Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Briefing on Proposals for Autism Legislation

1 October 2009

NORTHERN IRELAND ASSEMBLY

COMMITTEE FOR HEALTH, SOCIAL SERVICES 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)
Dr Kieran Deeny
Mr Alex Easton
Mr Sam Gardiner
Mrs Carmel Hanna
Mrs Dolores Kelly
Mr John McCallister
Mrs Claire McGill
Mrs Iris Robinson

Witnesses:

Dr Maura Briscoe	) Department of Health, Social Services and Public Safety
Dr Michael McBride	)
Mr Kieran McShane	) Health and Social Care Board
Dr Stephen Bergin	) Public Health Agency

The Chairperson (Mr Wells):

Members should have a draft copy of a Hansard transcript of evidence from the all-party Assembly group on autism's hearing on 17 September 2009, a draft abstract of the proposed legislation and a briefing paper from the Department of Health, Social Services and Public Safety. Members may find it helpful to keep those papers in front of them.

I welcome the team of witnesses. Dr Michael McBride is the Chief Medical Officer and needs no introduction. Dr Maura Briscoe is the director of mental health and disability policy. Dr Stephen Bergin's name has been mentioned many times when the Committee has discussed autism; I am glad to meet you, Dr Bergin. He is the chair and regional autistic spectrum disorder (ASD) network co-ordinator. Finally, Kieran McShane is from the Health and Social Care Board.

I am pleased to give you the opportunity to present evidence to the Committee. I apologise because I may have to leave after you have given evidence, but, if so, the Deputy Chairperson will take over. My leaving is not an insult to your evidence.

Dr Michael McBride (Department of Health, Social Services and Public Safety): I will say a few words before handing over to my colleagues to cover specific issues. We are all justifiably proud that health and social care services in Northern Ireland are delivered to individuals based on assessed need rather than a diagnosis or label, or a hierarchy of disability. As Chief Medical Officer, I consider that to be at the heart of the Health Service, as it should be.

From the outset, the health and social care service values people as individuals and directs resources to meet their individual needs. Those needs are assessed by professionals in consultation with families and carers, and individual circumstances are taken into account. Rightly, we promote equality and the non-stigmatisation of disabilities across the Health Service. As professionals, we are all committed to promoting the provision of services in response to the effect of disabilities or illness.

On many occasions, the Minister has said that mental health and learning disability are two of his priorities, and he has been proactive in addressing the needs of specific autism services. As members will be aware, he commissioned the independent review of autism services to examine and map the existing provision and to ask those involved to make recommendations on where improvements were needed.

Those recommendations were taken into account in the development of the Department's ASD strategic action plan, which was published in June 2009. The Minister also successfully secured £2·02 million for investment into autism services. That money is being invested in the reconfiguration and improvement of front-line services.

It is important to put that into context. Within a two-year period, the Department has gone from the announcement of an independent review to the publication of an agreed, consulted plan on autism, and it has made improvements in autism services. That underlines the importance that the Department has attached to the condition.

The primary aim of the three-year autistic spectrum action plan is the earlier detection and recognition of autism, together with prompt assessment and diagnosis, and appropriate and timely intervention and support for individuals of all ages affected by ASD, and their families and carers.

I have significant concerns about the proposed autism Bill, in relation to the substantive administrative costs that would be incurred and the lack of clarity about how the legislation will operate, given our equality legislation. The proposed Bill could discriminate against individuals with a similar range of disabilities as autism, such as speech, language and communication problems, but who are not on the autistic spectrum.

There is a wide range of autism-related disorders, with individuals requiring different levels of support and service provision. Those on the autistic spectrum may also have associated co-morbidities, such as severe epilepsy, which may be more important than the effect of the autism itself and which may make it more difficult for the individuals to integrate into society.

The proposed Bill could create a situation in which a diagnosis will be sought, or required, to ensure access to services rather than the clinical lead being taken by health professionals. Furthermore, that access to services could be prioritised over and above those with greater need because they do not have a specific diagnosis. Diagnosticians could be placed under inappropriate pressure to make a diagnosis of autism when it is not appropriate, and that could adversely impact on clinical decision-making and, potentially, on care.

I remain to be convinced that the pursuit of autism legislation would improve access to services for those affected by autism in Northern Ireland or their families in any way. Scarce resources would be redirected from front-line services to administrative processes, which could take years to develop across the proposed departmental structures. As the Committee will know, that is contrary to the overarching policy in Northern Ireland that is linked to the review of public administration (RPA), which, as we have discussed, seeks to cut down on administration and target resources to front-line services.

It is not clear that taking the route proposed in the draft Bill would take us beyond where the Department is already going, without the need for the proposed new administration and processes. The Department has been proactive in taking direct action to improve front-line ASD services, and, although more work is required, Dr Bergin and the regional ASD network are driving the implementation of the ASD action plan, and service improvements will be delivered and gaps addressed.

Overall, taking the proposed route of the Bill would be a very expensive and slow administrative approach, and, in my professional view, it is not the answer to a problem that the Department is already addressing by other means. The draft Bill represents an unrealistic challenge to create an unlikely source of help over an undetermined number of years.

Dr Maura Briscoe (Department of Health, Social Services and Public Safety): I will drill down a little into the Department's ASD strategic action plan and link that to some of the areas that are covered in the draft Bill.

The ASD action plan was produced by the Department in June 2009 and was fully consulted on. As part of that consultation, 450 responses were received, and those responses were overwhelmingly in favour of the action plan, which does not include a commitment to legislation. Furthermore, the Welsh ASD strategy, which has been held up as an exemplar, also contains no commitment to create legislation.

As Dr McBride said, we consider that the ASD strategic action plan delivers many of the goals identified in the abstract Bill, and I will drill down into that in a moment. I assure the Committee that the action plan is a living document; it is a three-year plan with a built-in accountability process to monitor the delivery of the actions. Those actions are primarily designed to improve the early recognition and detection of autism, improve assessment and diagnosis, facilitate appropriate and timely interventions, and develop the information and support that is available to individuals and families.

As members can see, the departmental briefing paper lists five bullet points denoting the themes of the action plan. First is the service redesign of existing services and, where appropriate, investment to improve autism care. Secondly, performance improvement includes an integrated care pathway and the development of standards and performance indicators. Thirdly, training and awareness raising has its primary focus on raising awareness in primary care, trusts' staff and families and, particularly, parents so that they understand more meaningfully the early alerting signals in the development of their baby or child. The fourth theme is the improvement of communication and information for individuals, families and carers. Finally, effective engagement and partnership working covers not only engagement across Departments but, in particular, engagement with parents, individuals and carers who are affected by autism, as well as the community and voluntary sector.

If those are matched with the themes in the all-party Assembly group's draft Bill, almost all the requirements are met in the ASD strategic action plan: for example, the draft Bill refers to quality standards, performance indicators, training, appropriate information, family support and, in particular, a regional advocate. Later, the Committee will hear from the regional ASD co-ordinator in Northern Ireland, Dr Bergin.

