Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

Mental Capacity (Health, Welfare and Finance) Bill

16 November 2011

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Ms Michelle Gildernew (Chairperson)
Mr Jim Wells (Deputy Chairperson)
Ms Michaela Boyle
Ms Paula Bradley
Mr Mickey Brady
Mr Gordon Dunne
Mr Mark H Durkan
Mr Sam Gardiner
Ms Pam Lewis
Mr John McCallister
Mr Kieran McCarthy

Witnesses:

Ms Catherine Harper	)	
Dr Paschal McKeown	)	Mental Health and Learning Disability Alliance
Ms Liz Main	)	
Ms Ursula O’Hare	)	

The Chairperson:

I welcome the representatives of the Mental Health and Learning Disability Alliance who are here to discuss the Mental Capacity (Health, Welfare and Finance) Bill. They have submitted a briefing paper, which is straightforward and comprehensive. I want to welcome, to say fáilte romhaibh to, Ms Ursula O’Hare, the Law Centre (NI)’s assistant director of policy and publications and chair of the Mental Health and Learning Disability Alliance; Ms Liz Main, a communications and public affairs consultant with the Royal College of Psychiatrists — we seem to have had the Royal College of Psychiatrists in a lot this past wee while, and I suspect that the situation will not become any different; Dr Paschal McKeown, an information and policy manager at Mencap; and Ms Catherine Harper, a peer advocate with the Irish Advocacy Network.

I invite you to make a presentation, after which we will take questions from members. Jim has indicated that he wants in first, and he will be followed by Kieran.

Ms Ursula O’Hare (Mental Health and Learning Disability Alliance): On behalf of the Mental Health and Learning Disability Alliance, I thank you for inviting us to give evidence as part of the Committee’s preliminary briefings on the proposed Mental Capacity (Health, Welfare and Finance) Bill. We welcome the opportunity to embark on what we hope will be a process of engagement with this Committee by members of the alliance as the Bill comes to you for important scrutiny next year. However, given that we are not yet at that stage and do not have a Bill before us, we hope that it will be useful today to confine ourselves to what we consider to be some of the important issues for the legislative process going forward and to make some observations on what we see as the key things that the Bill should achieve. We hope that we will be able to come back and talk to you when we have the meat of the Bill in front of us. This afternoon, we will split our formal presentation between me and my colleague Catherine Harper, after which all four of us will field questions. That is the harder bit.

I know that time is always important, but I will very briefly give you a little of the backdrop to the alliance. The backdrop to the alliance, as it is to the whole law reform project, is very much in the Bamford Review of Mental Health and Learning Disability (Northern Ireland). The alliance came together after the Bamford review, essentially as a means for all of us with a very deep commitment to the implementation of the Bamford review — from carer groups, user groups and the voluntary and community sector and professionals — to share our collective expertise on the issues affecting all those who will be impacted by this legislation. We are a broad coalition. We are committed to the development of effective, modern, ethical mental capacity law that will make a positive difference. That is our raison d’être. Members have a diverse range of expertise and particular focus on issues, so they will be very well placed to brief you on a range of issues.

We have been part of the Department of Health, Social Services and Public Safety (DHSSPS) reference group that has been looking at developing policy on this, and we are very grateful for the opportunity afforded to us by that process. As you know, when it finally clears the legislative process, this Bill will be the biggest piece of social legislation that the Assembly will have enacted — though I know that Mickey may say that that could be the Welfare Reform Bill. So, we do not underestimate the challenges that are before us. We have said this a lot, but it bears restating: the opportunity that is before us is, genuinely, a once-in-a-lifetime opportunity to craft law that will make a positive difference to the lives of all those affected. For that reason, it is important that the Bill that ultimately comes before the Committee next year meets those expectations.

The Committee knows that the need for this legislation is to fill a legislative vacuum in relation to capacity law. Scotland, England and Wales have already enacted such legislation. The Mental Capacity Act 2005 is capacity legislation to protect the rights of those who lack decision-making capacity. We have been lagging behind. The need for the introduction of capacity legislation coincided — probably by serendipity rather than by careful planning — with the Bamford review's final recommendations on developing new mental health legislation. In a sense, it opened up the space for us to do something truly innovative and world-leading: to create a genuinely single Bill that will regulate and provide safeguards for the care and treatment of all those who lack capacity, whether because of mental illness, learning disability or other reasons, perhaps those associated with the ageing process, such as dementia, or acquired brain injury.

What the Bill will do — I know that the Committee had a briefing from the Department — is establish a framework of protections for those who are directly affected by the legislation. It will also provide a framework for decisions about the care and welfare of those who lack capacity for all those involved with them, so that will include professional colleagues and others in the voluntary sector.

