completely different.

The Acting Chairperson:

I remind members to ask questions that elicit more information on the Bill.

Mr Callaghan:

My question may be more of a request. As the Chairperson said at the start of the session, I have heard nothing to convince me that the Bill is a bad idea. Luckily for the witnesses, I must be in

Drumahoe at 7.30 pm, so I will not take up too much time, since they have been here for quite a while.

On the suggestion about amendments to clauses, I agree with Paul Girvan that although the witnesses do not want to accept anything that is substandard they may want to be careful about suggesting amendments without thinking them through thoroughly. In particular, the suggestion about the timing of consultations with Departments is, I think, dealt with in clause 2(1), which provides for an overall two-year deadline for the publication of the strategy after the Bill is enacted. Consultation will have to take place within that two-year period, and anything beyond that will be dealt with as a matter of regulation.

Secondly, and as I said in the Assembly debate, as far as I am concerned, the Bill is silo-busting. I and my party's view is that, as the witnesses outlined, the Bill is all about getting Departments to look beyond their own prisms. Pardon the expression, but they are "imprised" by their own perspective and must move beyond that. A board representative said: "if it ain't broke, don't fix it". The issue is that service delivery is fractured; it is broken.

My question concerns the evidence base. It would be helpful if the witnesses would provide the Committee with tangible examples of fractured or scattered delivery in each trust or board area in which there is non-cost-effective duplication. Parents have told me the same thing that Audrey said about the number of appointments, and the more evidence that we have about people having to go to multiple appointments, sometimes to do the same thing, the better. Sometimes being on one appointment list delays getting on another and the person ends up getting referred down the line, and the whole process seems to be all over the place. If members are to support arguments in plenary debates and in dealing with the Department, the more detail that they have the better. That is something that all Members would welcome.

Mrs Cassidy:

The one amendment, which we heard from the Committee and support, concerns civil servants. An earlier draft of the Bill referred to "public servants", but after advice, it was changed to "civil servants". We would like the phrase "public servants" to be looked at again. It is a matter of interpretation, which is where our expertise ends. We will have to leave that to the Committee.

Mr Brady:

Thank you for your presentation. It seems to me to be fairly fundamental to the Bill. The previous presentation mentioned a “hierarchy of disability”. It seems to me that that was based on the premise that there would have to be a Down’s syndrome Bill, and so on. To me, that does not seem to be that relevant. I have represented numerous families since the advent of DLA in 1992. One thing that struck me was that if I represented a child with Down’s syndrome, it was a fairly obvious condition. The problem faced by families with children with autism was that it was sometimes very difficult to articulate how the children were affected and how the condition affected their and their family’s daily living. A legislative framework, or definition, would, obviously, make things much easier.

The impact on families has not been recognised, and that was mentioned earlier. Over the years, I have found that families were affected greatly. David Heatley gave some examples of that, including cases in which carers fell victim to ill-health, even more so than other carers might have experienced. In addition, going back 20 years there have been difficulties with early diagnosis. Mrs Cassidy said that early diagnosis may now become available. I found that children were waiting for three or four years, and, as a result, lost out on early interventions in education and speech therapy and so on. Now, it seems that those children are being diagnosed but are still waiting. We talked about watchful waiting, but children are waiting while no one is watching. That needs to be addressed, because as a euphemism, this situation is like a lot of the nonsense that we sit here listening to week after week.

It is the same with the Department for Social Development (DSD). The witnesses mentioned civil servants’ training. A civil servant interviewing an adult with autism, who is going to agree, on a particular day, that he could take up the suggested occupation of brain surgeon, is not really addressing the problem. It goes back to what the witnesses have been saying: there must be public awareness, but also awareness that is specifically related to the job that those people are doing. Huge numbers will be affected, and we are only now starting to realise how they are going to be affected.

Welfare reform is sanction-led, but we have a Minister for Social Development who says that he will not impose sanctions. I have seen it all before. It is sanction-led, so-called, reform, and the whole point of putting it into operation is to sanction people. It might be held off for a couple of months, but people will end up being sanctioned. People who interview adults with autism, in

particular, and young adults must be specifically trained. Lone parents were mentioned. Lone parents with a seven-year-old child or younger are being forced out to work. The objective is that that will eventually apply to lone parents with a one-year-old, but we do not even have a childcare strategy, never mind a proper childcare —

The Acting Chairperson:

Mickey, is there any chance that you could get to a question, please?

Mr Brady:

I wanted to raise those points. I am emphasising the need for the Bill. It will not create a hierarchy of disability; it will deal with a specific issue that needs to be dealt with.

Mrs Cassidy:

We were absolutely insulted when we first heard the phrase “hierarchy of disability” in connection with the Autism Bill and the stance taken by the Department and the board. We have always argued for the existing hierarchy of disability with regard to autism to be removed. This is about addressing a gap —

Mr Heatley:

It concerns equality.

Mrs Cassidy:

It is about equality. Just to reinforce what was said about the particular impact; research carried out earlier in the year shows that 80% of mothers of children with autism experience high levels of anxiety, with 50% on long-term antidepressant medication. That is independent research. It is not as though one wants to say that it is more stressful to care for children with autism than those with other disabilities. However, international research is saying that the stress levels of primary carers of children with autism are higher than for any other disability group. That is very powerful. It needs to be double-checked. We double-checked it.

Mr Heatley:

The research actually included terminal illness, which is hard to believe.

Mrs Cassidy:

It is incredible to believe that. However —

Mr Heatley:

It is because autism never stops.

Mrs Cassidy:

The nature of autism is that it is sustained for life. We have never had to pull those arguments out of our socks until we were faced with the claim that we were causing a hierarchy of disability. We could not believe it. That is far from the case. It is an equality agenda issue.

Ms Hanratty:

I want to pick up on the point about civil servants assessing people. If a civil servant assesses someone whose hearing is impaired, accommodation will be made to enable that person to have equal access in order to have a full assessment.

Mr Brady:

By law, someone must have an interpreter if English is not his or her first language.

Ms Hanratty:

Autism is a social and communication disorder. That needs to be recognised. Additional accommodation needs to be made for individuals with autism to have their rights and an understanding of their difficulties to be supported in assessments.

Mr Brady:

Alex will agree with me that the Committee for Social Development has asked for exactly that.

Mr Heatley:

It also concerns policing and justice.

Mr Brady:

That is why it is such a cross-cutting issue.

Mr Heatley:

Absolutely. It is good to see how knowledgeable the Committee is about the condition. Members, obviously, have great knowledge about how it affects people. It is very reassuring.

The Acting Chairperson:

Thank you for your presentation. Before I close the meeting, I wish everyone a happy Christmas and new year.