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Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Autism Bill: Regional Autistic Spectrum Disorder Network and Health and Social Care Board

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

Witnesses:

Mrs Fionnuala McAndrew	)	Health and Social Care Board
Dr Stephen Bergin	)	Regional Autistic Spectrum Disorder Network
Mr Kieran McShane	)	

The Chairperson (Mr Wells):

Folks, I suggest that we structure our questioning of all witnesses, not only the current group, by dealing first with the proposed amendment to the Disability Discrimination Act (DDA) 1995, followed by the proposal for an autism strategy and, finally, a third set of questions on any other issues. If members are content, we will order our questions in those three stages.

I welcome the witnesses, all of whom have appeared before the Committee previously in some capacity. Mrs Fionnuala McAndrew is the director of social care and children's health at the Health and Social Care Board; Dr Stephen Bergin is the chairperson of the Regional Autistic Spectrum Disorder Network (RASDN) and a public health consultant with the Public Health Agency; and Mr Kieran McShane is the commissioning head of children and families at the Health and Social Care Board and network project team manager for the Regional Autistic Spectrum Disorder Network. Kieran, I believe that, a few months ago, you gave evidence to the Committee in the Senate Chamber. Is that correct?

Mr Kieran McShane (Regional Autistic Spectrum Disorder Network):
That is correct.

The Chairperson:
You have 10 minutes in which to make a presentation, after which the Committee will ask questions in three stages, as you heard.

Mrs Fionnuala McAndrew (Health and Social Care Board):
Thank you, Chairperson, for the opportunity to make a presentation to the Committee this afternoon.

Reference has been made to the independent review of autism services. Committee members will be aware that, following publication of the regional action plan for autism, the implementation of recommendations in the report is being taken forward by the Health and Social Care Board through the Regional Autistic Spectrum Disorder Network (RASDN). The project structure for that network has been established under the leadership of Dr Stephen Bergin.

The RASDN project structure ensures a line of accountability from trust groups to a project board, which has representation at director level from the health and social care trusts; senior Health and Social Care Board officers; other statutory bodies; the Department of Education; the Department for Employment and Learning, and the Department for Social Development. It also has links with the criminal justice system. The project board is accountable to the Health and Social Care Board and, through the Department, to the Minister of Health, Social Services and Public Safety.

A fundamental and integral part of the network is the involvement and participation of the voluntary and community sector, parents, carers and service users at all levels in the project structure. At present, 10 voluntary and community sector organisations are involved in the reference group, which, as you know, is chaired by Lord Maginnis of Drumglass. They include groups such as Barnardo's**,** Autism NI, the National Autistic Society and Mencap, to name but a few. All those organisations can demonstrate active involvement in the design, planning and delivery of services to those with autistic spectrum disorder (ASD) and to their carers across children's and adults' services. They reflect the diversity of need. The predominant membership of the reference group, however, comprises parents, carers and service users. That is to ensure that those who are in direct receipt of services and who experience the realities of living with ASD have a voice in the planning, commissioning and evaluation of services. As part of the ongoing engagement, a series of stakeholder events has taken place across Northern Ireland. Those will continue as part of the project's infrastructure to ensure broad stakeholder involvement.

Given that the current membership of voluntary organisations involved with ASD represents a small proportion of the total users and carers who are impacted by it, the project seeks to ensure that it engages the hidden voices of the majority of those affected and that they have an opportunity to shape services.

Several work streams have been established within RASDN, including children and transitions; adults and transitions; training and awareness raising; and communication and information. If members wish to pursue the work of those work streams in their questioning, my colleagues will be happy to outline the work being taken forward.

We want to highlight some issues in connection with the need to enact additional and specific legislation. The DDA has already been referred to this afternoon, and I do not want to go over that ground, but we believe that that is all-encompassing. In addition, a number of clear statutory duties are outlined for trusts in the delivery of services to children with disabilities and their families, including those with autism. The Children Order 1995 is the primary legislation for children in Northern Ireland. Article 17 of the Order states:

> "a child shall be taken to be in need if … he is disabled".

Article 18 of the Order determines the statutory responsibilities of trusts to provide services for children in need in their area. We are, therefore, required to consider those children determined to be in need by virtue of article 17. In addition, the Order imposes a statutory authority on trusts, where requested, to carry out an assessment of the needs of the carer of a disabled child, and it imposes the duty to take that assessment into consideration in deciding what services to provide. Article 19 also provides for support for children in need within early years provision. The implication, therefore, is that there will be provision for support for children with disabilities within early years provision.

The Children (1995 Order) (Amendment) (Children's Services Planning) Order (Northern Ireland) 1998 also placed responsibility on a range of agencies to plan together in relation to children's services. The four legacy children and young people's committees, which are the operational arm of children's services planning, are now being condensed into one regional strategic partnership for Northern Ireland, which will have its first meeting in January 2011 after the RPA arrangements.

All the key strategic drivers of OFMDFM's 10-year children's strategy Our Children, Our Pledge and the departmental family support strategy Families Matter draw heavily on the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, which do not determine criteria, other than need. Those conventions have been ratified by the UK Government and, in the case of the UN Convention on the Rights of Persons with Disabilities, also by the European Commission.

The strategic and legislative principles within children's services are based on the requirements to consider a needs-based and person-focused assessment, and they should not be determined by criteria such as diagnosis, but on the basis of child/adult/carer first. I will quickly refer to the Carers and Direct Payments (Northern Ireland) Act 2002, which commenced in 2003. That legislation also provides a statutory right to a carer's assessment and makes similar provision for adult services as is provided for children under the Children Order.

Various work has been taken forward by the Department, which established the regional implementation team to look at providing consistency in models of service provision in children's services. That work resulted in the introduction of the understanding the needs of children (UNOCINI) assessment framework, which is a model for all children's services and is applicable to all agencies. Significant investment in and the roll-out of training for UNOCINI have been progressed, and a similar piece of work is now been taken forward on developing a tool for adult assessments. The legislative duties under the Chronically Sick and Disabled Persons Act are trans-generational and have relevance to children and adults.

