



Northern Ireland
Assembly

Committee for Health, Social Services and
Public Safety

OFFICIAL REPORT (Hansard)

Human Transplantation Bill:
CARE in Northern Ireland, Presbyterian Church in
Ireland, Society for the Protection of Unborn Children

6 January 2016

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Members present for all or part of the proceedings:

Ms Maeve McLaughlin (Chairperson)
Mr Thomas Buchanan
Mr Kieran McCarthy
Ms Rosaleen McCorley
Mr Michael McGimpsey
Mr Daithí McKay
Mr Fearghal McKinney
Mr Gary Middleton

Witnesses:

Mr Mark Baillie	CARE in Northern Ireland
Mr Gavin Norris	Presbyterian Church in Ireland
Mr Liam Gibson	Society for the Protection of Unborn Children

The Chairperson (Ms Maeve McLaughlin): We have with us Mr Mark Baillie, public affairs officer with CARE, and Mr Gavin Norris, public affairs officer for the Presbyterian Church. You are both very welcome.

Mr Mark Baillie (CARE in Northern Ireland): I will lead off, and then hand over to Gavin before we take questions. Thank you very much for inviting me to give evidence to the Committee on the Human Transplantation Bill. I appreciate that it has been a long day for you and you have been here quite a while, so I will endeavour to be brief. First, I will outline our general approach to the issue of organ donation before briefly considering some of the clauses on which we have comments to make.

The organisation that I represent, CARE, which stands for Christian Action Research and Education, believes that organ donation is a positive social good that can transform the lives of individuals, families and communities for the better. In considering the Bill, the core ethical principle at stake for us is the idea of organ donation remaining a gift. In the debate on the Welsh Bill, which has been discussed a lot, the Archbishop of Wales, Dr Barry Morgan, succinctly captured this when he said:

"Giving organs is the most generous act of self giving imaginable but it has to be a choice that is freely embraced, not something that the state assumes."

As well as this core ethical concern — that ethical concern feeds into this — we have some general misgivings about whether the introduction of an opt-out system in Northern Ireland will actually improve organ donation rates. Many of these issues came up earlier today from individuals who are far more qualified than me to comment, so I will not go into that.

We, as an organisation, respect the fact that, at Second Stage, the Assembly overwhelmingly voted in favour of the principle of introducing some form of opt-out system. Consequently, we decided to constructively suggest how the core ethical principle — the idea of organ donation as a gift — can be maintained if such a system is introduced. It is our view that the concept of gift in organ donation can be maintained in an opt-out system, but that clause 4 — Mr Brolly very succinctly illustrated many of the problems with clause 4 — would need to be amended significantly or perhaps removed to achieve that. The key point that I am trying to make is that an opt-out system can be introduced while maintaining the concept of gift.

I will now turn to the clauses of the Bill. I will comment on only a few of the clauses. You have our written submission so you can see the comments that we have made on the rest of the Bill. I will start with clause 4. Our chief objective when we looked at clause 4 was to ensure that it maintained the notion of organ donation as a gift. Our major concern is the idea of organs being taken from an individual with no form of affirmative consent being provided by that individual, their relatives or a close friend. If an organ were removed in such circumstances, we do not believe that that constitutes a gift at all. We actually feel that it sees the state overreaching its rightful place by effectively taking ownership of a person's organs after death. If some form of familial consent or consent from a close friend is given, we believe that the notion of organ donation as a gift is maintained.

Clause 4(2) allows a relative or friend of long standing to make the deemed consent effective if they affirm that the person would not have objected. As it stands and as we read it, clause 4 does not, in fact, provide the family with the opportunity to affirm consent. What it does, strictly speaking, is allow for the family to input the information that they have on the deceased's views. If the family had no explicit information about the views of the deceased regarding donation, the Bill provides the family with no role. We appreciate that, in practice, families would be asked for their views, but we do not see why you would legislate in a way that does not reflect the reality of what happens currently with regard to the family. We are concerned about that situation and, like the transplant surgeons — some of the individuals you heard from earlier — about confusion that could be generated if that was the situation.

I have met Mrs Dobson twice with regard to the Bill and read carefully the remarks that she made during the Second Stage debate. I appreciate that she believes strongly that familial consent is crucial. She has consistently made that point. We believe that clause 4 needs to be looked at again to ensure that familial consent is put in there. It is my understanding from Mrs Dobson that she plans to amend clause 4 to ensure that familial consent is required. In our written submission, we have suggested an amendment that you could consider. Mr Brolly has obviously got another scheme. You would have to look at that as well. It is certainly worth looking at that carefully when you come to the clause-by-clause deliberation.