I will now pass over to Catherine, who will give you an insight into what we consider to be the key issues that bear some thought at this stage, given that we have yet to see the detail of the Bill. I will then say a few words in closing.

Ms Catherine Harper (Mental Health and Learning Disability Alliance): The important thing about this Bill is that it has the potential to affect everyone, not just those with a mental health need or an intellectual disability. It will be not simply about health issues but about finance and welfare as well. It establishes a statutory presumption of capacity, and that capacity is decision-specific. We feel that, with a presumption of capacity, the capacity legislation will de-stigmatise as it no longer concentrates on labels. A single Bill with common safeguards, it means that all those who lack decision-making capacity will be treated on an equal basis under the same legislation. The Bill should create a framework within which decisions will be made about care and treatment for all those who have been deemed to lack decision-making capacity, regardless of whether that is because of an intellectual disability, a mental health need, acquired brain injury or a condition often associated with the ageing process, such as dementia. It will clearly affect a wide number of people and also their families and carers.

Diagnosis can have a profound effect. It becomes a stigmatising and damaging label. Instead of being an individual, a person is labelled, for example, schizophrenic. In my work as an advocate, the stigma of mental illness is one of the biggest hurdles to empowerment. Capacity legislation and, in particular, the single Bill could reduce that stigma, prejudice and discrimination. Such an approach will finally break down the stigma that is emblematic of the experience of people with mental health and intellectual issues. That is why it is critical that the Bill is genuinely a single Bill and offers the same degree of protections and safeguards to those affected by the new legislation. Safeguards, such as support for people to exercise their autonomy, advocacy and access to reviews of decisions, should be reflected in the principle. My colleagues can talk to you about the importance and potential impact of the Bill for some of the people who may be affected.

It is often said, but it is a truism, that the devil will be in the detail. We cannot comment on the detail at this stage. However, in respect of what we would like to emerge next year, we feel that it is important that we get it right. In terms of taking the measure of this legislation, when it emerges, we will be looking to see a Bill that is principles-driven. The four Bamford principles of autonomy, justice, benefit and least harm should be the four cornerstones of the legislation. That means that the legislation should provide an interpretative function for the principles and give them life and meaning in their translation into the substance of the Bill’s provisions. For example, the principle of autonomy should translate into supporting people to exercise their capacity to make decisions that affect their life, whether through appointing a nominated person or an enduring power of attorney (EPA) or through supporting people with communication difficulties to express their views and exercise their capacity about a decision that affects their life.

The Bill needs to be internally coherent — genuinely, a single Bill — if it is to be what the Department has termed a world leader in its innovation, with robust safeguards and protections for all those affected. Some members of the alliance have expressed concerns that the Bill should not create perverse incentives; for example, that advocacy services are directed at those subject to the Bill or community services to those subject to a community order under the Bill.

We want to see an engaged and meaningful consultation on the full Bill when it emerges. We want to see work commence on a code of practice, as that will be critical to guide the implementation of the new law among people who work with those affected. Preparation for the new legislation should start now. There should be training programmes to build the attitudinal change that will underpin the delivery of the new approach reflected in the legislation, and that should be coupled with public awareness raising.

Ms O'Hare:
Those are the broad headlines of what we consider to be the key issues that need to be considered. I am conscious that the Department briefed the Committee in October, and it has already given you an outline of the broad skeleton of the Bill. However, I want to close our formal remarks by saying that it is important that law does not sit in a vacuum. In reforming the law, it is critical that we do not lose sight of the need to build access to the very best services. Within the alliance, we want the very best legislative framework, but we also want services that will respond in a holistic way and centre on the person. In closing, our final message is that the law does not and should not sit in isolation and in a vacuum. I am happy to field questions to our panel if there is anything that you want to come back to us on.

The Chairperson:
Thank you, Ursula and Catherine. I agree with everything that you said about ensuring that it is holistic and that it is about capacity and protecting people. When we looked into this issue initially, we realised quickly that under-16s, for example, were not included at the beginning of the process. The Department said that it had met with the Children's Law Centre and that it was now of a mind to ensure that under-16s were included. I am very keen that they are included and

that that work will be taken forward.

At the same time, we have just had a quick discussion about people in the justice system. Again, I feel that it is incumbent on us to ensure that nobody is left out or left behind and that we have a piece of legislation that encompasses our most vulnerable people and people whose own life experiences may have shaped their mental capacity. We recognise that there are also those with acquired brain injuries. More people are surviving accidents and falls. They are surviving the physical side of things, but the brain injury can take an awful lot more work. It can be, and often is, with them for the rest of their life. Therefore, I am anxious that nobody is left out of this. Where are we with the under-16s side of things, in particular?