In going through the various legislation, we want to point out that a wide range of statutory provisions is in place and seeks to provide a range of supports and protection in law for those with disabilities, including those with ASD. The determination of need, which is focused on the assessment of an individual's unique circumstances and needs, in conjunction with that individual carer, is the primary focus of service delivery.

The Bill references the need for robust data collection and the utilisation of such data in planning. The board has a number of data collection processes in place, such as the child health information system, which allow for the collation of prevalence of conditions by diagnosis, age and locality.

Work is also under way to complete a children's services plan and database that can provide not only a breakdown of disability by local government area, but a directory of services available in those localities.

The Chairperson:
Mrs McAndrew, we are a bit tight for time. Many groups are due to give evidence, and we are trying to be fair to everybody by tying the presentations to 10 minutes. We have your document in front of us, so, when answering questions, feel free to deal with the points that you may not have made. For witnesses generally, it is better to start with a critique of our support for the Bill and then go on to more general points.

Mrs McAndrew:
I apologise if we have done it the wrong way round.

The Chairperson:
You are the first group, so I want to lay down some rules for the other groups.

Ms S Ramsey:

Thanks for your presentation and your paper. I take on board the point about the Children Order, which you described as the primary legislation on the issue et cetera. However, the Order's provisions do not always get through to some of the parents with whom I have dealings. We need to live in the real world and accept that that does not always happen. Sometimes, the law says that individuals are supposed to get A, B, C, D and E, but instead they receive the most basic package of help, if any. Recent court cases and judgements have shown that to be the case.

It is probably not fair to put my question to you; I should be putting it to the Minister. The Minister is keen to talk about parity legislation, parity with England, parity with here and parity with there. Why are we not seeking parity with England on this issue and trying to find instances of best practice there?

Secondly, I take on board that much good work has been done by individuals, groups, organisations and parents. However, you talked about the groups that meet at a senior director level across the board in the sectors of health, education, employment, criminal justice, et cetera. Are they working?

You went on to talk about the non-governmental organisations (NGOs). I do not see that parents feel the impact of some of the work that is done at that level. If we are trying to strengthen your hand, as officials, to ensure that you have a statutory duty, the relevant legislation must exist so that you have the necessary resources to kick-start that statutory duty. The Children Order is a statutory duty, but, in some instances, does not have an impact. We can quote recent court judgements to support that, such as the one in Fermanagh a couple of weeks ago.

Mrs McAndrew:

I will reply first, and Stephen Bergin will respond to the question of NGO involvement in the RASDN.

In our presentation, we were coming to the point that a range of extant legislation can make supports and assessments available to the full range of children and adults with disabilities. In fact, the judgement in the Fermanagh case that you mentioned underpinned that and said that the legislation provided for that to happen.

Ms S Ramsey:
The support was not followed through.

Mrs McAndrew:
The challenge within that is continuing to meet the demands and the needs of the people who need our services as a consequence of the provisions in the legislation. That case demonstrated the challenge that exists, in a full range of services, of continuing to meet that demand. If the conversation is about whether legislation is required to make that happen, the provisions exist in legislation already. The challenges are not with the legislation but are somewhat separate to that. They are about meeting demand. Stephen may wish to talk about NGO involvement.

Dr Stephen Bergin (Regional Autistic Spectrum Disorder Network):
It is important to recognise that the work that I have been leading is relatively recent. It has taken quite a while to assemble the project structure. The action plan arrived in the summer of 2009, but we have been talking about autism for the past two decades. It took between six and nine months to assemble the full project structure, and a key part of that was to get our parents, carers, service users and voluntary agencies on board. The full project structure has been in place only since March 2010, and, eight months later, we still are in our infancy.

Even in those eight months of having the full project assembled, we have made significant progress. When I was first here as part of the independent review, the big issue was waiting lists. Those were measured in years, which was totally unacceptable. That is no longer an issue, in general. across Northern Ireland. By April of next year, we will be on target to meet the existing 13-week elective care target in priorities for action. Four of the five trusts are on target, or thereabouts, and the Belfast Trust is the last remaining one to get on target.

During the initial months, we spent significant time standardising the previous dozen or so diagnostic care pathways across Northern Ireland, which reflected the 17 former trusts, into a uniform single diagnostic care pathway. That will be launched in the next few weeks, and it has taken a great deal of effort from the professionals. A key part of that has been the input of the parents, carers and service users, in that they are, effectively, co-authors of that important document, which will come out in the new year. The parents, carers and service users have done significant work to draft those documents, and a great deal of work is going on in the background.

The investment that we put in from the Department, which is now £1·64 million recurrently, is all going into front-line services and front-line practitioners, who will have a cohort of lead ASD co-ordinators across Northern Ireland — one in each trust — and have oversight of a dedicated and specific team for ASD in each trust area. Some of the investment is still going into the services, and, by the time that all of it hits the ground, there will be a service in, for example, the Southern Trust with 17 or 18 practitioners, that was not there in previous years. Those practitioners are being recruited now, some of them in the current financial year. If you invite me back here later in 2011, those practitioners will be bedded in. and you will see significant services in the trusts.

The Chairperson:
I remind members that we are discussing the DDA, not the strategy. The questions should be on the DDA.

Mrs O'Neill:
My question is on the DDA. You are very welcome to the Committee, and I am aware of the work that the network has done. I put on record that I commend that work, particularly that of the parents, carers and service users who have been involved. You said that the DDA is all-encompassing and does not need to be amended. Why does it not need to be amended, and why would amending it cause a problem?

Mrs McAndrew:
The DDA is viewed as all-encompassing because it is specific to disability, and children and adults with autism are viewed as being children and adults with a disability. Our one concern about amending legislation to make it more autism-specific is that it would mean focusing on one type of disability, and there is no specific legislation for each disability. The DDA was intended to be a generic, all-encompassing piece of legislation.

Your researchers referred to supplementary guidance that has been developed in England, Scotland and Wales, which may be a more appropriate route through which to make that explicit and clear, but, from the practitioners' perspective in health and social care, we view the DDA as all-encompassing.

Mrs O’Neill:

The legislation, as drafted, suggests an amendment to insert the words “social and communication”. That amendment extends beyond autism.