We consider that the Minister has all the necessary legal powers to ensure that actions are implemented in health and social care and that legislation is, therefore, not required to effect improvement. The Bill's potential to create a hierarchy of disability and the labelling of individuals is a concern. Such an approach is not in the interest of the population of Northern Ireland, nor does it promote equality or social inclusion.

We understand that the all-party group has estimated that the cost of the legislation would be in the order of £2 million or £2·5 million. That is, potentially, an underestimate, particularly when one considers how primary legislation is developed and that each Department would have to carry out a scoping exercise and a review of multiple layers of legislation. Not least would be the cost of the administrative infrastructure that would be required to deliver it. Inevitably, the legislation would require a full equality impact assessment, and, at this juncture, we are concerned about whether it would meet the requirements of section 75 of the Northern Ireland Act 1998.

The legislation required to implement change already exists. The ASD strategic action plan is a living document, and the lead in its regional co-ordination will be taken by Dr Stephen Bergin, to whom I now hand over.

Dr Stephen Bergin (Public Health Agency):
Let me explain my background: I was involved in the independent review of autism services and with the Health and Social Care Board structure, so there is some continuity between my previous work and my current position in the new Public Health Agency. That agency has a regional remit, so I have an overarching responsibility for autism, working with my colleagues in the new Health and Social Care Board.

Around nine months ago, I was tasked with my new role, which is one of a number that I have had to undertake in the agency. As Dr McBride said, it is a work in progress. We are working towards a three-year plan. What I tell you now will change from quarter to quarter and year to year, and we have an action plan to address within that three-year period.

As much as possible, I am careful to listen to parents, and I make an effort to go to see parents and children in their own homes to get a feel for what it is like to live in a family with autism. That has made an impression on me and has had an effect on how we have designed the service and how we intend to progress it. If members look at any of the project documents that I have put together, they will see that the key issue is that we need to put parents, carers and service users at the heart of planning. I am driven to do that. That must be reflected in the project structure. However, we have not yet arrived at that point. I will return to that issue when we discuss the reference group.

The project that we have put together seeks to address the needs of children, adolescents and adults — the full spectrum. We must address the full life cycle of autism, from initial suspicions at primary care level, or by health visitors, through to referrals in trusts. Autism is a cross-cutting issue that is at the interface of many agencies. When I speak to parents, it is not about health and social care issues that they mainly mention; rather, it is other aspects of society and life — for example, education. That needs to be built into the project structure; we are doing that.

As Maura said, we have an action plan to which we can respond. That action plan is the key driver of the infrastructure that has been set up. It will enable regional approaches to be set up, whether that be in diagnosis, referral or treatment. We have gone from a legacy position of 18 trusts down to five trusts. Therefore, there are different care pathways. We aim to standardise that position quickly within the next 12 months. The same care pathway will be in place whether someone is in the Northern Trust or the Western Trust. Parents should have the same experience in all trusts and, in due course, that will lead into the interventions and therapies that are delivered. The action plan clearly sets out the direction in which we must go.

The project structure is not simply about working with the trusts and health and social care agencies. We are careful to make sure that other agencies are brought in, but, as I said, it is a work in progress. We work with the Department of Education (DE), the education and library boards, the Department of Culture, Arts and Leisure (DCAL), the Department for Employment and Learning (DEL), the Department for Social Development (DSD), and, no doubt, we will work with other agencies such as the Probation Board and the Police Service of Northern Ireland. A regional project structure is in place, with regional subgroups to examine various themes in the action plan. That is a work in progress, and there is much work ahead.

It is not simply about new resources. There is £2·02 million in place, and we must consider the legacy of investment that has been put in place over the past 10 years. Several million pounds is already in place and has been dedicated to ASD and the wider childcare services that my colleague Kieran McShane will talk about. It is about re-engineering the existing infrastructure and topping that up with incremental benefits from the new investment that will be put in place.

The reference group is another element. I have been referred to as the “regional co-ordinator and advocate”. Parallel to me, but separate from me, Lord Maginnis has been identified as the regional advocate to champion the voices of parents, carers and service users, and to link in with the voluntary sector. Lord Maginnis is part of the infrastructure, and he will nominate parents, carers and service users to all parts of the regional development process. Therefore, it will be a joined-up process among parents, carers, service users and the statutory agencies.

We will submit a progress report to the Department, quarter on quarter, provide an annual report and reappraise the action plan and our progress and position by March 2011. We are in no doubt that we will not resolve all the issues within that timescale; for example, it may take a number of comprehensive spending review (CSR) cycles to address the full spectrum of needs.

Mr Kieran McShane (Health and Social Care Board):
Good afternoon. My name is Kieran McShane. I am a social worker and not, thankfully, a

doctor. I will give a brief outline of the existing commissioning and planning frameworks in children’s services and their applicability to supporting children with autism. I was the commissioning lead for children with disabilities in the old legacy organisation, the Southern Health and Social Services Board.

Although the area of children’s services planning focuses on children’s needs, it also recognises that the needs of children with disabilities are unique, individual and diverse. They require a continuum of provision and services throughout all partner agencies. The concept of the whole-child model, which acknowledges that there should be a range of provisions for children, such as access to universal services and specialists, supports the principle of acceptance and focus on the individual. Children’s needs, their families and their own uniqueness underpin a needs-led, early-intervention and outcome-focused planning model. That focus on continuous service also allows an ethos of early intervention, with the exception that children and families need change; therefore, support is required to change with them.

The principle of putting the child at the centre has been underpinned by ‘Families Matter: Supporting Families in Northern Ireland’ and the adoption of the family support model in Northern Ireland. That was based on the model that has been used by children’s services planning.

Another area that was highlighted in the overview report on children and young people is that of sharing inspection reporting in child protection services responsibly. That demonstrates clearly that there is an ethos and willingness for agencies to work together, despite the fact that, at times, we all speak different languages. There is a need for common processes to share and understand information. The report notes the applicability of that recommendation across all children’s services.

In 2007, work was undertaken across a number of agencies, both statutory and voluntary, on the implementation of a single assessment model: understanding the needs of children in Northern Ireland (UNOCINI) model. It allows for a common framework for the identification of pathway planning for children who are in need; that includes children with a disability. There are clearly defined mechanisms for referral, planning and review of services in partnership with families and within specific time frames. The importance of families is also emphasised in the links between UNOCINI guidance and the Carers and Direct Payments Act (Northern Ireland)

2002 in acknowledging the needs of carers, adults, siblings and young carers.

In the former Southern Board area, all stakeholders, parents, young people, agencies and disciplines that deal with children with a disability have established a joined-up method of working that is based on the experiences of children and young people with a disability in their families, under a banner that we define as Wraparound. One vital area of learning from that Wraparound process has been the identification of key themes and concerns across a range of disabilities; issues such as access to early-years services, respite, young carers' support, transitions, and speedy processes for medical and therapeutic provision that are not diagnostic-specific.