Dr Paschal McKeown (Mental Health and Learning Disability Alliance):
You are right: that is an important issue. For some members of the alliance, it is certainly a very live and important issue. There is a range of views within the alliance. However, the view on which we hold true is that children and young people who come within the legislation should have the same safeguards as everyone else in the legislation.

Ms O'Hare:
We understand that the Department is reviewing the policy on that, and we look forward to working with the Department and feeding back thoughts from our members. However, we are conscious that the Children's Law Centre has met the Department to discuss the issue.

The Chairperson:
The Department has indicated that it is of a mind to look at it, but we are anxious that pressure is put on it from a number of directions so that we can ensure that nobody is left out.

Dr McKeown:
We do not want anyone to be in a worse situation after the legislation than before it. Clearly, children do enjoy some protections under mental health legislation.

The Chairperson:
It does not make sense to me that a huge piece of legislation such as this could be brought in around protections and capacity and exclude children. Why would that even have been considered in the first place?

Dr McKeown:

I think that you would have to ask the Department that. There is no doubt that assessing the capacity of children is a complex issue. How would it be done? What process would you use? Speaking more from Mencap's position than from that of the alliance, I think that there must be compliance with the United Nations Convention on the Rights of the Child (UNCRC), which does not put an age on capacity but looks at the age, the ability and the level of understanding of a person or child. That is Mencap's position.

The Chairperson:

I know children who are very sophisticated and very astute. They know what they want, though they do not always get what they want — obviously, for the right reasons much of the time. However, children know what they want, and they know what they do not want. It is very important to include them.

Mr Wells:

Obviously, the alliance is a who's who of those involved in mental health provision in Northern Ireland, both voluntary and professional bodies. Is there anybody who is not in your group and should have a seat at the table, as it were? Do you encompass the entire field?

Ms O'Hare:

As you say, it is a broad coalition. We are always looking at other organisations that might have an interest in these issues. For example, there are issues associated with the ageing process, such as dementia, and the Alzheimer's Society is represented. The alliance very much has an open door. I cannot think whether there are any other organisations. Liz, do you want to come in on this?

Ms Liz Main (Mental Health and Learning Disability Alliance):

I think that some organisations may not have joined for internal reasons of working out who is who or whatever. I do not think that there is anyone who is in stark contrast. Perhaps there is the Long Term Conditions Alliance and those sorts of people. We are very much a mental health and learning disability alliance, and the legislation will apply to a huge number of other people. It could apply to anybody sitting at the table and possibly will. It would be very valuable to seek opinions from groups that are looking at things from a perspective other than that of mental health and learning disability. The British Psychological Society is not on the alliance, not because of any fundamental differences but simply because it has not joined for its own reasons. There may be other voluntary sector organisations that have not joined because of logistical reasons, and they may want to have a voice.

Mr Wells:

I ask that question because I am probably the only one here who is old enough to have been here when the previous legislation went through in the mid-1980s. At that stage, all those involved — a lot fewer than there are today, I assure you — got together as one unit and produced a joint paper encompassing the sector's views. That meant that the Committee that I was on, which was called the health and social services Committee in those days, was able to have a relationship with one individual whose job was to liaise with the Committee and to give the views of the voluntary sector. That saved a huge amount of time. At end of that process, we, therefore, had the sector's joint view, an alliance view. I hate using the word "alliance" — I get spooked every time I hear it.

Ms O'Hare:

When the alliance meets the Alliance Party, we have those conversations.

Mr Wells:

It is an unfortunate title, but anyhow.

That meant that a huge number of issues were sorted out. The Committee then either accepted or rejected the consortium's views. Most of the time, it accepted them. It was a loose consortium; it was not organised. That left us to deal with the issues that nobody could agree on, and there were actually very few of those. There was little divergence between the various sectors. Is there a possibility of that happening this time?

Ms O'Hare:

There is a broad range of organisations involved in the alliance. We have been working hard to analyse the policy proposals as they have been emerging and to look at where we share common ground. I am very conscious that there is a range of expertise around the table, and if we have the opportunity to talk to the Committee again, depending on which particular issue the Committee wants to explore, there may be different people sitting where I am sitting now. I certainly hope that we can be a helpful resource for the Committee in the scrutiny process, given the extent and breadth of the expertise within the alliance. I hope that we will have the opportunity to come and say, “This is the alliance’s view on x and y”.

Mr Wells:

You said that this is the largest social legislation. I think that it will probably be the largest legislation — full stop. It is, therefore, a major minefield for us to tread through.

Ms O’Hare:

It is a major piece of work.

