



Northern Ireland
Assembly

Committee for Health, Social Services and
Public Safety

OFFICIAL REPORT (Hansard)

Human Transplantation Bill:
Committee Deliberations

13 January 2016

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Ms Maeve McLaughlin (Chairperson)
Mr Alex Easton (Deputy Chairperson)
Mr Thomas Buchanan
Mrs Pam Cameron
Mrs Jo-Anne Dobson
Mr Kieran McCarthy
Ms Rosaleen McCorley
Mr Michael McGimpsey
Mr Daithí McKay
Mr Fearghal McKinney
Mr Gary Middleton

The Chairperson (Ms Maeve McLaughlin): We are now commencing the Committee's deliberations on the Human Transplantation Bill.

Mrs Dobson: Chair, as the Bill's sponsor, may I make a few comments before we go into the deliberations?

The Chairperson (Ms Maeve McLaughlin): Yes, if you keep them brief.

Mrs Dobson: First, I am grateful to the Committee members and to everyone who has given evidence to the Committee so far. I have met departmental officials a number of times, including just before Christmas, when they presented me with a number of draft amendments. I understood that those were to be with the Committee before Christmas, but I gather that, at this stage, they are not. I praise the staff in the Department for their professionalism and hard work. I have the amendments in draft form, and I understand that they are still with the Minister for consideration three weeks on. Chair, I would welcome your advice on whether I should share the amendments with the Committee, as, in the main, I feel that they would be helpful in strengthening the Bill. Would it be better for the Committee to approach the Minister again, following his letter of 30 November? He described in that letter the first key document that the team will produce, and, as that was supposed to come before Christmas, I would welcome your advice.

The Chairperson (Ms Maeve McLaughlin): It is clear that those are the Department's amendments, so they will have to come from the Department.

Mrs Dobson: Can we perhaps write to the Department?

The Chairperson (Ms Maeve McLaughlin): The Department knows at this stage that we are waiting on those amendments to be received. Do we have a date?

The Committee Clerk: We have communication that says that the Minister acknowledges —

The Chairperson (Ms Maeve McLaughlin): He is giving them his fullest consideration. This is ongoing, but it is appropriate that the amendments come from the Department.

Members, the purpose of our deliberations is to discuss the written and oral evidence that we have received and to decide whether we want to pursue Committee amendments. The relevant papers are in members' meeting packs. Copies of the Hansard report of the evidence session on 6 January are now on the table. Do any members wish to declare an interest?

Mrs Dobson: I declare an interest as the sponsor of the Bill.

The Chairperson (Ms Maeve McLaughlin): Thank you, Jo-Anne.

I remind members that, as we touched on a few minutes ago, at the evidence session on 6 December, officials indicated that the Department would be developing amendments to ensure that the Bill gives clear direction on a number of issues. It was hoped at that stage that the draft amendments would be available around the time of the Christmas recess. Draft amendments have not been received yet, and the Department has advised the Committee Clerk that the Minister acknowledges that this is an important issue and that he is currently giving it his fullest consideration and will respond in due course. Procedurally, the Committee will have to consider formally any amendments proposed by the Department or the Bill sponsor when we have our formal clause-by-clause consideration of the Bill, which, again, is on 27 January. I stress that we will have to formally consider any amendments at that point on 27 January. We will have to wait and see whether we receive anything before that date. That is our current timeline. I advise members that, during the deliberations, I will refer directly to the evidence document at page 86 of your meeting pack.

I will move to clause 1, which deals with the duty to promote transplantation. Fifteen organisations and individuals commented on clause 1. The comments focused mainly on the nature of the campaign and the associated costs. Do members wish to raise any issues on clause 1 at this point? No. OK. I seek agreement that we move to clause 2.

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Clause 2 deals with the authorisation of transplantation activities. Three organisations and individuals commented on this clause. Comments focused mainly on the licensing requirements for storage activity, the scope of the Bill to provide for the transplantation of any relevant material to be lawful with deemed consent, the use of donated material, and the circumstances in which consent would not be needed. At this point, do members wish to raise any issues on clause 2? Is there agreement to move to clause 3?