There is some way to go towards providing the best service for children, adolescents and adults with a disability. However, existing legislative commissioning and partnership processes have evolved, and continue to evolve, in the progression of our aspirations and goals.

The Health and Social Care Board also acknowledges the work that has been undertaken by the Children with Disabilities Strategic Alliance, which brings together all organisations that work across the children with disabilities sectors. The group — I believe it comprises more than 30 voluntary sector agencies — has undertaken work to develop its manifesto. Its stated position is to ensure that policy that impacts on the lives of children and young people with disabilities is informed by their needs and circumstances.

We can talk about frameworks and models, but the reality for families is their experiences. I want to share my personal experience of that reality. I am a parent of four children, three of whom have been diagnosed with special needs. One child has autistic spectrum disorder; one has speech, language and developmental difficulties; and one who has Down syndrome, with associated sensory impairment.

I have spoken to many families. My situation is not unusual as regards dual diagnoses and other disabilities. The issues for my family are the same as those that have been identified through the Wraparound process, as well as the importance of looking to the future, those children's needs and families' worries. The needs of the siblings who do not have a disability are also important and how the needs of their siblings affect their lives.

I feel strongly about those issues. They impact on my family and others. I do not see how any specific legislation on autism will impact on, and change, that situation at present. As a parent, both ethically and morally, I would have great difficulty in saying to one of my children that, although he or she could have the Rolls-Royce of services, the rest would have to wait until there is diagnostic-specific legislation to meet their needs.

I have four children, each of whom is unique and special. None of them is known by a diagnosis. Each is known by his or her name and individual identity. I am convinced, professionally and as a parent, that the current route, which is needs-focused and not diagnosis-led, is the right road towards delivering for my children and for other families.

The Chairperson:

Thank you, Mr McShane, in particular for your personal insight, which has been very useful. I will ask some questions, after which I will hand over to the Deputy Chairperson, as I am afraid that I will have to leave the meeting at that point.

I notice that you made very little, if any, mention of the autism advocate. The action plan and legislation are not mutually exclusive. There is no reason why the action plan could not be brought forward and carried through by your advocate, and the services that you envisage could be provided, albeit with legislation.

People representing autism have forcefully argued that autism has a unique set of circumstances. It is a complex condition that involves so many statutory agencies that the only way to deliver effectively for the needs of the estimated 20,000 people who are affected is through legislation and giving an advocate the role to ensure that it is properly implemented. It has been put to us that we are not dealing with a “normal” condition. I hate to use that word, but it is the only one that I can think of. Many people feel that sincerely.

We have had many letters, e-mails and phone calls from parents who are caring for autistic children and who feel that this is their best opportunity. Funding is also attached; when cuts and the results of the comprehensive spending review arrive, those will give some protection to ensure that there is adequate funding to treat a large number of young people. That point has been made, of which I am sure that you aware.

I do not understand the logic of saying that there is an action plan. The action plan can continue whether or not legislation is in place. Many would argue that the action plan would be much more effectively implemented if there was legislation. We need to deal with those points.

Dr McBride:

Stephen Bergin is, I would argue, our advocate and co-ordinator at a regional level as we implement the action plan. My fundamental concern about the legislation is that it seeks to address a problem that we are already addressing through the action plan: the establishment of the ASD network and the appointment of a regional network co-ordinator.

Aspects of the ring-fenced funding to which you referred may have a perverse effect. Currently, there is different funding for different programmes of care. Dr Bergin may mention that in his answer.

Dr Briscoe:

Is there a need to spend millions of pounds on legislation when the contents of the draft Bill are already part of the action plan? Individuals may ask that question. We do not need legislation to carry out that role. We believe that regional ASD co-ordination involving other agencies that we have put in place, which translates down into local co-ordination, is better than the infrastructure that is proposed in the draft Bill.

I reiterate Dr McBride's comments; it is inappropriate to label people, particularly given that autism is a spectrum disorder with mild to moderate levels of severity on that spectrum and on other co-morbidities. It may be that other issues such as phobias, anxiety and depression would be predominant.

To ring-fence money for autism would raise the question of how people would access the extensive investment in respite care, speech and language therapy, to name but a few. The action plan is committed to prioritising the issue.

Dr Bergin:

We have started to develop some of that cross-agency working. Only this morning, Kieran McShane and I were in discussion with a representative from the new education and skills authority (ESA). Even though the ESA, technically, will not go live until 1 January 2010, we talked about joined-up training across the respective sectors. The strategy is already live, and we are making some headway with it. I am tasked with working with other agencies, so, as things stand, I am already doing that work, and I intend to expand it.

Mrs O'Neill:

I am aware of the work of Wraparound; it is an excellent project. However, the problem is that that project was not replicated across all trust areas. That fed into the reasons for the review in the first place. It was recognised that there was a lack of services.

I suppose that those who are lobbying for the autism Bill have fears about strategy as opposed to legislation. Strategy means that, if other priorities come up, perhaps autism work will take a back seat. That is a genuine fear. Will you tell us whether, for example, some of the £2·02 million that has been allocated to the strategy could be redirected to another area that the Department might deem to be a higher priority? Has that money been ring-fenced for the autism strategy so that it cannot be touched?

The action plan recognises that cross-departmental working and co-operation are important. Am I right in saying that there is no policy mechanism to ensure that that happens? The plan might state that Departments such as the Department of Education, or the Department for Social Development, which has responsibility for housing, must feed into the strategy and work together. Is there a policy mechanism to ensure that that happens, because there are genuine concerns that cross-departmental working is more of a tick-box exercise and that it will not happen in practice?

Your briefing paper mentions that you do not want to create a hierarchy of disability; no one on the Committee wishes to see that happen. You also said that the proposed Bill will not promote social inclusion. Has the Department done any work with bodies such as the Equality Commission to find out how they would feel about such a Bill?

Dr McBride:

I will start with the concerns about a strategic approach versus legislation. Strategy is about action and making things happen. That is what we are doing at the moment. We have a strategy document and an action plan, and, as you have heard from Stephen, we are taking actions. We are making every £1 of that investment, along with the current investment in the service, work by reconfiguring services and ensuring that we standardise them across Northern Ireland in the way in which you mentioned. It is much easier to do that now that there are five trusts and an integrated health and social care system, which is unique in the UK.

Legislation presumes that, somehow, there are obstacles in the way of progressing a strategy. The engagement is demonstrable. Stephen described the way in which the regional group represents all community and voluntary sector organisations; each trust now has a nominated director who has lead responsibility for autism services in the trust area; all trusts have a co-ordinator to liaise with the Departments; and DEL, DCAL and DSD and the Department of Health, Social Services and Public Safety are represented around the table. There are examples of good collaborative working in practice as well as in the action plan. I am confident that not only do we have buy-in and commitment but that it is a living process and that progress is being made.

As to whether we need to do more to ensure better cross-departmental working, I will let Maura tell you what the Department is doing to ensure that that happens.