Mr Wells:

It would be so useful to have a unified view and a spokesman to give the sector’s view instead of our having to plough through 30 or 40 different submissions, which are all saying basically the same thing at the end of the day. I suppose that we are asking the voluntary sector to do some of the spade work on our behalf.

Ms O’Hare:

We are working very hard on that.

The Chairperson:

I think that we need to be careful to ensure that minority voices are also heard.

Mr Wells:

I agree.

The Chairperson:

I welcome your question, Jim. I would have thought that dementia services would be listed there and that NIACRO (Northern Ireland Association for the Care and Resettlement of Offenders) would be a useful organisation to have on board. However, we are not presuming that people were not included. The more people on the alliance, the better it will be, because that will help us. We want to ensure that the Department and the Committee are also doing their bit. We are not expecting the Mental Health and Learning Disability Alliance to do all the work. Your focus will be very important. However, I would not ask you to go away and write it, because that is not your responsibility.

Ms O'Hare:

It is important to echo the point that there is a range of voices, all of which must be heard. This is very important legislation. It is important that the range of voices is brought to bear.

Mr Wells:

I accept that there will be those whose views are not encompassed in any overall document and that they have to be given the same right to articulate their views. However, it would be helpful if there were consensus on major issues that everyone could sign up to. Have you, as a group, given any thought to how you will manage what is going to be a very complex process for you, as it will be for us?

Dr McKeown:

We do not have a plan as such. However, I can certainly talk from our organisation's perspective. There is absolutely no way that Mencap, on its own, has the expertise to deal with the range of issues involved. So, we certainly value the expertise of the other alliance members. That has actually helped to inform our position on a range of issues.

As you said, the process is about agreeing where we have issues in common that we can stand over and be firm on. It is also about identifying the issues on which organisations or interests take different but valid perspectives. The alliance offers the opportunity for a greater understanding of where the differences and commonalities lie. To some extent, we have been responsive to what the Department has produced. When the reference group was there, the alliance would have met to discuss the issues and the policy positions that the reference group brought to our attention. That is the way in which we have worked in the past.

Mr Wells:

Have you worked up a unified view on the issue that the Chairperson raised about the under-16s and those who are in custody, young offenders and so on? Is that the common position held by the alliance?

Dr McKeown:

There is a diverse range of issues around children. The alliance has been able to understand better what the different positions are.

Mr Wells:
And the Department of Justice?

Ms Main:
Again, we really want to see what is being proposed. It is incredibly complex. Do you want to set up barriers to people if they are refusing treatment while knowing what the problems and implications of that may be? That would be truly autonomous. People would take one view or another on that. We would like to see what is being proposed and how it is being proposed, because it is difficult to just extend it. I am not saying that it is wrong to just extend it. However, because of that, the alliance has not been able to say absolutely to blanket it in or blanket it out.

We do not want to get legislation that is pushed through for the sake of the timetable, without justice being considered and looked at properly. One of our main points is that you have to get it right. That may mean holding this up to include justice or deciding not to include justice, but do that in a proper decision-making process, where you look at it all and work out how it gets included. It is better to hold up the Bill and get it right than it is to rush things through. We really want to see what is being proposed on justice, which we acknowledge will be a complex area. Scotland drew the line on it and said that it was a little too hard, but just because Scotland did that is not a reason for us to do so.

Mr Wells:
Hear, hear.

The Chairperson:
You probably find yourselves in an invidious position. You are the Department’s reference group in its drafting of the legislation, but the Committee looks to the alliance and its members for help in its scrutiny of it. Therefore, it is important that you are autonomous of both organisations so that you can give us the proper advice and support. There will probably be things on which you disagree with the Department that you will wish us to bring forward. This is a huge and challenging Bill, but if we do not get it right it could be 40 years before the next piece of legislation on the issue is brought forward. Many people will fall into the mental health and learning disability bracket in that time. We cannot afford to make a single mistake in this

legislation or to leave anybody out.

Ms Main:

We would like to see what you are able to do and whether you can put pressure on the Justice Department to catch up. That would be very helpful.

The Chairperson:

We have done a bit of work on that by speaking to the Justice Minister and the Chair of the Justice Committee, as well as its members, some of whom are here. I am keen. We had a bit of juxtaposition, because the Department wrote to say that it was putting the Mental Capacity (Health, Welfare and Finance) Bill off until the end of the mandate, and we wrote back stating that we do not want to lose the Bill and that we need to bring it forward. So, we are arguing that it should be brought forward, but in a way that includes justice. We still do not want it to be pushed back, because, as you know, if we do not get it through and signed off in the current mandate, we will be into another consultation period and all sorts — a new mandate and, possibly, a new Minister. We need this to be done now.