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Clause 3 deals with the issue of express consent in relation to adults. Two organisations/individuals commented on clause 3. The comments focused mainly on the nature of qualifying relationships, the status of the organ donation register and the word "harvesting", which was used in the explanatory memorandum. Do members wish to raise any issues on clause 3?

Mr McKinney: Reflecting on the evidence that we received last week, some of the discussion around clause 3 depended on people's views on removing clause 4. This is probably the core of the Bill and where there is most controversy. In going through clause 3 and then hitting clause 4, I feel that the debate cannot merely be had in that simplistic way, unless this is just simply process. The best thing for me to do is probably just to note and reflect on what we heard last week. It appears that there needs to be room for significant amendment if it is to proceed.

The Chairperson (Ms Maeve McLaughlin): I am conscious of that as well. Clauses 3, 4 and 5 are connected and are at the core of this.

Mr McKinney: They are all connected. I suppose that is the best way to describe it.

The Chairperson (Ms Maeve McLaughlin): One of the suggestions from last week's evidence on clause 3 was to include in the table another part on the consent of a qualifying person in instances where "none of the above" applies. I am just mindful of timeline for the Bill. I suggest, members, that we instruct the Bill Office to consider an amendment on that issue. If members are in agreement that we proceed on that basis, we will move to clauses 4 and 5; they are all interrelated. Are members in agreement that we instruct the Bill Office to look at the inclusion of the consent of a qualifying person in relation to clause 3?

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Clause 4 deals with deemed consent in relation to deceased adults. Eighteen organisations or individuals commented on clause 4. Suffice it to say that there was a significant focus on the principle of deemed consent/opt-out, its outworkings and the role of the family. Do members want to comment? This is only in evidence — we can do with it what we choose — but one of the suggestions was the removal of clause 4 on the issue of consent. That was fairly consistent in all the evidence that we heard last week. I may be putting members on the spot slightly, given the time constraints, but do we want to instruct the Bill Office to look at the implications for the Bill of the removal of this clause? Bluntly, I suggest asking whether the removal of clause 4 on the issue of deemed consent changes the nature of the Bill. Are we, as a Committee, saying that we should be more focused on the primacy of family consent? We, as a Committee, need to be clear about what it is that we are attempting to do. I am making the suggestion that we instruct the Bill Office to look at the Bill with the removal of clause 4 on the issue of deemed consent. Are members agreed that we do that?

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): We can continue our work and reflect on the evidence that we receive from the Bill Office.

This is all interrelated. Clause 5 deals with express consent in relation to excepted adults. Five organisations or individuals commented on clause 5. The comments focused mainly on the need for the Human Transplantation Bill to be considered in the context of the Mental Capacity Bill, the definition of an excepted adult, and how international students and armed forces personnel will be informed about the new law.

Members, I do not wish to pre-empt your views, but one of the suggestions was that clause 5 is almost not needed and, in effect, becomes redundant when you rework clause 3. We may choose to take a similar approach as to clause 4 and seek to instruct the Bill Office to consider the Bill in light of the removal of clause 5. Are members comfortable with that? Again, none of this is decision-making at this stage. We are simply making instructions to the Bill Office to see what comes back. Are members content with that?

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Clause 6 deals with express consent in relation to children. Three organisations commented on clause 6. The comments focused mainly on whether parental responsibility can override a child's competence, who is responsible for a child in care, how a child will be judged to be competent and the ability of a child to appoint a representative. Do members wish to raise any issues in relation to clause 6 at this point? There was an issue around age. There was some evidence and questioning around the age of a child being dropped to 16. I do not know whether members have views on that at this stage. I will take that silence as there being nothing major.