Dr Briscoe:

I reiterate the point that the action plan has a built-in accountability process. We will, therefore, expect the new Health and Social Care Board, through Stephen's regional group, to account for those actions, the timelines for which are set out in the action plan. A clear accountability and monitoring arrangement is, therefore, in place.

Members are familiar with the departmental priorities for action for 2009-2010, in which ASD is clearly specified as a priority. There are plenty of examples of cross-departmental working: the Chief Medical Officer mentioned the issue of ASD, and the Bamford review has a cross-departmental action plan on mental health and learning disability. Therefore, the infrastructure exists to address the issue of ASD cross-departmentally.

Another example of cross-departmental working is the work that is done to address domestic violence and sexual violence. Therefore, there is plenty of cross-departmental working without the need for legislation.

We have not engaged with the Equality Commission specifically on the abstract of the Bill, because that is not the Department's document. However, we took preliminary legal advice on the basis of the abstract. Although it is difficult to comment on any abstract, the legal advice highlighted the need to promote equality of opportunity under section 75 of the Northern Ireland Act 1998. If we were to pick out one area of the abstract for examination, it would be the unique access to services. If a child with autism has a unique access to services, where does that leave a child with a learning disability whose needs may be very different?

Mr Gardiner:

I thank the departmental officials for their presentations. Can you deliver on the abstract of the Bill without legislation? Can you deliver that service? At a previous Committee meeting during which Autism NI gave evidence, I spoke about the issues of budgeting and the costs. How much will it cost to deliver the legislation that Autism NI outlined at that meeting? Do you have those figures to hand? I hope that I am not embarrassing you.

(The Deputy Chairperson [Mrs O'Neill] in the Chair)

Dr Briscoe:

It is very difficult to cost the legislation based on the abstract. Delivering the primary legislation will involve the following: the policy to be developed and consulted on; the legislative process through the Assembly; further consultation on the policy; policy development in, probably, every Department; and every Department scoping the policy against their extant legislation. There also needs to be public consultation on not only the equality impact assessment but the policy and the legislation.

The cost of the administrative infrastructure across all Departments and the advocate post were estimated at approximately £100,000. However, we believe that the cost of delivering the administrative infrastructure alone will be intense. We think, therefore, that the sum identified is probably an underestimate.

With regard to health and social care, we believe that we can deliver what is in the abstract. Obviously, we have concerns about the unique access to services, so we will not support that approach. We think that the ring-fencing of funding identified in the abstract may not always be to the advantage of individuals.

Mr Gardiner:

What is the timescale, if you had to go through all those loops and jump all those hurdles?

Dr Briscoe:

That is a very good question. To develop the policy — and I am not sure what that policy might look like — would take a long time, and it would need a public consultation. We are working on, and coming to the Committee with, a single Bill on mental capacity and mental-health legislation. The basis of the Bill is to promote individual decision-making, regardless of what the underlying cause of mental impairment may be. That Bill, and all its processes, is unlikely to be introduced before 2011.

Mr McCallister:

I declare an interest as a member of the all-party Assembly group on autism, although I may come at the subject from a slightly different angle than others in the group. I will stick to the same line of questioning that I had for Dominic Bradley and Arlene Cassidy. During the autism debate, the Minister made it clear that, from a Department of Health, Social Services and Public Safety perspective, he did not feel that he needed any further legislation, and that has been reiterated today. Others were questioning the fact that a private Member's Bill is being introduced in England by a member of a party to which I would be linked. The difference is that that legislation is more about having better record keeping from local authorities.

Dr McBride said that we have a very different health and social care structure here. Do you think that we are better placed to work with the strategy? I like the fact that the strategy is a living document. If we legislate, are we fixed absolutely to that legislation? I assume that, if the Minister wanted to change a strategy, or if the Committee wanted the Minister to change a strategy, it could be done relatively quickly, as opposed to changing legislation if it turned out to be poor or if some people were falling on the wrong side of the line. Will you illustrate the difference in the time frame between those two approaches?

Dr McBride:

I will make a few brief comments and then hand over to Dr Briscoe. You are absolutely correct. The strategy informed the action plan, and the action plan will change, as Dr Bergin said, as more evidence becomes available across the CSR, and, as we move into the next CSR, the action plan will continue to be refined. Many of the tasks in the action plan are already completed and some are under way.

Legislation can be amended if necessary, although the process can take longer than amending an action plan and agreeing — in a health economy the size of Northern Ireland — that some priorities are now greater than others and that that is where we should be targeting out finite resources.

The English local government and central government arrangements are very different, and Maura will talk further on that.

Dr Briscoe:
As I understand it, the English legislation, which is a private Member's Bill, is being introduced because the Secretary of State cannot compel local authorities to map and carry out the data collection that is required on autism. We have an integrated health and social care system here, and a key action in the ASD action plan is to try to improve the mapping and data collection in our systems. The mapping and data collection has already started, and it is of fundamental importance. I must emphasise that we are not comparing like with like; this is a completely different way of achieving delivery in completely different circumstances.

Dr McBride:
Again, it is back to the question: what is the problem that we are trying to fix? The Secretary of State for Health in England, as I understand it, does not have the powers to direct or require local authorities or, indeed, councils, to collect the information that is required. In Northern Ireland, our Minister has the power to obtain that information from the trusts, the Health and Social Care Board and the Public Health Agency. Those are different powers, and the difference is critically important.

Dr Briscoe:
When I mentioned the Secretary of State, I meant the Secretary of State for Health in England.

Mr McCallister:
The proposed Bill requires the establishment of an autism strategy, which would bring England into line with us; it would be playing catch-up with our system.

I want to ask a question about linking in with Departments, because there is a concern about getting everyone to buy into this. Are you confident that you can achieve that, given that there are huge differences of opinion? I know that Dr Bergin was on the Maginnis review team. You successfully changed some teacher-training policies and had some new modules added. What is happening with the Department of Education strategy? There is a big debate about the Centre of Excellence for Autism in Middletown. How do you shape and design a policy when, it seems, some Departments are responding in a different way to yours?

Dr McBride:
Perhaps Dr Briscoe will answer that question, and Dr Bergin will talk about specific aspects of the working relationship.

Dr Briscoe:
It is early days yet for the regional ASD group, but a commitment exists. We have written to other Departments and have received feedback from them and their agencies. It is important to recognise that this is about implementation as well as everything else. It is right to say that some of those matters are linked. I am aware that the Department of Education is conducting a consultation on the proposals that have emerged from the review of special educational needs and inclusion. The regional ASD group is trying to promote integrated ways of working and producing assessments.

Dr Bergin:
The involvement of the Department of Education is the most important element, although there are interfaces with other agencies and authorities. I am pleased to say that this process started six or nine months ago, and I am working with the education authorities at a very high level. One of the designated directors of the new education and skills authority is part of the process; that individual has nominated senior educational psychologists and education officers to sit throughout our entire project structure.