Mr McCarthy:

That is exactly right. This Committee and those in the alliance will be dedicated to doing it. As has been said, it will be a world-beater. It is in all our interests to get it right and to go for it now. I was encouraged by what Jim and the Chair said about justice catching up. I will certainly do what I can in that regard. My policy is that, together, we can do it, do it right and have this small place of Northern Ireland being a world leader.

I also congratulate you on your name. *[Laughter.]* I am delighted to hear "alliance" being mentioned over and over again — keep that going.

I have three questions, which you can answer separately as they are quite lengthy. My first question relates to your paper. I strongly support the full implementation of the Bamford review — I always have done since it was published — and endorse the principles-based approach to the legislation. Will you describe in more detail the importance of the four principles mentioned in your document and how those can be enacted in the legislation?

Ms O'Hare:

The principles should really be the four cornerstones of the legislation. As an alliance — there is the "alliance" word again — we have been clear that the principles need to be upfront in the legislation, as Catherine mentioned, because they should guide decision-making under the legislation. It is not simply the principle of autonomy that should drive and underpin the legislation. That should be done by the four principles of autonomy, justice, benefit and least harm. Although they should be in the Bill to guide the decision-making of the actors who are charged with implementing the legislation, what we really want is for life to be breathed into those principles. We want meat to be put on the bones, so that the detail of the Bill — the devil really is in the detail — reflects and gives meaning to those principles.

We spoke about the importance of the principle of autonomy, but we also see the principle of benefit as critical. We have suggested benefit as opposed to best interest, because the Bill is about driving attitudinal change and changing mindsets, and language is important. Members of the alliance have expressed the view that the term "benefit" conveys a sense of objectivity, whereas "best interest" conveys a sense of paternalism. It comes from England and Wales's Mental Capacity Act 2005. Bamford did not pluck the word "benefit" out of thin air. We feel that language matters in driving attitudinal change. We want the principle of benefit to be articulated clearly in the Bill.

There is also the principle of least harm, which is about minimal intervention, and the principle of justice, and Liz might want to say a word about why that matters to us.

Ms Main:

People sometimes confuse justice in the Bill with criminal justice; it is certainly not criminal justice. People also sometimes ask why you need justice to be in the Bill when there are lots of equality laws, human rights laws and everything else. Well, there are two reasons for that. The first is that, in a less than ideal world, all those laws could be repealed, so you want justice to be built into this law. It really should be stand-alone legislation as far as justice is concerned. The second reason is that it reminds everyone all the way through that they are dealing with vulnerable people and that they must be fair. It is about fairness, and that needs to be in the Bill. It would be wrong to say that it is superfluous and take it out.

Mr McCarthy:

So, in your opinion, it is important, perhaps vital, that those four principles are contained in the work that we are involved in.

Ms O'Hare:

We would like the legislation to be built on those four cornerstones, if I apply a building analogy.

Mr McCarthy:

During the evidence session with the Department a few weeks ago, I raised the issue of implementation with respect to training and the need for the code of practice to be produced at the same time as the legislation. I would be interested to hear more about your take on that area. For example, what measures will be required, over what period of time, and with how much estimated investment for all the appropriate people to obtain the necessary training? Will you also comment on the required change in attitude to which you refer?

Ms O'Hare:

Sorry, sometimes it is hard to know who is best placed to answer which questions.

Ms Main:

A lot of the training is going to be for professionals, and a lot of it is about attitude, which Paschal might be able to talk about. I do not see why the training should not start now. We know that it is going to come in and that there are capacity requirements internationally. We may not have the letter of the law and the absolute finessing of it, but there is absolutely no reason why every medical student, nursing student, social work student, occupational therapy student and those in continuing professional development should not be told that we are going to be doing things in a different way and that they should start thinking about it now. They should be told about the things that they will need to think about and the things that constitute capacity, albeit it will probably not be the letter of the capacity assessment. That should really go on the syllabus as of next year, I would say. That would cut down enormously on the need to have a long implementation period.

How much is it going to cost? Who knows? It will depend on how they go about implementing it. An enormous amount of it will be about attitude and understanding, not just saying that you will think this way but letting people understand why they are doing something differently. It is vital that the code of practice is there from day one so that we do not get into the situation that we had in England, where the code of practice did not come in until 15 months after the legislation was enacted. It is vital that that is ready to go. I know that our organisation and, I am sure, other professional and voluntary sector bodies, would be very willing to peer-test and road-test some of that as soon as it is available.

Ms Harper:
I work in the home treatment team in Belfast. The individual has very little awareness of what is happening, and I think that it is important that the person who is going to be affected by the legislation is given some information.