I will move on to clause 7, which deals with express consent in relation to transplantation activities involving excluded material. Three organisations and individuals commented on clause 7. They focused mainly on express consent for two transplantation activities involving excluded material. Do members want to raise any issues in relation to clause 7? If not, we will move to clause 8.

Clause 8 deals with deemed consent in relation to activities involving material from living adults who lack capacity to consent. Five organisations and individuals commented on this clause, focusing mainly on deemed consent in relation to activities involving material from living adults who lack

capacity and the need for that matter to be considered in the context of the Mental Capacity Bill. In cases of donation after circulatory death, the issue was raised that donors will be alive at the time of consent and that there was the possibility that organs could be removed from an individual without their consent. Do members want to raise any issues in relation to clause 8?

Ms McCorley: A lot of concern was expressed about this clause but the Department said that it will look to develop amendments, so we are waiting for that to happen.

The Chairperson (Ms Maeve McLaughlin): Yes, it did. I suppose, alongside that, we could also instruct the Bill Office to consider an amendment, because I am mindful that the BMA and others talked about the need for clarification. Indeed, some evidence suggested the removal of reference to living adults who lack capacity. I am seeking agreement to instruct the Bill Office to draw up an amendment to clause 8.

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Alongside that, we are waiting for the Department to come back with any suggestions or amendments. The issue is living donors; that was the concern. We will instruct the Bill Office to address the issue of "a living adult" in clause 8(1)(i).

Mr Easton: I have major concerns about that, and it will need to be addressed to get my support. I do not want to see decisions being made about someone's organs when they are still alive.

The Chairperson (Ms Maeve McLaughlin): I am just looking through the notes. It deals with a living donor after circulatory death. That is OK; we are happy to do that. That is important.

We will move to clause 9, which deals with appointed representatives. Four organisations and individuals commented on clause 9. Their comments were mostly on the identification of appointed representatives, the recording mechanism, their role, and dealing with conflicting views. Do members want to raise any issues in relation to clause 9?

Mr Easton: Chair, I have quick general question. What happens if somebody has appointed as a representative somebody they are in a relationship with, and the relationship then breaks up on bad terms? Where does that leave this? We have not considered that.

The Chairperson (Ms Maeve McLaughlin): I suppose that goes back to the whole issue of qualifying relationships and status. It goes to the very heart of presumed consent and deemed consent.

Mr Easton: It might be clear when you are with somebody who is obviously your partner, and that is all well and good because you are in a good relationship. However, if that relationship deteriorates and breaks up, and somebody does not bother to change their representative, there could be a situation 20 years down the line when they have remarried. There are a lot of queries.

The Chairperson (Ms Maeve McLaughlin): It might be helpful at this stage if we, as a Committee, are clear on the purpose of the Bill, particularly in light of some of the evidence that we heard last week on the importance of family consent in relation to this. Family is a priority, almost; that is probably too strong a word, but there is the primacy of family. If we are instructing the Bill Office to consider changes to this, we will reflect to it that our objective is around the role of the family. If we reflect on some of last week's evidence, we see that it was nearly in relation to this starting off as a family consent Act, which has changed, for whatever reason, and we need to move back to that sense of it. I think it would be useful if we said that the objective of the Bill is to look at the role of family and the primacy of family. That may allow the flow of some conversations. I take it that that basic premise is what we are saying we are in agreement with, in line with the evidence last week that family consent is paramount.

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): We will move on to clause 10, which touches on the point that Alex raised in relation to qualifying relationships. Four organisations commented. The focus was on the list of relationships, whether they are of equal standing and the definition of, for example, "a friend of long standing". Bearing in mind the conversation that we have just had about the primacy of family, do members wish to raise any issues at this juncture? No. OK.

I will move to clause 11, which deals with the prohibition of transplantation activities without consent. One organisation highlighted that policies and procedures should be in place from an early stage to ensure that all involved understand their responsibilities, should an offence be committed. Do members want to raise any issues in relation to clause 11, or is it self-explanatory? There are no comments.