There are about 10 different elements of the project structure, and senior Department of Education officials are represented at each of those levels. They are on all the individual local forums of the trusts. We want to streamline the service provision model between education and health and social care, in the trusts and in localities. We want to ensure that not only is the local service joined up but that the same arrangement applies in Belfast and in the other trusts. There is a job of work to be done, but the right people are involved. The director, whom I mentioned earlier, will reciprocate in due course and ask for board and agency representation to join the new education and skills authority when it is up and running in the new year.

I hope that we will get good, joined-up and robust models between education and health and social care. In due course, we will ensure that that is communicated to the people who really matter — parents, carers and service users. We must resolve issues, work through care pathways and referral criteria, and ensure that our information is evidence-based in all localities. I will need time to work on that, after which I will report back on progress.

Dr McBride:

I will ask Kieran McShane to comment on the involvement of education professionals on the diagnostic side, which is just as important.

Mr McShane:

There has been an extensive history of working together at an operational level. One area of good practice that we have considered is, ironically, in the Southern Trust, but we hope to transfer that across the rest of the region.

The advantage of DE staff being involved with DHSSPS at the diagnostic stage is that children are subjected to one process and are not meeting numbers of professionals. That also means that children are identified early to both services and that joint planning can take place very early. The relevant DHSSPS and DE ASD services have a long history of working together, and they offer joint training ventures, particularly on Asperger syndrome.

Mrs I Robinson:

Without being rude — and I take what you said, Kevin, as a man experienced in having children who fall into some of those categories — with the greatest respect, the difference between us is that we are elected, and you are not. We are reflecting the real desires of families with children within the autistic spectrum. Many of us have been involved with Autism NI for a number of years, and I pay tribute to that organisation for trying to push this issue up the agenda. I am delighted that, regardless of your reluctance to consider legislation, at least you are here and talking about what they would like.

Was anyone from Autism NI on Lord Maginnis's reference group and did they have an input? If not, why not? A document or an action plan is exactly that: a plan. There have been many well-intentioned plans: 'The Way Forward'**,** the Appleby review, and so forth. However, they are just plans, and health turns out to be a postcode lottery. That is exactly what we do not want.

We want legislation because it will highlight and target the real needs of children across that whole spectrum. If it is good enough for Hillary Clinton to push in America, it is, with the greatest respect, jolly well good enough for elected representatives in Northern Ireland to push it. The Committee's minutes of evidence of 17 September, which must be considered realistically and honestly, state:

> "Equality issues that are related to autism are based on a lack of understanding of ASD as a social and communication disability. Autism is neither a learning disability nor a mental-health condition. Consequently, the unique needs of people with autism are not addressed or recognised in disability legislation."

Maura said that we are labelling people with autism. We label people with a disability in the Disability Discrimination Act 1995, and no one is putting their hands up and saying that we cannot have anything else with a name to it.

I am concerned that politics are being played out here; I say that with deep regret. Many of our colleagues from the Ulster Unionist Party, Sinn Féin and the Democratic Unionist Party went to America, and we all signed up to pushing the agenda for people who are practically tearing their hair out looking for help. It is so different right across the Province.

In one area, some help will be available, but, in others areas, there is no help at all. This is not simply a health issue; the DHSSPS is the lead Department, and we are asking all the other Departments to take responsibility for the issue in their own target areas.

Your dismissal of the potential of a Bill is very negative. If you are saying that legislators should not make legislation because the process is too lengthy, we would have absolutely no legislation. Every Bill will take time, and every Bill must go through a long and painful process.

In Northern Ireland, we have to go through much more consultation with various interest groups because of section 75, which increases bureaucracy. However, we have been charged with the responsibility of representing constituents who want legislation for autism. It is imperative that we all do our best to facilitate that. If we approached all issues negatively, nothing would ever be done. How do the witnesses view ASD when it does not fall into the category of mental health and is not classed as a disability? If you do not recognise that ASD is a social and communication disability, what are you saying that it is?

Dr McBride:
I apologise if anything in our evidence came across as negative. All we were seeking to do was to ensure that there was informed discussion on a very important issue. The Minister has indicated that ASD is one of his top priorities along with mental health and learning disabilities, and we wanted to give our views on that and answer members' questions. There was nothing negative intended in our contributions.

Our concerns centre on whether the proposed legislation furthers the issues and challenges what we are trying to address, such as a better standardisation of diagnosis and early intervention, support and care for people affected by autism, their families and carers. Or does it deflect both our energy and resources from implementing an action plan that will make a difference to front-line services and the experiences of patients, service users and families? That is the question on which we are seeking an informed discussion today.

As a professional, I uphold underpinning principles with regard to healthcare and the NHS. Those principles include access to services based on assessed need and the promotion of equality of access to those services. I have significant concerns that the impact of the need for a diagnostic tag to provide unique access to services may be detrimental to individuals with more severe learning disabilities or communication problems who may not have been diagnosed with autism. There is no more poignant example of that than the one that Kieran McShane shared with us.

As was discussed on the proposals in England and as was mentioned with regard to the United States, the circumstances and needs are different in different jurisdictions, because there are different healthcare structures, healthcare economies and powers available to authorities. We need to acknowledge that. Our present assessment is that we do not need the proposed legislation to improve front-line services and ensure better standardisation of care for service users and their families.

We went through an extensive process of consultation and involvement. We conducted an independent review, and Stephen will talk about the degree of interaction and involvement with a range of stakeholders. We had a strategic document that was published and was consulted on between September and December 2008. We had an action plan that went out for consultation, and we had over 450 responses. From that process, and from the range of workshops that were held across Northern Ireland, we have had a very engaged process.

If we look back to the responses that were received about the action plan, they were, by far and away, completely in support of the strategic approach. Perhaps Stephen will outline the degree of involvement of a range of stakeholders in the process to date.

Dr Bergin:

My intention is to work with as many people as possible, particularly service users, parents and carers. Whether or not we have legislation, I am doing that, anyway. That drives the process. It is the absolute matter on which we must deliver. My intention is to make sure that parents, carers and service users shape what the service provision model will be in due course — this year, next year and thereafter.

I keep myself separate from the rights and wrongs of any proposed legislation because my task is to deliver on the action plan. I have spoken to a sizeable constituency across all five trust areas, and I do not think that I heard one person say anything about an autism Bill and what I need to be doing. They have asked me to look at issues such as the referral process, weekend services and summer schemes — matters that I can resolve with cross-agency working. I am getting on with it anyway, and I have the means and resources at my disposal.

Mrs I Robinson:

With all the input that you have from the various groups, was Autism NI represented?

Dr Bergin:

In the present infrastructure?

Mrs I Robinson:

No, when Lord Maginnis was dealing with the plan.

Dr Bergin:

I cannot answer that; I was just a member of the process. You would have to put that question to Lord Maginnis.

Mrs I Robinson:

Can anybody answer that?

Dr Briscoe:

Are you talking about the reference group?

Mrs I Robinson:

Yes.

Dr Briscoe:

The reference group will predominantly be the interests of users, carers and families, as I understand it.

Dr Bergin:

I thought that you were talking about the independent review because those were the words that you used.