I will move on to clauses 6 and 7. Clause 6 allows children to expressly consent to the donation of material covered under clause 2 while they are alive or after they die as a child, even through their own consent if they are considered capable of making such a decision or by appointing a representative. Clause 7 allows a child to expressly consent to transplants involving excluded material, which will be defined in future regulations. We note that the current situation allows children who are aged 14 and over to join the organ donor register. It is our view that organ donation by children is a controversial subject and requires sensitive deliberation by the Assembly and the Committee. I want to raise two issues that we have about the clauses as drafted.

First, how will a child be judged competent to consent to giving their organs? Will there be an assumption that, if a child is over 14, they are competent to consent? That needs to be thought about carefully. There is a test in the Bill in clause 18(3) which states that:

"if it would appear to a reasonable person that the child has sufficient understanding to make an informed decision",

they are competent to consent. We would advise that you look at that closely to see whether it is appropriate.

Secondly, we are concerned about the ability of a child to appoint a representative. It is our belief that a child's parent or guardian is their natural representative. We question in what circumstances a child should be able to appoint someone outside their family to represent them. We understand that there are circumstances where that would be appropriate: for example, the child has no parents caring for them through death; the child is in foster care; or the child is 16 or 17 and married and wishes that their spouse represent them. In all other circumstances, however, we are concerned that appointment

of a representative could be seen as undermining a parent or guardian's responsibility for their child. We have suggested an amendment to clause 9 in the text of our submission to ensure that only in appropriate circumstances could a child appoint a representative.

The last clause that I want to come to is clause 8, and then I will hand over to Gavin. It has been the subject of much discussion from what I have heard of your deliberations today. Basically, as we read it, this allows the law to deem consent for adults who are unable to give their consent while they are alive in circumstances of the kind specified by regulations made by the Department. There is no indication in the text of the Bill, though, of the circumstances that might be considered applicable, as there is in clause 7(3), nor any explanation why this might be in the individual's best interests. Most importantly, there are no safeguards on who can agree to such a donation. We are very concerned that vulnerable adults who cannot consent should have the full safeguards of the law, and it is not clear that that is the case as the clause stands. We are not reassured by the regulations made under the Welsh legislation, which state that an adult who lacks capacity to consent is:

"deemed to have consented to the activity where the activity is done by a person who is acting in what they reasonably believe to be P's best interests."

There is no clarity on who might make this decision. On the basis of evidence stated earlier, our preferred option is that clause 8 be removed from the Bill. We understand that regulation 4 of the Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 already applies in Northern Ireland, so we see no reason for retaining the clause. If you desire to retain it, you should closely consider the detail of where it can be used. I will stop there and hand over to Gavin.

Mr Gavin Norris (Presbyterian Church in Ireland): Thank you for the opportunity to give evidence this afternoon. I appreciate that this has been a long day for the Committee, and I will endeavour to be brief.

The Presbyterian Church in Ireland, along with many other Christian Churches and groups, supports the practice of organ donation and believes it to be a profoundly Christian act in every way. It is a good thing for us as a society to discuss and to bring about opportunities for the gift of life to be made through organ donation.

In confining my remarks to clause 4, it is fair to say from the outset that Christians hold a diversity of opinions on the question of an opt-out system. In the UK, for example, Christian Churches have taken different stances on the issue. Practical concerns about whether or not an opt-out system will actually improve donation rates certainly inform these positions, but so too do important ethical questions about the implications of regarding life as a gift and our obligations to seek the well-being and flourishing of others. Those who have a greater degree of unease about opt-out systems tend to emphasise that a gift can be made only by consent and that the specialness of a gift, particularly where it is a part of oneself, is in the voluntary sacrifice. Others may take a more consequentialist approach, arguing that, if a change in the law could be shown to significantly increase the number of organs available for transplant and have the effect of prolonging and improving the quality of more lives, that would be welcome. Of course, when these arguments are considered, it is often with a harder version of opt-out in mind, systems in which the removal of organs could, at least on paper, proceed without the express consent of the deceased or their family.