I will move to clause 12, which deals with offences by bodies corporate. There are no comments. Do members want to raise any issues in relation to clause 12 at this point? No. OK.

Clause 13 deals with prosecutions. One organisation commented on clause 13 to ask that consideration be given to who should make a referral to the Director of Public Prosecutions. Do members want to raise any issues in relation to clause 13? No. OK.

Clause 14 deals with the annual report on transplantation. Four organisations and individuals commented on clause 14. The comments focused mainly on the frequency of reports, their content and the mechanisms to gather data. Do members want to raise any issues in relation to clause 14 at this point? No. OK.

I will move on to clause 15, which deals with preservation for transplantation. No comments were received in relation to clause 15. Do members want to raise any issues? No. OK.

I will move on, then, to clause 16, which deals with coroners. Again, no comments were received in relation to it. Do members want to raise any issues? No.

I will move to clause 17, which deals with relevant material. No comments were received in relation to clause 17. Do members want to raise any issues? No. OK.

I will move to clause 18. Four organisations commented on clause 18. The comments focused mainly on the age from which the opt-out system should apply. Do members want to raise any issues at this point? OK. To recap, clause 18 deals with the issue of relevant material. I am looking to the Committee Clerk for advice on that. An issue had been raised about the Bill allowing for the transplantation of solid organs. Was that in clause 18? No, I am going to jump back slightly.

Clause 17 also referred to "relevant material", although previous clauses that dealt with deemed consent had referred to "solid organs". Maybe, alongside this process, we could ask the Bill Office to look at an amendment to that clause that would remove the reference to "relevant material". Some of the evidence we heard was very clear about solid organs, yet there is scope in clause 17 for "other relevant material". So, I suggest that we instruct the Bill Office to consider drafting an amendment that looks at the removal of "relevant material" and outline what that would mean for the remainder of the Bill. It seems that there is scope for much more than just solid organs, so we need to be very clear about what the clause means. Are members in agreement that we instruct the Bill Office to consider that?

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Thank you, members, and apologies for jumping back.

We were on clause 18, which deals with interpretation. Again, that focuses on the age from which an opt-out system should apply. Are there any issues that members want to raise?

Mr Easton: Under the terms of the Bill, you are automatically on the register. Fearghal and I were just discussing whether, if you are below the age of 18, it is in the Bill that parental consent is needed.

The Chairperson (Ms Maeve McLaughlin): That goes back to the issue of the age being dropped to —

Mr Easton: Does that not need to be in the Bill, though?

The Chairperson (Ms Maeve McLaughlin): Clause 18(1) states:

"child" means a person who has not attained the age of 18 years".

That brings its own issues around parental consent.

Mr Easton: Could it be put in the Bill as well to make me more comfortable? What if the child is adopted or does not have parents? That is something we have not thought about.

The Chairperson (Ms Maeve McLaughlin): I understand the point that you are making, but I assume that "child" brings its own set of requirements. Whether a child is in care or does not have parents, a guardian or a qualified adult still has to make decisions on their behalf.

Mrs Cameron: I imagine that that is the case, but can we get clarification that it is?

The Chairperson (Ms Maeve McLaughlin): Where would we get clarification from?

Mr Easton: The Department.

Mrs Cameron: The Bill Office, maybe.

The Chairperson (Ms Maeve McLaughlin): I assume that you are asking whether defining someone as a "child" means that adult consent is required. Is that what you are asking?

Mr Easton: Yes, in cases where the child is adopted or has no parents.

The Chairperson (Ms Maeve McLaughlin): I am trying to work out who would clarify that.

Mr McKinney: These things are all interlinked. I was going to save these comments for the very end, but it is probably appropriate to make them now. Jo-Anne, I assume it is true that you welcome amendments.

Mrs Dobson: Yes.