Dr McKeown:
The point that Catherine made is a really important one. It is important to start the training of the professionals who are going to be involved. In relation to learning disability, that might be about understanding learning disability itself or about understanding how people with a learning disability can be assisted to make decisions. Training on communication would give greater understanding of how people communicate their wishes and preferences. That can be done now. It does not need to wait for legislation. Catherine’s point is very well made. We should not forget that people with a learning disability, or other groups who may be affected by the legislation, also need information and training on the new legislation, as do their family carers.

One of the big barriers that the Bamford review identified as preventing people with a learning disability and people with mental health problems from exercising their rights was a lack of information and knowledge about rights and a lack of support to be able to enjoy their rights. The legislation gives a real opportunity to put that right and to make sure that, if doubt is created about my capacity to make a decision, even when that doubt is there, I get assistance so that I can be assessed properly and can contribute to that process, and, if it is deemed that I lack capacity, I get the right support through that process. That has to happen, in some senses, now.

It is about attitudinal change, but it is also about how we do things. We do not know the cost, but the training has to happen anyway, so it should be built into professional practice. It is really important not to forget those who are affected by the legislation. They too need to benefit from the training and knowledge that is out there.

Mr McCarthy:

You have the wee bit of benefit of knowing what happened across the water. You can pick up from what happened there to avoid that.

Finally, I have a question about data and benchmarking. You point to current gaps in statistical data collection. Will you indicate what types of data that you feel need to be collected in the future and how that would benefit taking the legislation forward? Will you also say a bit more about why benchmarking is so important in monitoring the possible increase in the use of compulsion, perhaps with examples from other jurisdictions?

Ms Main:

Trying to get your hands on information about exactly who is detained in Northern Ireland is very difficult. All that we really know is that, overall, the numbers have been coming down a little bit. We have women and men detained, and the information is broken down into whether they have a mental disorder or learning disability. There is nothing beyond that. The numbers are not even given trust by trust. There is, therefore, a huge gap in knowledge about what is happening at the moment.

We need to do a basic benchmarking exercise, so that we know where we are now. Someone should probably do a study of the mental health population and look at who is detained now, who is informal and who is being treated in the community, for instance, and those people should be assessed to see if they have capacity or lack capacity. They should be assessed to see whether it is likely that they would come under the legislation and the interventions that they may be getting. If that was done, you would have an idea of where we are now, and you could, perhaps, forecast where we would be if the legislation was to be implemented as expected.

When community treatment orders were introduced in England and Wales, it was forecast that 600 people a year would be affected. In fact, there were 3,000 people in the first year, because, once the legislation was there, it was implemented rather freely. All that they really know is that most of the people who are coming under the legislation are from ethnic minority communities. At the moment, we do not have a large black and ethnic minority community here. That may change. The likelihood is that, were it to change, you would see the pathway to care being a compulsory pathway for those people more frequently. It may be for ex-offenders. It is about knowing what demographic is under compulsion and being able to track that demographic to make sure that legislation is not being unfairly applied to some people. I guess that is where the justice principle would come back.

Dr McKeown:

We have very little data on learning disability in respect of children and adults and, in particular, mental health interventions. We have very little information around learning disability or even around the kinds of decisions that are being made — whether they are made every day or whether the interventions that are being made on people's behalf are significant or serious. I think that we need to look at the populations that are likely to be affected by the legislation, and we should have a baseline now so that we can measure the changes and the impact of the legislation in five or 10 years, for instance.

The Chairperson:

Kieran, I will bring you back in at the end, if that is OK, because you have had quite a bit of time and I want to be fair to everyone. Gordan is next, so you might want to nip out, John, and come back, if that helps.

Mr Dunne:

You are very welcome. We welcome the opportunity to meet groups such as yours at this early stage.

The new legislation will provide for a capacity-based approach to all decisions relating to health. What is meant by that? Does it mean that it will be a broad approach looking at all aspects? The emphasis is on "capacity-based".

Ms Harper:

It is the capacity to make decisions that might affect the individual. It is a two-stage test: a diagnostic test and a functional test. I think that the Department was looking at a way of using that test to decipher whether the person has the capacity to make decisions.

Mr Dunne:

So, it is in relation to individuals.

Ms Harper:

Yes.

Mr Dunne:

There are obviously major gaps in the Mental Health (Northern Ireland) Order 1986. Will you summarise those? There was quite a bit of mention earlier about the fact that one of the cornerstones is justice. Does that imply that there is injustice at the moment?

Ms Harper:

I will mention one. The Mental Health Order has the nearest relative provision. You do not decide who the nearest relative is; it is decided for you. It is quite flawed. The new legislation, however, proposes that the individual will say who their nominated person will be. It is about being given choice, in advance, to make decisions, whereas the current Order does not allow for any kind of forward planning.