Our council for church in society recognises that the Bill before us is different in that the Bill sponsor has expressed a wish to retain the role of the family in providing consent for organ donation to proceed in the event of the deceased's wishes being unknown. If that is what the Bill provides for, it would certainly mitigate concerns about loss of consent and the loss of the concepts of a gift or donation. However, in saying that a qualifying person or persons must affirm that the person would not have objected, the Bill is unclear on what the role of the family is in those situations. That raises two ethical concerns. First, that it would create confusion for families at a time of already significant distress. Secondly, that the legislation could actually deprive us of organs that would be available under the current system, as what is currently in place allows families to take the decision; a point that I believe was made by one of the consultant surgeons back in December. We would simply ask and suggest that a simple change be made to give families the final say on whether to donate or to object when the deceased's wishes are unknown. That would not only resolve the issues around consent and donation as a gift but make the Bill less restrictive. I will stop there.

The Chairperson (Ms Maeve McLaughlin): Thank you. Mr Gibson has just joined us. Would you like to come forward? I will give you a minute to catch your breath. You are very welcome.

Mr Gibson is the development officer with the Society for the Protection of Unborn Children. We will take your submission, and then we will open up to comments and questions.

Mr Liam Gibson (Society for the Protection of Unborn Children): Thank you, Chair. I apologise for being late. I was detained because I was trying to prepare some materials for the Committee. I have brought a copy of some of those materials in paper form and on a flash drive. I had hoped that a colleague of mine from London, Dr Anthony McCarthy, a bioethicist who works for the Society for the Protection of Unborn Children, would have been here today to make this presentation, but he was not, in the end, available. He was not able to change a long-term commitment. He has, however, sent me a statement that he would have made today had he been able to get here. I will read it out, as it is quite brief. I am aware of the very detailed submission by CARE; this is a much more general look at the issue.

Organ transplantation is potentially life-giving and a very important social contribution. However, it raises fundamental issues surrounding respect for the human body, the meaning of gift giving and, indeed, diagnosis of death. These are serious issues that need to be faced by anyone wishing to promote ethical forms of donation while protecting donors and the common good. In seeking to benefit patients whose need for organs may be urgent and compelling, the rights of potential donors and their families must always be respected.

Any ethical approach in this area has to rely on scientific data that must not be oversimplified. Attention must be given to serious contemporary debates in the scientific community as well as amongst moral philosophers and bioethicists. Tests for diagnosing death vary from country to country and, indeed, within a single country, while a growing body of specialists regard standard tests as potentially unreliable. This includes those who favour abandoning the dead-donor rule and simply taking vital organs from those agreed to be still alive though perhaps unconscious and close to death. If such specialists are correct, we will in some cases be dealing with operations to remove vital organs from what may still be living human beings. This is a genuine risk that must be faced in making laws on organ transplantation and promoting it to the public.

Donor hearts, for example, are in practice harvested from so-called beating-heart cadavers, something unknown to many members of the public, though, of course, known to transplant teams. It is also well known to transplant teams that heart-beating donors move when organs are taken, unless paralysed with drugs, and that their blood pressure goes up when the incision is made. It is worth noting that some anaesthetists recommend that the supposed cadaver be anaesthetised when his or her organs are retrieved. Most organ donors, including those who give explicit consent before they die, are unaware that their heart may be beating when their organs are taken and that they may be pink, warm, able to heal wounds, fight infections and respond to stimuli etc.

It is also the case that supposed brain-dead people, such as a pregnant woman who is given high-tech medical support, can appear to survive for months, demonstrating integrated bodily activity of a kind, arguably, that indicates that life remains. While not all kinds of organs may be taken from beating-heart donors or after tests for death of a more controversial kind, the fact must be faced by those who become donors that they are mostly quite unaware of the state in which their body may be when certain organs may be taken. A programme to promote organ donation that glosses over those facts is surely irresponsible, as is presumed consent and the harvesting of organs from mentally disabled people and from children.

In view of the uncertainties surrounding diagnosis of death, there are real dangers in an opt-out system. If opt-out legislation is to go ahead, those who recognise the dangers should at least try to increase the opportunity for relatives to object and to restrict organ harvesting from children and mentally disabled people to non-beating-heart donation. It is difficult for potential donors generally to learn the facts about organ harvesting from beating-heart donors, and this will be still more difficult for children who will, generally, have less opportunity to become aware of the facts and controversies in this area.

Even if an adult donor has given fully informed consent to organ donation after death, objections to donation raised by close relatives should be seen as overriding. This is particularly the case with the retrieval of organs from beating-heart donors, which can be most distressing for relatives who believe — not without evidence — that their loved one may still be alive. There are also some general concerns about respect for the feelings of relatives, including in situations where no information exists

on the donor's wishes but relatives are reluctant for organ harvesting to go ahead. Relatives should not be asked merely for information on the wishes of the potential donor, about which nothing may be known; organ harvesting should not take place against the relatives' objections as a matter of humanity. The state should not be presumed to own the bodies of its citizens, whether in life or in death; rather, its role is to serve the interests of persons whose bodily existence and remains should be honoured.