Mrs McAndrew:

That is correct.

Mr McShane:

The issue with the term “social and communication”, and the debate has touched on some of the points, is that the Department recently issued another consultation on a speech and language action plan, which recognises the broad needs of children with speech and language and communication difficulties. A significant proportion of those children will receive a service: speech and language, early intervention or dealing with early identified developmental delay. Following that intervention, a significant proportion of those children will have most of those particular issues addressed. The concern is that a significant number of children have speech and language difficulties at present. We know that our services will intervene and that there will be good prognoses for those children, but should they all be covered in the DDA under disability?

Mrs O’Neill:

I hear what you are saying, but why not? That is the first thing that came into my head. If the Disability Discrimination Act were amended to include “social and communication”, it would reach out and protect those kids who have speech and language developmental problems, so why not?

Mr McShane:

The point was made that, for some of those children, the duration of some of those difficulties could be quite short-lived over their lifespan. It could be one or two years. Once they start school, they receive the additional benefits of the education system, such as socialisation and speech and language therapy input. That changes the children, and they make significant progress in that period. It is not a lifelong disability per se. We know of a number of children who have developmental delays for a number of reasons, some of which will be diagnosed and some of which will not, but we have services in place to address those. We deal with them through generic and core services, such as speech and language or occupational therapy, and the same issues apply across a range of disabilities.

Mrs McAndrew:

Our view of the DDA is that it affords protection to a group of people. It recognises that people with a disability have certain rights. It does not provide access to services. As I said previously, that is by way of an individualised need assessment of need. Our approach to assessing and supporting need, notwithstanding the challenges of demand, is that we regard disability as all-encompassing.

Mrs O'Neill:

You made the point that the DDA affords protection to all children, but it does not. One of the cases that was raised with the Committee a number of weeks ago involved someone who had applied for disability living allowance (DLA) but was refused, because autism was not included in the Disability Discrimination Act. We had the papers to show that that was the reasoning from the tribunal. Surely widening the scope of the DDA to include "social and communication" would work in that person's favour?

Mr McShane:

I will replace my professional hat with my parental hat. When I was before the Committee previously, I shared the fact that I have four children, three of whom have separate disabilities. From my considerable experience of working with families, one of the major issues for Down's syndrome families is the fact that they do not receive DLA other than through an appeal, because the structure of the form precludes some elements of the condition. The issue about changing the DDA to include autism is that, in some respects, some of the DLA forms are better suited to ASD than to other conditions. That is well known and well evidenced by Down's syndrome.

Mrs O'Neill:

Thank you for that. It is important for us to look at the whole picture and try to get our heads around it.

The Chairperson:

You made a strong statement in your submission that you did not get a chance to come to, Dr McAndrew. It states:

> "The HSCB would contest this assertion and would be concerned that legislation pertaining to one disability will create the potential for a hierarchy of disabilities and will create greater inequalities. At this point in time there is no legislative provision which relates to any one condition such as Down's Syndrome, Cerebral Palsy etc and to create such distinctions is at

variance with good practice”.

That point has been made before. Those on the other side of the argument say that, when other legislators have defined autism as a disability, there has not been a stampede of other groups who represent particular conditions demanding parity of legislation. People whose relatives have Down’s syndrome, cerebral palsy and other complex conditions do not demand that they be brought within the definition of the DDA. What makes you believe that the Bill is the thin end of the wedge and that it would cause problems in the future?

Mrs McAndrew:

Our perception is that the Children Order and the DDA are all-encompassing. It is of concern to us that the focus would be on specific conditions rather than on the broad spectrum of people with a disability. We should look across our services — universal services as well as specialist services — to support people with disabilities who live in our communities.

We contest the notion that not including autism in the DDA creates inequalities. We are expressing, for the Committee’s consideration, our view that the perspective should be one of creating more integration and universality, rather than of defining people by their medical condition. We seek to approach people by assessing their whole-life situation rather than relying purely on a medical diagnosis to access certain services. I come back to the fact that we are talking about individualised and person-centred assessments, rather than diagnoses being the lead elements.

The Chairperson:

Along with Mickey Brady, I have spent many hours attending tribunals in Ballybot House. In the real world, when a person goes before a tribunal, hard legal hooks are sought on which to hang the award of DLA, carer’s allowance or whatever. If autism or a related condition does not appear in the legislation, the outcome is that the appropriate benefit cannot be awarded.

I am still slightly intrigued as to why making the DDA more embracing and comprehensive would lead to inequalities. I would have thought that making certain that everyone who has a disability is included in the DDA would place everybody on an equal footing. Someone who has a broken leg, for instance, definitely scores points, as does someone who clearly has acute depression, but someone who has autism does not tick either box. I am missing something, and I would like you to expand on your thinking.

Mrs McAndrew:

We take your point.

Mr McShane:

I cannot comment about other Departments, agencies or services concerned in health and social care. Reference was made to the International Classification of Diseases (ICD) 10 definition that autism is a disability. I note the comments that were made about the Welsh model. If you examine that in the context of the Northern Ireland family support model contained in Families Matter, it clearly has a tier 1 to tier 4 structure as well. That gives access to all at a universal level, and, moving through the tiers, to a specialist intervention. We already have a Province-wide departmental strategy, which has been rolled out and encompasses the particular issues about that eclectic approach.

I am a commissioner for children with disabilities. Many of the issues related to autism are also identified by families with Down's syndrome, cerebral palsy, and so forth. Those issues include access to special needs assessments in schools, access to respite and access to transitions. There is a commonality in the world of disability, and, sometimes, that provides strength in trying to address the issues. Such commonality has an overall benefit.

Mr Easton:

Thank you. Fionnuala, a wee minute ago, you used the word "perception", which concerned me. You described it as your perception that "social and communication" should not be included in the DDA. Perhaps I am not the only one who picked up on that. What you tell us is, therefore, not a reality: it is just your perception. Do you see what I am saying? I want to point out that other conditions, such as fibromyalgia, are not supported under the DDA. It is a medical condition. Therefore, other conditions that are not covered by the DDA must also be considered. It worries me that you have not come to us with hard facts, but with perceptions.