Mr Dunne:

There are obviously a lot of gaps.

The Chairperson:

The nearest relative might not be the person who you feel will have your best interests at heart.

Ms Harper:

For example, there was a case where a child was abused, and the nearest relative was the abuser. It is totally flawed at the moment.

Mr Dunne:

Do you think that a lot of issues need to be addressed?

Ms Harper:

Certainly, the empowerment and autonomy issue needs to be addressed. It is very important to the people who I meet that they have the autonomy to make decisions rather than the paternalistic situation whereby we decide for them.

Mr Dunne:

A lot of people are unable to make the decisions.

Ms Main:

That is where supported decision-making through the nominated person in the form of advanced planning will come into play. This legislation will effectively turn the Mental Health Order on its head. It says that, instead of us doing things to you, you will have as much autonomy as possible. People can be autonomous in one area but not in another. They may lack capacity to make one decision but not another. This Bill will be decision-specific, and, where you can maintain your autonomy and capacity, you will do so. That is hugely important because the Mental Health Order is all-encompassing. It says, “This is it”, and it is very stigmatising.

The Chairperson:

That is where early diagnosis of conditions such as dementia comes in, in that you are able to make decisions about enduring power of attorney etc when you have your best capacity. Hopefully, that will be part of it.

Mr McCallister:

You are very welcome. It has been an interesting discussion so far, and some interesting issues have been brought out. You have mentioned attitudinal change a number of times, and that will be one of the most difficult things for us, as legislators, to achieve. Sam, Jim and I were on the previous Health Committee that scrutinised the Safeguarding Board Bill. When you look at the evidence and know broadly what you want, it is a case of getting that change right throughout the entire system to reflect the concerns about how you safeguard and make sure that people are taken into account whatever their capacity. I suggest that making that change will be very difficult regardless of the way in which we approach the legislation.

One positive is that — I am not counting on the First Minister resigning when I say this — we have a window at this stage of the Assembly cycle when we are at least three and a half years away from an election, possibly even four and a half years if the term is extended. So, we have time to take account of the justice system, and we do not need to rush. I am supportive of the Chair’s opening comments about how we include youth because we do not want to leave people behind. We have been debating another issue that involves youths who are detained and how to look at the legislation in that area.

You are clearly very passionate about and committed to this, and you want to build it on the four cornerstones from the Bamford review. How will we get that into legislation and change the face of mental health and learning disability across Northern Ireland and in every service and every part of government that interacts with people? That will be incredibly difficult.

Dr McKeown:

One way to do it is to see people with a learning disability or with mental health problems as rights holders. That change has to happen. Rather than other people making decisions on a person's behalf, even if they are good decisions — this is not to say that the decisions would not be the best ones for the person — it is about seeing the person as someone who has inherent value, who contributes to the society in which they live and who has autonomy. That is really important, and it will start to bring about the attitude change.

Kieran, you talked earlier about the indications of change. It is a bit early, but colleagues in England say that the capacity legislation has led to people starting to see people with a learning disability, including those with severe communication difficulties, differently. It is about seeing people as being rights holders and being in charge of their life. They need support to be in charge of their life. It is about recognising, particularly for people with a learning disability, that the nature of the disability will mean that most people will need extra help to manage or to make decisions. It starts with the premise that they need extra help, and it is about making sure that they get that help so that they can make decisions.

Ms O'Hare:

It is vital that we get it right and that we incorporate that approach into the legislation. There is ample evidence of law driving social change. In long-gone case law and legislation, I would not have been considered a person because of my gender. Law can make a difference, and getting the law right can make a difference. As Catherine and Liz have said — they may want to come back to you on this, John — it is important that training is an integral part of the piece. Similarly, public discourse needs to develop.

Ms Main:

Public discourse is very important. A lot of very good work has been done on stigma here in relation to challenging people and them getting help for themselves. There has not been an integrated stigma discrimination campaign that focuses on the discrimination side and works to change attitudes. You see that in England, in particular, which has a very good campaign. Scotland also has a good campaign, and Wales is just starting to roll out a campaign. In England, they are very much measuring attitudinal change and seeing that it is possible. Until there is that sort of full-scale campaign right across all areas, particularly schools and the medical arena — so much discrimination occurs in the medical arena — you need that preparation as well if it is really to make a difference.

Ms Harper:

We are a home treatment, which is about keeping people away from hospital. That seems to work better. Although they are not even in hospital, they still feel stigmatised. They wonder what will happen when they look for a job. People feel as though their life is over; they think that there is no hope for them and that nobody will ever employ them. Home treatment leads to quicker recovery because people are in the community and do not need a period to adjust to going to hospital, but they are still stigmatised in their own homes.