Dr McCarthy lists some sources on the questions of diagnosis of death. He says that it should be noted that the prestigious President's Council on Bioethics in the United States is divided on the issue of brain death. I have the materials that Dr McCarthy wanted to present, except for the report of the President's Council on Bioethics, which is 168 pages long. I thought that I would give you that on a flash drive.

The Chairperson (Ms Maeve McLaughlin): I appreciate that; thank you very much. We have heard a few similar messages today, and we are hearing a similar theme in this session, which is that the legislation as it is drafted could detract from current rates of donation.

Mr Baillie: I would say that that is potentially the case. Mr Brolly illustrated the issues in a stronger and more colourful way than I was planning on. Certainly, amendment is required. As far as I can see, you are trying to avoid confusion. Any kind of confusion could lead to a story in the press that could have devastating consequences, including loss of life for people who may have got a donation but, because of the story, the donation is withdrawn. We have seen examples of that in other countries. It seems to me that familial consent needs to be front and centre and you will have to decide what that looks like.

I was thinking about Mr Brolly's proposal and it occurred to me that these things are often more complicated. Having been involved in the drafting process of another private Member's Bill in the Assembly, I have seen at first hand that that can be quite difficult to do. I would be interested to hear what the draftsman of the current Bill makes of what is proposed there. Certainly, the key point on which I agree with him is that familial consent is crucial. The gift needs to be maintained, or you may have a practical problem.

The Chairperson (Ms Maeve McLaughlin): Obviously, with that, the family wish is paramount.

Mr Baillie: Yes.

The Chairperson (Ms Maeve McLaughlin): That is central to any legislation going forward.

Mr Baillie: Yes. Basically, you will have a problem if people think the state is taking ownership of organs. That could cause people not to give their organs, so there must be some form of positive consent. You need to look carefully at how that should be done. I think that that has been conveyed by lots of people today, from what I have seen of the deliberations.

The Chairperson (Ms Maeve McLaughlin): I am hearing that the relationship — the notion — of gift, as drafted, is altered, because the relationship between the donor and the state is altered in the draft legislation.

Mr Baillie: When I spoke to Mrs Dobson in person, it was manifest that she believed that gift is crucial and that the family's role is imperative. She accepted that this was a first go and that amendments may be helpful. In that meeting, she said that it was a bit like the Human Trafficking and Exploitation Bill — the Bill that came in at the start was drastically amended over time, and rightly so. That was necessary to make it fit for purpose. The Committee should be willing to do that, and I think that Mrs Dobson would agree. The Committee particularly needs to look at the options on how to get familial consent in there; that is the key thing, I think.

The Chairperson (Ms Maeve McLaughlin): Am I hearing that it can be done with an amended Bill?

Mr Baillie: Yes. My only concern is the speed at which you are trying to do this. The Human Trafficking and Exploitation Bill had six months in Committee, and they gave an eight-week consultation. Correct me if I am wrong but, in this case, there was a two-week period to respond. We struggled to get our response in. I know that some of the other Churches wanted more time. You

have only two months in which to deliberate on this. The transplant surgeons said that we should wait and see what happens in Wales. There is a case for that.

You could certainly improve on what you have got, but I wonder whether it would be best not to try to force it through in this mandate. "Force it through" is the wrong phrase: might it be best not to try to rush this through? Make sure you get it right, because the consequences of getting it wrong could be serious. Again, that is up to Members and parties in the Assembly. That is our perspective.

The Chairperson (Ms Maeve McLaughlin): OK. Has either of the other two gentlemen any other thoughts?

Mr Norris: We have a simple approach. As it is, our church in society council has said that, if there is explicit consent from the individual or the qualifying person, as the previous contributor said, it would eliminate a lot of the ethical concerns. We would not see a problem if that were dealt with.

Mr Gibson: One thing that also needs to be emphasised is that there needs to be a backup, once the Bill goes through, whatever state it is in. Public information is crucial and is vital to any success in developing the aims of the Bill. That is a serious concern that really needs to be looked into and considered through the drafting process.

The Chairperson (Ms Maeve McLaughlin): An education and awareness process and the duty on the Department to do that is one of the common themes throughout this. No one else wishes to comment, so I thank all three of you for taking the time to be with us today. We will reflect on everything you have said. Thank you very much.