Mrs McAndrew:

We expressed our view from the Health and Social Care Board's perspective. It is difficult for us to comment on another Department or another agency's practice and procedures. I am not quite sure what facts I could present to you. We are concerned about moving away from a generic piece of legislation, which should pertain to all people with disabilities, and becoming quite specific about those who are included or cited in the legislation and those who are not. We are drawing that to your attention this afternoon.

Mr Easton:

Please, excuse the way that I phrased my comments. Kieran, you mentioned that the autistic spectrum is broad and that, perhaps, it should not be included the DDA because — if I frame this in the correct terms — the condition might last for a couple of years or could, sometimes, be lifelong.

Mr McShane:

No. I want to clarify that. I made the point that some speech and language difficulties can be short term, whereas autism is a lifelong condition. We get feedback from our colleagues in the Department of Education and, certainly, from speech and language therapists. Part of the rationale for the recent action plan was to help to address some of those broader generic speech and language and communication issues that are being identified and will, now, be challenged through that particular action plan for speech and language.

Mr Easton:

Thank you for clearing that up.

Mr Girvan:

Thank you for your presentation and submission. You have demonstrated with your evidence that the DDA does not cover every condition. You said that there are a number of failings in your systems, in diagnosis and in ensuring that people are seen and dealt with fairly, and that it is only since the strategy was introduced that you have attempted to catch up and put something in place to ensure that people are seen within a reasonable time. If people were to present with major depression, they would be treated immediately and would not have to wait some time for their problem to be diagnosed. That is part of the issue. By saying that the DDA covers everything, you give yourselves a get-out clause. You are not addressing the issue correctly. It is necessary that ASD be included. You mentioned that you deal only with your own agency. The Bill in its entirety will deal with other agencies, which require some form of cover to ensure that they deal with issues through legislation. We must ensure that that point is covered. Will you explain whether the strategy was the only thing that kicked you into operation? The condition has existed for ever, yet it is only relatively recently that matters have started to fall into place. I appreciate that the Department has, probably, had to react to the issue in light of the Bill's being proposed.

Mrs McAndrew:
I will ask Stephen to comment on that.

Dr Bergin:
The Health and Social Care Board has existed for only the past 18 months. Prior to that, I was with the Southern Health and Social Services Board, where we had a strategy in place for a decade. The Department provided investment for children's services; Kieran has been highly involved in that. Other board areas had their respective strategies, although, admittedly, not all of them. We have gone from a situation in which there were 17 or so trusts down to five. The scenario and the lay of the land are, therefore, quite different. However, we are not at a baseline of zero. It is not as though we only started during the past 12 or 18 months.

Mr Girvan:
I appreciate that.

Dr Bergin:
The action plan has just started.

Mr Girvan:
However, it has taken a long time for that to come into operation.

Mrs McAndrew:
In addition, we have been dealing with increasing demand for years because of the rising number of people being diagnosed as autistic. There has been an issue with waiting times for access to assessment and treatment, but I am not sure that that means that we have not recognised autism as a condition under the DDA or that we have not been trying to deal with it. That has posed us challenges in respect of the length of time that people have waited for assessment and treatment. However, through investment over recent years and by particularly focusing on that area, we have made significant improvements.

Mr Girvan:
You said that an increasing number of people are being diagnosed.

Mrs McAndrew:

Statistically, that is the case.

Mr Girvan:

Are you saying that the sector is ever increasing, or have those people always been there but never been diagnosed? Were they, therefore, being failed by the system?

Dr Bergin:

It is a mixture of new cases in the younger age groups and an older, prevalent cohort that has been there for years and is, perhaps, now being detected. The age of diagnosis has decreased in recent years. Ten years ago, diagnosis was at an average age of five or six but it is now much earlier, at about two or three years of age.

I will pick up on a point made earlier, which is that an autism diagnosis cannot be rushed. We are talking about somebody presenting within a maximum number of weeks, but the diagnosis process is complex, as members probably know, and we are putting in place a standardised, agreed process by which to address that. It is rare for someone to come through the door and leave with a diagnosis of autism after one session. Rather, diagnosis is an iterative process over months of observations.

Mr Girvan:

I appreciate that, but I come back to the perception that the Disability Discrimination Act 1995 encompasses everything. Relatively recently, I dealt with a mature lady who had problems, and she was in her 40s when she was diagnosed as having an autistic spectrum disorder. That lady had been failed by the system. She had been treated for all manner of social problems without her condition ever being properly diagnosed. It took some time for that to happen, and then it was only through referral and the proper process. However, until recently she was failed, so we are not even talking about the situation 10 years ago, because that happened in the past 18 months. That lady was 40 years of age. I appreciate that the condition is being picked up in people earlier, but that lady had lived her life thinking that there was something seriously wrong with her, and she was relieved to find out that she had a condition for which she was able to get help.

Dr Bergin:

Much of the emphasis has been on children, and we need to catch up with adolescents, younger adults and older adults. I have told the Department that that must be a bigger thrust in the strategy. We are working on the adult diagnostic care pathway now, and it will follow hard on the heels of the children's care pathway. We hope that, by around the start of the next financial year, each trust will have a diagnostic hub for adult services. That is looking forward, but I agree that there are deficiencies in adult services.

The Chairperson:

Members, we would like to be home for Christmas. We have not yet finished the first round of questions on the DDA, so Pól Callaghan will be the last to ask a question on that subject before we move rapidly on to the strategy issue, unless anyone has a burning issue that has not been raised.

Mr Callaghan:

Chairman, you will be pleased to hear that I will be brief. The last paragraph of the briefing — members received the table only today, so we are working on the hoof — states:

> "There is a danger that when citing disability as determined by condition alone, that this lends itself to an interpretation of a medical model which is reliant only on diagnosis"

Is it not the case that the DDA part of the Bill does not rely on diagnosis at all? The Department told the Committee that the provisions did not rely on diagnosis. It seemed to think that that raised issues about autism not being specified in the DDA-related part of the Bill. I am just not sure how that paragraph of the submission relates to the DDA provisions in the Bill.