Mr McCallister:

The Bill is needed because it will encompass a wide range of people, including those with very severe learning disabilities. Your point, Paschal, was about how people’s rights can be exercised without having to always revert to the courts system. They should be quite easily accessible, so that they are known to service users and providers. They should become par for the course. Achieving the attitudinal change will be a pretty massive feat. I know that we will not achieve that instantly, but at least we are starting the discussion now and getting different services geared up. In answer to Kieran’s question, you talked about getting training going now. Liz made the point about looking at some of the numbers so that we have more of an idea of what level of service and investment we are likely to need. There is a huge job of work to be done to see where we will be.

The Chairperson:

We have been at this for nearly an hour, and I do not want to be unfair to our panel. Unless anyone else has a burning desire to get in, Paula will be the final member to speak.

Mr McCarthy:

Chair, you cut me off, so I want to —

The Chairperson:

I cut you off about 15 minutes in, Kieran, so it was not unfair.

Mr McCarthy:

I want to finish by congratulating the alliance on its excellent work.

The Chairperson:

You are a skitter. You will get in at the end.

Ms P Bradley:

Thank you for your presentation, which has been extremely worthwhile. I come from a background of hospital social work, where I encountered capacity and consent issues daily. Everything to do with that was so untidy that the social work profession was left not knowing how we should progress, and the medical profession was in exactly the same position. Therefore, I am happy to see the work that you are doing and to hear you talk about people being in charge of their own life. A lot of people forget that capacity issues apply only to single issues. We can have capacity on one thing but not on something else, and that needs to be highlighted. There is a stigma surrounding any sort of mental health illness where capacity is an issue, and it needs to be highlighted that, although someone may be capable of managing their finances, they may not be capable of doing something else. Well done. I look forward to working with you, and thank you for coming. Keep it up.

Dr McKeown:

The important thing about the legislation is that people do not have a label that dictates what choices and decisions they can make in their life, regardless of what they can do or cannot do. That is the important step change in the legislation. It is not that, because you have a learning disability or a mental health difficulty, something happens automatically. That is the step change that the legislation should bring in.

Ms P Bradley:

Capacity is also changeable. If someone has a capacity issue, it does not mean that that is the case for the rest of their life.

Dr McKeown:

Exactly. As a result of an intervention, particularly in the case of people with a learning disability, your capacity to be able to make decisions should improve. As you gain experiences and skills, you should get better at making decisions.

The Chairperson:

Yes, if you get the right stimulation, training and empowerment.

Kieran, I will let you in for five seconds.

Mr McCarthy:

I can hear in your responses to all our questions that there is passion in your voices. You want to see the legislation done, as we all do. As we said earlier, the legislation will be world-beating. We want to get in there. We have the opportunity. John said that we have three and a half or four years to do it, and I hope that we can do it well within that time frame and that we can all leave this place with our heads held high. If we pass the legislation, we will have done something for the most vulnerable people in society. Well done to you, and keep flying the flag of the alliance.

Mr McCallister:

They have more members than the Alliance Party.

The Chairperson:

This will certainly not be the end of it. We will need to have you back as we progress through the legislation's Committee Stage. Although we may have a bit of time, this will take time, and we need to take the time to get it right. I am not complacent at all, and we need to move quickly. Earlier, we discussed writing to the Health Minister about his engaging with the Department of Justice and the Justice Minister now in relation to the justice side of the legislation. With the approval of Committee members, we should perhaps include in that letter that we want the Health Minister to work on the code of conduct as a parallel piece of work so that it is ready at the same time as the legislation.

The point was made about getting the subject on the syllabus. In October, I had a meeting with the Alzheimer's Society. On the back of that, I asked the Western Health and Social Care Trust to ensure that all members of staff in the new hospital in Enniskillen have dementia training, for example, so that every member of staff has the right level of training and that we can hold that hospital up as a centre of excellence. I made the point that porters, people in surgical teams and everybody needs that training, because people with dementia, for example, are not just in the dementia ward — they are right across the health service. Again, we should probably make the point that that is a parallel process. This should be a continuous and contiguous process so that all the boxes are ticked when the legislation comes through.

We could have kept this session going for four hours. I am sure that there are still plenty of questions, but, for now, I thank you for coming along for this first session, and we look forward to seeing you again. If issues come up throughout the process, do not be afraid to send them to us in writing as well. You can keep us abreast of what is going on and help to ensure that, when it comes to our scrutinising of the legislation, we are not starting from scratch and are well ahead of the game.

Ms O'Hare:
We will certainly do that. Thank you for taking the time to hear us. We hope to see you again soon enough.

The Chairperson:
Thanks a million, everybody.