The Deputy Chairperson:

I think that Iris was referring to the independent review group that was established.

Dr Bergin:

The member's first question mentioned the reference group, and her most recent question mentioned the independent review, which are two different things altogether. The reference group is the current process whereas the independent review took place in 2007-08.

The reference group is led by Lord Maginnis. It is a separate but integral part of the process. Lord Maginnis was identified by the Department to assist me in being an advocate for parents, carers and service users. He started his engagement in that process during the summer, but I have been involved in the process for about nine or 12 months.

Mrs I Robinson:

I am just trying to get to what the make-up of the group is.

Dr Bergin:

As things stand, the reference group is Lord Maginnis. He has just initiated that piece of work. He does not have a reference group as such — his task is to establish the reference group. In the terms of reference, it is his task to identify parents, carers, service users and voluntary sector representatives to engage with me and become constituent parts of the project structure. He only began that process a matter of weeks ago.

Mrs I Robinson:

I find all that quite strange. The fact that Lord Maginnis belongs to the same party as the Minister does not go unnoticed. For the record — and I apologise for the words that are used — I will let you know just how well Lord Maginnis is doing. This is an e-mail to David Heatley, who is the vice-chairperson of Autism NI. He had been in communication with Stephen to try to ascertain what was going on and why things were slowing up. Obviously, there is a lot of interest in seeing what will happen when the Minister makes his decision. In response to one of the e-mails that David sent in an attempt to find out what was going on, Stephen sent the following:

> "David, let me be clear: I am bloody hard to bully, so do not even try, to my face or, as you seem to prefer, behind my back. I am still waiting to hear Ken's proposals."

The Deputy Chairperson:

I do not know that it is in order to read that out at a Committee meeting.

Mrs I Robinson:

It is important to make people aware of the mentality of those who are supposedly looking after the welfare of the children in our community who suffer from autistic spectrum disorder.

The Deputy Chairperson:

With respect, we are all interested in improving the lives of everyone with a disability. We are talking about autism today. I have allowed you enough leeway, and other people want to come in.

Mrs I Robinson:
I am happy to stop there, but it is important to put on record the attitude that has been adopted.

Mr Easton:
I am surprised by the officials' response. This has not been the straightforward evidence session that I expected, and, indeed, it has thrown a few spanners in the works. Will you confirm that the £2·02 million is DHSSPS money rather than money from other Departments?

Dr Briscoe:
Yes; our Department secured that additional resource through the comprehensive spending review.

Mr Easton:
It will cost £2·5 million to set up everything that is proposed in the Bill. I assume, from what has been said, that that cost will be split between other Departments as well as the Department of Health, Social Services and Public Safety. Therefore, extra money, on top of the initial £2·02 million, will go towards ASD.

You said that the proposed Bill will duplicate some of the work that you are doing under the action plan, but there is no need for duplication. The Bill and the action plan would run side by side, so it will be easy to establish whether something has already been set up. There will be no reason for duplication, and money will not need to be spent on work that you are already doing. Indeed, your action plan will be enhanced by extra money that will come from other Departments out of the £2·5 million. It will be extra money, because there will be no duplication.

Your action plan will not be jeopardised by its running alongside the legislation. If anything, the Bill will provide extra resources for the action plan because it will bring in money from other Departments, which you are not doing. I do not accept the argument that there will be a duplication of resources.

Have you expressed your concerns about a duplication of resources to the all-party Assembly group on autism, and, if not, why not? It is late in the day for you to come to the Committee and say that there will be duplication without having spoken to the relevant all-party group. It would be somewhat worrying if you have not gone to the all-party group, which is the source of the proposals.

I take it that the Minister is also opposed to any legislation on ASD. I do not accept the argument that other health areas will not be treated to the same standard if there is legislation on one issue. The impression has been given that related conditions will not receive the same level of recognition or support, but I do not accept that at all.

I do not accept that the legislation will highlight autism or make it better served than any other medical condition. Why can the two not run hand in hand? It is a way to obtain more resources from other Departments to enhance the situation. Moreover, you should have spoken to the all-party group by now.

Dr McBride:

The fundamental question is: is the legislation necessary to improve services in Northern Ireland? Our considered opinion, which I have shared with the Committee today for its consideration, is that the Minister does not require legislation to implement the action plan. The resource has been sufficient to implement the action plan already.

In its own right, legislation does not improve front-line services or experiences for individual service users, families or carers. Investment in front-line services, better co-ordination of services and standardisation of services does improve experiences. That is the aim of the action plan. I am concerned that the introduction of legislation will deflect energy, resources and valuable time. Actions would still need to be put in place, such as those used in England to develop a strategy and an action plan that underpins it. Northern Ireland has sufficient statutory and legislative powers to ensure that we direct finite resource to achieve meaningful improvements in services for users, families and carers.

Dr Briscoe:

I have attended the all-party group on at least one occasion. I have not been invited to discuss the Bill. We first became aware of the £2 million, which is considered the appropriate resource, during the discussion at the Committee meeting on 17 September. Given that the Bill is an abstract, it appears that considerable resource, including that to commission a regional agency, will be put into administration. A regional agency would have a considerable administrative infrastructure that spans all Departments, and nominated leads would have a considerable infrastructure. We want money to go to front-line services rather than to administration. I am happy to talk to the all-party group.

Mr Easton:
It seems to be OK in England. The all-party group said that extra money would come from other Departments. It suggests that £2·5 million would be required. Is it not better to request a meeting with the all-party group and work together to cut out the bits that cross over? In that way, the legislation could proceed at the same time as the action plan. I am not knocking the action plan; I am sure that it does a good job. I do not dispute that it has received support.

In the past couple of weeks, I have received numerous e-mails from parents and organisations asking me to support the autism Bill. Although the action plan is going ahead, parents and carers do not seem to be totally satisfied with your way forward and are looking for something on top of that. That suggests that they are not quite happy at the moment. That needs to be addressed. You need to have a meeting, whether you are asked or not; perhaps you should write a letter to Dominic Bradley about that. If the Bill goes ahead, there is an opportunity for extra moneys to be made available. Different Departments and organisations should be working together, whether a regional agency is established or not, and if is extra money is available for health, you should grab it before you lose it.

Dr McBride:
The question is: what is the need for legislation? If the assessment is that the Department and Minister have all the relevant legislative powers, as we have indicated in our evidence, why would we deflect time, energy and resource into taking forward legislation? The purpose for which the legislation is being introduced in England is already in place here. My concern is that, at a time of significant financial constraint, of which we all need to be mindful, we would be deflecting resource into administration and cross-departmental processes, rather than taking that resource and using our collective energies to improve front-line services. On the basis of my understanding of the situation in Northern Ireland, there is no necessity for legislation. However, what we in this Chamber all share, as do all the other stakeholders in Northern Ireland, is a desire to move forward urgently to progress the improvements in service that we all accept need to happen.