Mrs McAndrew:

The final sentence was more general; it was not specific to DDA. However, generally speaking, and for our purposes, the existing legislative provision includes autism. We are a bit concerned that the Bill would create a model, across health and social care provision for people with a disability, that would be based on the social model of disability. Our concern is about too much focus on the stipulation of autism in legislation. I do not mean that it would be a step backwards, but it would create a new perception that a medical diagnosis would be required to access services and support. The Health and Social Care Board has tried to move that situation forward so that a medical diagnosis is not the only way to access assessment and support.

Dr Bergin:

The definition of someone's needs within the term "autistic spectrum disorder" does not convey sufficient information. All sorts of co-morbidities come with individuals. The co-morbidity may relate to mental health, epilepsy, gastric conditions, and so forth; the list goes on and on. The term "autism" could have a wide spectrum of meanings, because it is divergent in its individual presentations. The point of that sentence is that the presenting need should be assessed.

Mr Callaghan:

We are not talking about the DDA clause, because it does not include the word "autism" — indeed, some people have an issue with that. Therefore, we are talking about the provisions in clause 2 and beyond. However, the Department is already rolling out an autism strategy. Given that the Department's entire argument to the Committee, and, it is fair to say, the board's argument today, strongly rely on the fact that services are already being rolled out, I do not understand any principled objection to the specification of autism in clauses 2 and beyond. That objection formed part of Dr Bergin's presentation in particular. That is entirely commendable, but I do not understand why that is an issue as far as the Bill's provisions are concerned. Do you understand what I mean?

Mrs McAndrew:

I understand your point. Our view is that, when it comes to enacting the Bill, the extant legislation is an enabler. The judgements that we have had and the cases with which we have dealt make it clear that the extant legislation is an enabler of the provision of services and supports to people with autism. That is the crux of our presentation.

The Chairperson:

Is your question on the strategy, Kieran?

Dr Deeny:

I have a quick question on the DDA.

The Chairperson:

As long as it is quick: in case I ever get knocked down near Omagh, I have to be careful.

Dr Deeny:
I take on board exactly what the three folk said, and I agree with much of it. I thank them for coming today. Is the point that people are uncomfortable that the one named disability will be autism, whereas we are dealing with many different disabilities? Cerebral palsy, Down’s syndrome, muscular dystrophy and all sorts of genetic disorders have been mentioned. Is the concern about a hierarchy of disabilities?

I agree with Stephen that many people with autism have significant additional problems. The whole person must be taken into consideration. As a medical professional, I agree that the Bill should not be in any way construed or constructed so that decisions are made based on medical conditions. The focus must be on need, and a holistic approach is required.

Mr McShane:
I will speak from a personal perspective. My wife and I have four children: one has autism, one has Down’s syndrome, and one has undiagnosed speech, language and developmental difficulties. Our fourth child is a little girl, and I am extremely concerned about her. She does not have a condition, but I worry about the impact on her needs. In the world of autism, it is not uncommon to have more than one condition in the family. Is it right that, within one family, the premise should be based on the fact that legislation exists for one child, as opposed to a process that focuses on the individual needs of all children?

I argue that the child who has the greatest need is probably the one without the condition, because of the impact of the others’ conditions. At present, our legislation, strategy and practice ensure that we have a holistic assessment of a child and a family in the context of our family support model. From a personal perspective, that leaves me much more satisfied that we are dealing with the issues within the DDA. In some ways, legislation will not change things. The important thing is the application of services on the ground and the impact —

Mrs McAndrew:
In case there is any doubt, we understand that the proposal for the amendment to the DDA does not specify autism. We are not trying to ignore the fact that it talks about social and communication issues.

The point that we are trying to make is that the provisions of the current legislation extend adequately, in our view, within health and social care, to people with autism.

The Chairperson:

We must now move on to the strategy.

Mr Easton:

It appears to me that the Department's strategy has no impact on or relationship with other Departments. That is why it is not working to my satisfaction. I cannot speak for anyone else. The Bill forces all Departments to co-operate, organise training, and so forth to address autism and the issues surrounding it. Do you not believe that that is a much better approach than the one that the strategy offers?

Dr Bergin:

One would think that I was expected to sort out the world of autism for Northern Ireland. How long would that take? It was never going to happen in one year. We must be realistic. It takes time to build up relationships with other agencies and with the personalities involved. I have been working on that. The key focus was to build up that relationship with education. In every trust and in every regional group, there is a key relationship with educational psychology and education sector staff. They provide advice to those groups.

That has worked the other way as well. Kieran and I are members of the education sector review team of the autism review. A key link has been established with the education sector, and we intend to progress that in the new year through more joined-up thinking, from the top down in the Department, between health and social care and education to create a more structured, robust way forward.

With regard to other agencies and sectors, relationships have been built up, and I talked about those regionally and locally in trust settings. If members were to go to the Southern Trust, they would see the relationships with the various agencies, for example, Craigavon Borough Council, where partnerships have been developed on leisure services. The relationships are being built up bit by bit across the region but, as the Committee will appreciate, the building of so many relationships with so many agencies is a highly complex process, and it takes time.

Mrs McAndrew:

The board believes that integrated planning across agencies and Departments is critical to meeting the wide-ranging need of anyone with a disability, including people with autism, as a principle. An example of that is through children's services planning, which is a mechanism that we employ. Currently, there is no statutory duty to co-operate under children's services planning, but we have an effective, multi-agency planning system that has been running for nearly 12 years. In principle, it should be integrated, multi-agency and multi-disciplinary.

Mr Easton:

The Bill, therefore, is a good development.

Mrs McAndrew:

In principle, it can be achieved, and it is achieved elsewhere in our planning and commissioning of services.

Mr Easton:

However, the Bill would force you to do it, right across all Departments, whereas now you sort of do it, if you know what I mean. Do you not feel that having all Departments involved could lead eventually to extra moneys coming in from other Departments for autism? Equally, their training would help to get people with autism diagnosed more quickly and help them to meet their specialist needs. That applies not only to education and health but to the Department for Social Development (DSD) when it comes to possible benefits and to the Department for Employment and Learning (DEL) because people at university also have autism. Do you not think that savings could be made there?