Mr McKinney: The strongest way of doing that would be by Committee amendment, if we can reach some sort of agreement on these or at least some common understanding. Given some of the evidence that was produced last week, the chance of the Bill getting further support in its present form is unlikely. At the same time, given all the comments that have been made, we are all still keen to see that organ donation is strengthened and bolstered and that those who are suffering at the moment, and who could otherwise achieve a donation, would be better off under some new arrangements.

The big issue at the centre of it, of course, is family consent. Last week, we heard some people suggest a very simplistic and straightforward way of doing that. That, in itself, has to be tested, so I recommend the approach that you are suggesting, Chairperson, which is that these amendments are referred to the Bill Office for consideration. Are we talking about a wholesale scoping out of clauses 4, 5 and 6, with a common set of proposals around family consent and who is a qualifying individual to do that? If that was the case, that would go to the heart of addressing your concerns, because family consent would come in at whatever age.

I do not think that we want to exclude under-18s, because some under-18s may consent, as has been suggested by the BMA. If there was a common set of proposals here that allowed for the family consent, it might mean that there could be, as was suggested last week, a reasonably quick way to do this that would shorten some of the processes and assuage some of the concerns that people have. In the debate some time ago, Alastair Ross intervened in my contribution, and I said quite quickly back to him that I did not have concerns. It was only afterwards, on reflection, that it occurred to me that it was OK for me to say that, but it was not going to help reach a common ambition of promoting organ donation in the way that we should.

We do need to reach agreement around these things, and the best way to do that is probably around family consent. That would satisfy me, as someone who does not have concerns, but it would also satisfy those who do have concerns. That is the position that the Committee should try to get to. Therefore, I am suggesting that if we can, as a Committee, we should ask for that work to be done quickly, consistent with the evidence that we heard last week. The evidence that we heard last week was important. If that was to happen, we could probably reach a position that would alleviate major concerns that people around the table have and still achieve the common ambition that we all have.

The Chairperson (Ms Maeve McLaughlin): That is why I was making the point earlier that our view as a Committee is about the primacy of family consent. If we are now instructing the Bill Office to look

at clauses 3, 4 and 5 in particular, which are central to this, and examine the possibility of making the relevant changes that would allow family consent to be paramount, then we could have different and more robust legislation, in a very tight time frame.

Mr McKinney: In a tight time frame and consistent with all our ambitions.

The Chairperson (Ms Maeve McLaughlin): Those changes in relation to family consent would address the issue that you raised around this particular clause. I am hearing general agreement that the Committee's wish is for a Bill that makes family consent paramount and that the Bill Office is instructed, on the basis of that objective, to make the amendments that would be deemed necessary. We will then, obviously, scrutinise what comes back. Is that OK?

Members indicated assent.

The Chairperson (Ms Maeve McLaughlin): Thank you, members. Are you OK with that, Alex?

Mr Easton: Yes.

The Chairperson (Ms Maeve McLaughlin): We were on clause 18. We will move onto clause 19, which is about orders and regulations. No comments have been made on clause 19. Do members want to raise any issues about clause 19 at this point? If not, with members' agreement, we will move onto clause 20, which is "Consequential amendments to the Human Tissue Act 2004". One organisation commented on clause 20, stating that living donation is adequately covered and managed by the Human Tissue Act. Do members, at this point, wish to raise any issues in relation to clause 20?

Clause 21 is the commencement. One organisation commented on the commencement dates for the Bill in light of the experience in Wales. Do members wish to raise any issues in relation to clause 21? If not, we will move to clause 22, which is the short title. One individual commented on clause 22, highlighting that the word "donor" or the word "donation" should be used at least once in the Bill. Do members wish to raise any issues in relation to clause 22?

We now move to the schedule. Two organisations commented on the schedule. The comments focused mainly on required amendments to the codes of practice in relation to the Human Tissue Act 2004. Do members wish to raise any issues in relation to the schedule?

That concludes the initial deliberations on the Human Transplantation Bill. The final deliberations will take place at next week's meeting, including the consideration of any of the text or amendments that we have requested today. Questions will be put formally on the clauses at our meeting on 27 January.