Mr Easton:

The legislation —

The Deputy Chairperson:

Sorry, Alex, you have had two opportunities to speak. Other people wish to speak, and we are running out of time. Alex suggests that the Department speak to the all-party Assembly group on autism to try to find a way forward. Perhaps you will consider that.

Dr Briscoe:

The abstract of the draft Bill mentions:

> "a managed ASD infrastructure with joint financing arrangements."

To my mind, that is predominantly an administrative arrangement. That is already in place; why would we need legislation? Although we are moving away from the main points, the abstract also states that autism is a set of conditions that:

> "necessitate a unique degree of access to services across the Departments of Health, Education, Employment and Learning, Social Development, and Culture Arts and Leisure."

The pivotal point is that we should be promoting equality among disabilities and not a hierarchy, so that one label or diagnosis is given a unique access to services.

I recognise that a triad of factors is taken into account in diagnosis, including social inclusion, communication and behaviour, but that does not mean that all people with autism are affected by all of those. Multiple other conditions are also affected by those factors.

Mrs Hanna:

I found the discussion very helpful, because I am trying to understand why the proposers of the Bill feel so strongly about it and to compare it with the action plan. The issue is delivery, and I suppose people feel that, if it is enshrined in legislation, it is more likely to be delivered. We have been reared on everything being put in writing and in legislation. I can understand that that is where they are coming from and that that would demonstrate a stronger commitment. There are so many competing priorities, and we are all aware of the budget implications of every decision we make.

The action plan and the proposed Bill contain matching themes. However, I am not sure what is missing from the action plan. You talked about accountability and timelines. I suppose that what is missing is a guarantee that something will happen and that people will have access to services.

Is autism a unique condition? Many of my questions concern diagnosis. At present, a paediatrician makes a diagnosis. As Kieran McShane said, educationalists are now involved as well. Many of the complaints that I have received concerned waiting lists for a paediatrician, in particular from people with young children who appeared to be a bit disturbed or withdrawn, and they had real concerns about what was causing that. Dr McBride spoke about the difficulties and pressures of diagnosis. I do not understand: is autism difficult to diagnose and is that part of the problem?

Dr Bergin talked about the groups with which he works. Although we say that autism is not specifically a health issue, it seems that a health model is being used, and that has budget implications. In my view, almost 50% of the model concerns the Department of Education and other Departments and agencies.

What power does the Minister have over mapping and data collection? The fact that we do not have data is an issue. In so many ways, the situation is vague. The figures that are bandied about are not as precise as they should be. Autism has been discussed for several years, but there seems to be little specific and accurate data. It is essential that we have that data.

Dr McBride:

Autism is difficult to diagnose. I will ask Stephen to talk about the difficulties with diagnosis, whether this is simply a health model, and the mapping and data collection, which are important issues and a challenge in England. I will ask Maura to address the question about accountability — delivering on the action plan, the priorities for action target and accountability arrangements through the board, the agency and the trusts.

Mrs Hanna:

Perhaps you could talk about diagnosis, given that there are difficulties with that issue.

Dr Bergin:

In some cases, autism can be extremely hard to diagnose, and, in other cases, it can be very easy. It does not necessarily follow that the more obvious cases are easy to diagnose. A spectrum condition does not manifest in the same way; it can be diverse. The symptoms and signs are not unique to autism. Autism might account for one quarter of a disability, but a range of other syndromes and conditions shares many of its features. The problem lies in distinguishing between them.

A GP or health visitor working in primary care might pick up on developmental delay, but that presentation is not unique to autism. It takes intricate skills to identify the specific features that a paediatrician and a multidisciplinary team will endeavour to identify. A GP or health visitor will not necessarily see a case of autism; they will see a developmental delay or a problem with communication, which will then be referred to the generic community paediatrician — the GP paediatrician in the trust — who deals with everything. That GP will ascertain the key suspicious features and, in turn, will bring in the multidisciplinary team and a higher level of expertise. There is a graduated approach.

In some instances, especially with a child around the age of two, three or four, autism is very obvious; in other instances, it is not so. Ideally, all cases should be identified as early as possible, around the age of two, three or four. However, higher functioning autism is less likely to present at that age; it is more likely to be ascertained around the age of nine, 10 or 11. If autism is not diagnosed early, it can be diagnosed in adulthood. Therefore, there is no singular process by which a diagnosis can magically be made on a patient's third birthday. Indeed, there is no singular diagnostic or psychological test that will pick up all cases of autism. It is quite complex.

Dr McBride:

The perception is that the action plan is very much a health model.

Dr Bergin:

Kieran McShane has already referred to that process. The ambition is to create a joined-up strategy between DHSSPS and the Department of Education, and that is already live. We want to make educational psychology an integral component of the diagnostic team in each of the five trusts. Kieran has already spoken about how that works in the Southern Trust model, and it is the Department's aspiration to introduce that across the remaining trusts.

The Department wants to create a multidisciplinary diagnostic team with several specialists from a diversity of backgrounds, including paediatricians, child psychiatrists, speech and language therapists, occupational therapists and educational psychologists. That would allow the patient to be assessed by people from different backgrounds who could carry out different profiles and psychological tests. That team effort would make diagnosis easier.

Currently, diagnosis can take a few months. In some instances, diagnosis can be made as soon as the patient walks through the door, but it is more likely to be several months before a confirmed diagnosis is made. The process of diagnosis can be difficult, and, at its most complex end, it could take two or three years to make a confirmed diagnosis. However, that would be unique in its own right. By and large, more than 90% of patients are diagnosed within three to six months from the point of referral from primary care. Indeed, the priorities for action target for diagnosis is 13 weeks from the initial point of referral.

Mrs Hanna:
Will you provide some more detail on mapping and data collection?

Dr Bergin:
In relation to practitioners and cases, we do not have a register of individuals with autism that goes back over decades, but we have begun to track that in the past two years. The education sector has had a database of that nature for several years, and the Department has access to that data. That database shows that there are 797 children with autism in the education sector. Ideally, we would like to map that database, replicate it and use it for planning. That would allow the Department to map services for the future so that adult services could be planned for younger children when they reach their mid-teens to late teens. In short, the Department does not currently have the database that the Committee has described, but it is its ambition to establish one.

The Deputy Chairperson:
Is there a target in the action plan to compile that data?

Mr McShane:
Legislation was put in place in 1995 and in 1997 with respect to children's service planning. That legislation means that children and their needs must be assessed before those needs are examined.

Children in need are a concern, and that category is widely defined. However, in the legislation that deals with children's services, a child with a disability is clearly determined as being a child in need. That child's needs may be met by a range of services, but each family is different. A child who has a high level of complexity may have a great deal of support from its parents or siblings, while a child of lesser complexity could have a more common disability or its family may not be able to care for that child in a way — *[Inaudible.]* Therefore, the service provided must reflect the needs of the child in any given family. Those children may be on different places on the spectrum, but when one applies the concept of where that child is in the child model that I discussed earlier, one must be able reflect the fact that services are targeted at need.