Mrs McAndrew:

As far as being forced to work on a multi-agency basis, that is a principle to which we already adhere. We have a range of examples where we do that without the force of legislation, because it is the right thing to do. It is good practice, and it means that we can give consideration to how we pool our resources, whether money or staff on the ground, to support a range of people. There are many examples of how that is achieved without our being forced by legislation.

As for working with other agencies, education is a particular example of funding being set aside over recent years for autism services. Within the trusts, there has been an engagement with education to consider how their money and our money, together, can develop more effective resources in a locality, rather than Departments simply thinking about their own money. Those pieces of work are ongoing.

Mr Easton:
Do you not feel that the training that the Bill would enforce on all Departments would be beneficial to you? That does not happen at the moment.

Dr Bergin:
You would be surprised at the amount of training that is going on. We have just completed a baseline scoping. This is part of the problem with training initiatives in Northern Ireland: it is a joint venture between us and the education sector, and we found 277 different initiatives across Northern Ireland, which is a small area. That needs to be co-ordinated, tied down, prioritised, structured and managed, but that is not happening. Our plan is to make it happen and to get it structured and prioritised. It would be wrong to say that there is no training across agencies; there is.

Mr Easton:
Does the Department of Agriculture and Rural Development (DARD) carry out training?

Dr Bergin:
I would have to go through the list of the 277 initiatives —

Mr Easton:
I am talking about Departments.

Dr Bergin:
I cannot speak for DARD, but I can tell you that there is an extremely long list of initiatives. It surprised all of us how much training is going on. It is primarily baseline awareness-raising training, as opposed to professional-type initiatives.

Mr Easton:
Do you know whether the Department for Regional Development (DRD) or the Department of the Environment (DOE) provide training?

Mrs McAndrew:

We can provide the Committee with a report on the training initiatives and who is involved, if you would find that helpful.

Mr Callaghan:

I want to start with the point on hierarchy, which you raised in your briefing paper. The Chairperson also mentioned it. Are there specific strategies within the board for Down’s syndrome and cerebral palsy? Is it not the case the Department has itself recognised that autism is different, in that it has a dedicated autism strategy?

Mr McShane:

The ASD action plan was issued at the same time as the acquired brain injury action plan. One of the issues with strategies and recognising that there are issues for ASD was the acknowledgement that other conditions also have issues. Currently, approximately 6,000 children each year acquire minor brain injuries. There is no legislation for them, but there has to be a strategy on how they are followed up and what happens in relation to best practice and providing the best service for those children, many of whom manifest the same attributes as a child who may present with ASD. We have several strategies for issues that are pertinent to particular groups. I cited the example of acquired brain injury, the strategy for which was issued at exactly the same time as the ASD strategy.

Dr Bergin:

Wearing some of my other hats within health and social care, I head up work across eating disorders, addiction services, forensic mental health and people with personality disorders. The Department has issued a whole raft of network and strategy areas. It is not unusual to have action plans across all sorts of discrete areas.

Mr Callaghan:

It is not a criticism of the fact that there is an autism strategy, far from it. The Committee will have to consider the impact of the argument, because it seems that nothing is required in the Bill to which the Department or the board has a principled objection. You do not seem to be arguing against any one action that the Bill requires of the board. In many instances, the board’s argument is that it is doing certain things anyway. The issue seems to be with the statutory requirement.

Your briefing mentions dual diagnosis. There is nothing in the clause amending the DDA that prevents the application of the DDA to anyone with a dual diagnosis. The clause does not mention duality of diagnosis, but autism is the threshold at which the DDA applies. It not an exclusivity clause that excludes people if they have autism and some other condition, including some of the examples that Dr Bergin provided.

I assume that the current strategy provides for people who have dual diagnoses or multiple diagnoses, and I do not understand why a strategy as mandated by a statutory duty in the Bill would not be similarly facilitating of people with dual or multiple diagnoses.

Mr McShane:
There is a level of complexity to the response, so bear with me. We have a number of children who are now diagnosed as having a disability, and very few childhood disabilities come on their own. Unfortunately, there tend to be associated conditions with them. For example, some of the major issues with Down's syndrome are sensory difficulties in the form of, for example, hearing loss and so on. There are a range of issues.

Coming back to the point that was made earlier, our focus is on the assessment of need in regard to the individual child and their family. That need is not premised on the fact that a child has a range of conditions or on the impact of the autism per se, but on the impact of the condition on the child and the family and how that changes the child's and family's life. A point was made on the recent judicial review. That review cited clearly that the failure in that instance was the failure to look at the wider context of the whole family.

On your question about dual diagnosis, we have x number of children coming through our system with complex medical needs who would not have survived ten, or even 5, years ago. A lot of those conditions are not recorded on any list for the DDA, yet those children still have very complex needs. It is an ever-evolving problem, and we have ranges of complexity in children's disability services, and that is pertinent not only to autism. If you were to ask me what is more important for a child whose co-morbidity is autism and Down's syndrome, my response would be that the needs and circumstances of the child should be assessed.

The Chairperson:

Mr Callaghan, do you have another question?

Mr Callaghan:

I have one more.

The Chairperson:

I will come in on that and steal your valid point. I apologise profusely to the Deputy Chairperson for stealing her slot. Pól made the interesting point that a cross-departmental strategy might bring synergies and efficiencies that will save money. That was the first time that I heard that point being made, and it strikes me as an extremely useful suggestion. Has the Department or the board considered that as an option to reduce their opposition to the idea of preparing a strategy?

Mrs McAndrew:

Do you mean a specific autism strategy?

The Chairperson:

Yes, it is logical that, if all Departments were to co-operate on a single strategy, waste and duplication would be bound to reduce.

Mrs McAndrew:

On a general basis, that is correct. I cannot quantify what the efficiencies and savings might be, but, previously, I referenced children’s services planning, and that is exactly the principle behind that. We are looking at strategies that mean that all agencies that have something to offer to an individual or a family work together in considering how they provide the services. Very often in the past, that work took place in silos. To develop a more comprehensive service across all of the agencies, we must examine how we can develop a plan that means that we all consider the part that we contribute to the family or the individual.

As a principle, that is beneficial to the families and the individuals, and it helps to contribute to more productive and better quality services and more efficiencies. We are considering that model in a range of areas.

The Chairperson:
Are you not making his point for him?

Mrs McAndrew:
I agree with the point about multi-agency planning and delivery of services.

Dr Bergin:
There are deficits, particularly in certain services, that another agency could not duplicate. We have to work in partnership with other agencies, but if I am looking for structured psychological therapies within adult services, other agencies will not be able to contribute to that. They will assist with an individual's wider needs, whether that is housing or leisure, but additional services are required.

As I said, we have done a great deal of work on the children's side, but if our next focus is to be on adult services, unless more money is contributed to health so that we can acquire the necessary practitioners and therapists, we will require a significant amount of new resources.

Mr Callaghan:
Given the time frame, it would be helpful if you could give the Committee some idea of what potential additional resources might be required.

I do not mean to put people on the spot, but Mrs McAndrew, you talked about more integration and more universality. However, it is not unfair to say that the Hansard report will show you that we were talking about that happening within the realm of the board's competence.

Dr McShane said —

Mr McShane:
It is "Mr". I am a social worker.

Mr Callaghan:
It would be easier if I were to call you Kieran, because you can call me Pól. The same goes for everyone else.

I cannot comment about other agencies and other services. However, when the officials from the Department were here, they told us that they did not have a clue about what was in the DENI strategy. They explained that that was because DENI had not published its strategy, which was only at the developmental stage. I will not speak for the whole Committee, but when my party colleagues and I hear things like that, we become seriously concerned about the lack of co-ordination.

Fionnuala, I understand what you are saying about the aspiration to co-operate and what you and Stephen were saying about the co-operation that has been going on. We are trying to help you to better achieve your goals by forcing Departments and agencies outside your remit to co-operate with you and deliver services in a better way.

To be honest, I am quite puzzled by the pretext of the board and the Department, which is one of hostility to a Bill that, as far as I can see, is all about helping to deliver services and, in many ways, getting other agencies and Departments to provide assistance to you.

Mrs McAndrew:
We welcome any measures that help us to work more collectively with other agencies. The concern is that we have examples of how we already do that without being forced to do it through a legislative requirement. We do not need a Bill to tell us to work with people and to co-operate with them.

The board will welcome any guidance or strategy that comes forward and helps us in our endeavours to make that a reality, so that we can work more effectively together to deliver more effective services for people. However, having considered the clauses in the Bill, we are not convinced that we need legislation to achieve that.

The Chairperson:
I apologise to the Deputy Chairperson. I got a bit confused because she gave way to let Alex in. I thanked for her that by leaving her out entirely. I will have to go at some stage during this session, and the Deputy Chairperson will take over. If she cannot stay to the end, we have to agree, as normal, on who will then take the Chair. That honour and appropriate remuneration normally falls to Alex, but that is just tradition and custom, it is not a rule. If members are happy enough, Alex will take over if the Deputy Chairperson has to leave.

Mrs O 'Neill:

With the best will in the world, other Departments will always be a wee bit reluctant to assist or to get involved while there is a lead Department. During the debate on the Safeguarding Board Bill, we discovered that having a statutory duty to co-operate is beneficial. I think that that would do no harm, in fact, it will help, and, as Fionnuala McAndrew said, the board would welcome any assistance.

One clause requires trusts to provide data on the prevalence of autism. In your submission, you stated that that was already being done. Among the issues that we have come across is that we cannot get statistics, figures or a breakdown in answer to questions about prevalence that are asked of the Department. Since it was established 10 months ago, I am sure that the network has had that experience. What are the biggest challenges that you face in trying to measure prevalence? What has the network done to address such problems?

Dr Bergin:

All cases of people in younger age groups who present to primary care, educational psychologists and health visitors are now captured in the regional data system via a standardised approach. That data has been collected over the past 18 months or thereabouts. Therefore, children's services are recorded on a regional database, and those statistics are now available.

However, if we consider the adult population, the question is how many of those have presented to health and social care. It is unlikely that all of those individuals present to health and social care, and, therefore, only a proportion of them are in the system. Unless we undertake population-based studies at significant cost, how will we find those individuals, unless they present to health and social care or to another statutory agency? They are hidden. They have needs, but, unless they present to an agency with a diagnosis, it is difficult to ascertain how many there are. .

We can rely on fairly consistent worldwide and Europe-wide statistics that indicate how many people we would expect in each service across the full age spectrum. A population-based study in the adult field, at a cost of tens of thousands of pounds, may be the only way to do that. It has been done in other areas. What would it tell us that those international statistics have not already verified? It would tell us about individuals, but undertaking such a study would cost a significant amount.

Mrs O’Neill:

However, it would be a study of benefit not just to those on the autistic spectrum, because you could —

Dr Bergin:

I would not deny that.

Mrs O’Neill:

Who asked the question of the Minister but could not get any statistics? That was brought up during the debate, but I cannot remember who asked the question.

Dr Bergin:

Incidence statistics are much more reliable than prevalence statistics, the former representing the new cases as they come into the system, because we now capture those as they present.

Mrs McAndrew:

That is only what is known to services.

Mrs O’Neill:

That is obviously important for service planning.

Mrs McAndrew:

Yes.

Mr McShane:

On the issue that Mrs O’Neill raised, another strategy was recently launched that looks at sensory and physical disability. It has been difficult to try to break down those figures. That goes back to the issue of co-morbidity. If a child has, for example, three separate conditions, is he or she recorded three times? We have a broad child health information system database. There are currently codes on that system for: childhood autism, atypical autism, Tourette’s syndrome, Asperger’s syndrome and PDD, which are the conditions addressed in the Bill. That child health information system is under review by colleagues in the Public Health Agency, but it has been in place for the past 20 years. The issue has been one of its applications, but we hope that its existence will provide us with a template and foundation on which to build. It covers all childhood disabilities, not only ASD issues.