The needs of children with autism, like children with any other disability, change as they evolve. Social activities, the transition from childhood to teenage years and puberty, and access to situations that other young people can access will also change. Those issues are relevant to children with Asperger syndrome, and they must be examined.

Previously, the Department has not been good at co-ordinating issues across five trusts, or through the old legacy boards and trusts. We now have one Health and Social Care Board to examine good practice across the five trusts and to ensure delivery. As a commissioning organisation, the board will not be able to have five different models exercising five different services to children across Northern Ireland. That is clearly not in the interest of children and families; neither is it in our interest.

The issue of disabilities will be reviewed. Such debates do not apply only to the issue of autism but to other disabilities. There will be change, and, I hope, the template for the autism model and plan will provide the template for other disabilities.

Mrs Hanna:

The problem is that a diagnosis seems to be necessary to access services. There is a debate around diagnosis and labelling, but we are told that there is much unmet need from people who are not diagnosed. If those people do not have a diagnosis, it is difficult for them to be signposted onwards.

Dr Briscoe:

I am happy to send the action plan to the Committee. We have a referral pathway, and we recognise that people need support even without a diagnosis. The support does not start when somebody is diagnosed; early support is needed to get information and to assist the individual as well as parents and carers. That is an important point: in our model, support should begin when the suspicion or early identification of need arises, not when the diagnosis is made.

The first action in the plan, under the theme of service redesign, is to establish the current level of ASD provision, complete service mapping of ASD services, and so forth. In drilling down through the plan, one will see aspects that relate to the establishment of baselines on waiting times. That relates to our priorities for action on the targets for waiting times between assessment, treatment and care.

We have not yet discussed the important issue of ASD in adults. By far the largest group that responded to the consultation were adults with ASD.

Dr Deeny:
How independent was the independent review panel? Did it have certain limitations? I am shocked that we cannot be told whether Autism NI was involved in the review. I would be even more shocked if Autism NI did not have an input into the independent review. It would be worthwhile knowing whether it had an input.

Arlene Cassidy from Autism NI gave evidence to the Committee two weeks ago. She said highlighted a weakness and a serious limitation in a single departmental action plan. She stated:

> "In addition to that, the report commissioned by the Committee for Health, Social Services and Public Safety, 'Autism Spectrum Disorder Services', categorises current single departmental initiatives as not holistic. Lord Maginnis of Drumglass, in his evidence to this Committee in his capacity as chair of the independent review of autism services, recorded the serious impediments that his review experienced and the future implications of the lack of co-operation among Departments."

Does that expose a weakness and suggest that the review was limited?

At that meeting, I mentioned Baroness Pitkeathley. When she introduced the Second Reading of the Autism Bill in the House of Lords, she stated:

> "This Bill is an excellent example of how relatively small changes in legislation can make huge changes in the lives of people with disabilities and their families".

If that is not the case, why would she say so? With all due respect, Kieran, several families have told Committee members that they need an autism Bill. You have experience of autism in your family, but that is what the families tell us as their elected representatives. Why are the vast majority of families, through Autism NI, saying that they need the Bill? I assume that those families have seen the strategic action plan, but they maintain that the Bill is right for them and for their families. Why did Baroness Pitkeathley make such a positive comment about the Bill?

I return to the independent review: how independent was it? Is its weakness not that it was carried out by a single Department and that, according to its chairperson, it faced serious impediments because of a lack of co-operation among Departments?

The Deputy Chairperson:
There are many autism groups other than Autism NI, and I am sure that you agree that all of them should have a role to play in the new reference group.

Dr McBride:
I will ask Maura Briscoe to respond first, after which Stephen, who was involved in the independent review, will outline its membership. I hope that that will provide Kieran Deeny with assurances about its independence. Kieran McShane will cover the input from families and carers, which, as everyone agrees, is vital.

Dr Briscoe:
The Deputy Chairperson made my point for me: potentially, several autism groups in the system have different views to Autism NI. I also stress that other groups have an interest in autism. There are, for example, several excellent learning disability groups in the community that will have a view. Other disability groups may also have a view.

In response to Dr Deeny, the predominant issue raised in response to the public consultation was adult autism, not legislation.

Dr Bergin:
The panel comprised six members, with Lord Maginnis as the chairperson. Professor Rita Jordan is an eminent, world-renowned professor and is president of Autism NI. Professor Michael Fitzgerald is from Dublin, and I am a consultant in public health and public health agencies. Heather Crawford is head of speech and language therapy services in the Southern Trust, and Sandi Hutton is a senior consultant community paediatrician from the Western Trust.

The chairperson would have to tell the Committee about anyone who was consulted thereafter. I should not do that on his behalf. I was a constituent member of the review team, and it was an independent process. Any further questions would have to be directed to the chairperson.

I have already stated that the action plan and the network group are recent establishments. I have spoken to Autism NI, and I spent a morning and an afternoon with people from that group in recent months, as I have with other autism groups in the voluntary sector in Northern Ireland. I have made a considerable effort. My phone number has been available, and my door was open to those voluntary groups at any time in recent months, and they know that. They can get hold of me any time of the day or night. I have been not only been to the groups' head offices, but I have been asked to attend local meetings and have done so, often at short notice. My door has been open to anyone in the voluntary sector.

The Deputy Chairperson:
Kieran, if it would help, perhaps the Committee could ask the Department to provide some information on how the members of the independent review team were selected, because that question has been asked a few times. Perhaps the Department would provide us with that information at a later date.

Dr Deeny:
The other question that has not been answered was about the chairperson's comments on a review based on a single Department not being holistic and that he felt that there was a lack of co-operation among Departments. Does that not illustrate a weakness, or a severe limitation, in the review? We have all mentioned the fact that it is a cross-departmental issue. It covers a wide range of issues, not only those to do with health.

Dr McBride:
I do not have the exact quote in front of me, and I do not wish to take the quote out of context. That would mean that I would have to interpret your reference. Perhaps it referred to cross-government working in other jurisdictions. Mention was made of the much smaller, established process that is in place in Northern Ireland, through which we work across government on a range of issues. That is how we can bring about real and meaningful improvements to all the services that we provide for the population of Northern Ireland.

I add the ministerial group on public health to the examples that Maura gave. Through that, we all work across government under the aegis of the Investing for Health strategy, which is a cross-government public health strategy. It is vital that we work in that way. There are many good examples in this jurisdiction of strong and productive cross-government working. I have not seen that quote, and I do not know its context.

The Deputy Chairperson:

I quoted it in the Chamber. He was speaking about his review and how he found it most challenging to get Departments to work together. That is the context in which he was speaking.

Dr Briscoe:

The independent review contains a recommendation on increased levels of co-operation between Departments and agencies, and we feel that, in the way that we have set up the regional ASD network, we have tried, in the spirit of that recommendation, to promote co-ordination between Departments and agencies.

The Deputy Chairperson:

That was quite a lengthy session, but it was important to exhaust all our queries. We are committed to considering the issue further and, perhaps, to talking to other people. I thank you for your contributions.