Mrs O'Neill:
OK. Thank you.

Dr Deeny:
It is good that we are discussing such an important topic. As I was going to the bathroom —

Mr Callaghan:
Stop.

Dr Deeny:
I should not be saying that, but we go to the bathroom from time to time. However, I thought that, with the carry-on in the city this week, we saw an awful example of how our disabled children are treated by others. We also saw the wonderful public response.

I remember you well, Kieran, not only because you have a good first name, but because you have three children. I hope that they are doing well. The strategy refers to the autism awareness campaign and the autism awareness training. I know that the campaign is simply a public exercise to make people more aware of autism. Perhaps you could summarise some of that.

Obviously, the training is more detailed for those of us who are involved, but it must include everybody. One of the briefing papers highlighted that teachers and health and social care professionals were not mentioned, but training will have to apply to everyone involved, not just those working with children, but those working with adults with similar conditions. What is the difference between the two, and what will it entail? Will the training be a large programme to roll out?

Dr Bergin:
Our priority has to be the diagnostic care pathway, because that will be available to us now. Our priority is to implement that in 2011. We need to ensure that the expert, front-line, senior professional staff receive standardised, high-level, competent training in complicated areas of

work. Our initial priority in 2011 will be to make sure that the cohort of staff in each of the five trust areas who are participating in children's diagnostic work — there are about half a dozen in each trust area — are all competent and fit for purpose to undertake a standard diagnostic care pathway.

The next bit of that work will be to implement the adult diagnostic care pathway. We will work with the Royal College of Psychiatrists and the division of clinical psychology to ensure that adult psychologists and psychiatrists are better able to undertake adult diagnosis. We had a workshop with them in June 2009, and they accepted that there is a lower level of expectation of adult services compared with children's services. Incrementally, over time, we will build up that expertise in diagnosis. Parallel to that, we will scope the need to undertake interventions in the training that practitioners require. If we had a wider range of resources, we would be proposing to undertake a much wider range of training, but we have to focus on the key priority areas in front of us now. Diagnosis and interventions are our focus in 2011.

Dr Deeny:

As a GP, I suggest to the board that each trust is supposed to take a half day every quarter for learning for GPs. I know that the Western Trust stopped for a while, but it has restarted. Autism would be an ideal topic on which to update GPs.

Dr Bergin:

I should have mentioned that all of our 600 or so health visitors undertook a half day or a full day of specific ASD training early in 2009. Across adult services in particular there is a wide range of social care staff, community psychiatric nurses, and psychology and psychiatry professionals. During 2011, I would like at least to ensure that, in your area, for example, in a community mental health team of six, eight or 10 people, at least one or two receive more advanced training. As you probably know, there is very little medical undergraduate, or even postgraduate, training in ASD, and we need to address that as a priority.

Mrs McAndrew:

We will take that comment about GP training on board.

Dr Deeny:

What is the difference between the two? Is the public training simply to make the public aware of people with autism or how to pick up on it quickly in, for example, shops?

Mr McShane:

In our world, the focus is on those front-line staff who come into daily contact with children and families. As Stephen said, we have done some work with the health visitors, but social workers, care assistants, and so on are the face of the Health Service and have contact with the greatest proportion of the population. We need to make them aware of ASD issues and of its particular traits in order to tailor their support and intervention to the individual.

Dr Deeny:

You are talking about the people who work with the kids — the professionals. I am talking about a broader base of the general public.

Mrs McAndrew:

We are talking about the staff who work in universal services and the voluntary sector who may come into contact with those children. You are making the point about a much broader base.

Dr Deeny:

Yes, because many people do not know what ASD or autism is. If you asked them about ASD they could not tell you what it is. It may be an opportunity to send out a message.

Mrs McAndrew:

It is not something that the regional network has taken forward at this point, but we take that comment on board.

The Chairperson:

That ends the second round of discussion, which was on the strategy. We will move on to any other items that members wish to raise in this session.

Mr Callaghan:

I hoped that someone else would go first, Chair. Kieran raised an important issue about a hierarchy of disability. It is something of which we must be cognisant. As I understand the provisions of the Bill, and from reading what the Department said to us at their evidence session, it does not contain any specific financial provision. If there is no financial provision specified in the Bill, it seems to me that you cannot presume that any requirement will be put upon any public authority, including the board or trusts, to skew resources away from, for example, cerebral palsy services into autism services. The statutory duty on the health board, trusts or other agencies is essentially to set out how they will deal with autism through the strategy. I think that, with due respect, it is putting the cart before the horse to suggest that that is a reason not to enact the Bill. In a way, that goes back to the argument about not letting the perfect be the enemy of the good. Over a number of years or decades, future Assemblies may decide that there will be a Bill for cerebral palsy or for various other services. Who is to know? However, the issue before us is whether there should be a Bill dedicated to autism.

The Chairperson:
Mark Durkan would be proud of some of your one-liners, Pól. You have been well trained.

Mr Callaghan:
I promise that they are all mine, Chair.

The Chairperson:
I must say that Pól has encapsulated what many in the Committee are thinking. You say that the system works well, but that you do not want it to work better. It is a philosophical argument that I also find difficult to grasp.

Mr McShane:
As a country boy, I would probably retort with, if something is not broken, why fix it? We have clear diagnostic criteria that state that autism and associated conditions are disabilities. The same criteria apply across Down’s syndrome and whatever. At this point, we are not making any distinctions across those particular internationally agreed criteria.

Mrs McAndrew:
We think that we are working well and are doing everything that we can to implement the action plan. I respectfully suggest that there is nothing in our submission that indicates that we do not want to work better. We always want to work better. The only difference in our submission is that we suggest that the extant legislative provision directs our endeavours in relation to children and adults with autism. That legislative provision already exists. The challenges for us relate to demand and resources, not necessarily to the legislation. That is the crux of what we are saying.

However, I say categorically that we will use every opportunity, all policy guidance and whatever might be the outcome of the Bill to work better. That is our intention.

The Chairperson:

As there are no further points on the generalities, I thank you all very much. It has been quite a long session, and I am glad that members were able to elicit information on the sections of your submission that you did not reach.