HEALTH COMMITTEE

Thursday 8 September 2005

Session 2

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HEALTH COMMITTEE
20th Meeting 2005, Session 2

CONVENER

*Roseanna Cunningham (Perth) (SNP)

DEPUTY CONVENER

*Janis Hughes (Glasgow Rutherglen) (Lab)

COMMITTEE MEMBERS

*Helen Eadie (Dunfermline East) (Lab)
*Kate Maclean (Dundee West) (Lab)
Mr Duncan McNeil (Greenock and Inverclyde) (Lab)
*Mrs Nanette Milne (North East Scotland) (Con)
*Shona Robison (Dundee East) (SNP)
*Mike Rumbles (West Aberdeenshire and Kincardine) (LD)
*Dr Jean Turner (Strathkelvin and Bearsden) (Ind)

COMMITTEE SUBSTITUTES

Paul Martin (Glasgow Springburn) (Lab)
Mr Kenneth Macintosh (Eastwood) (Lab)
Mary Scanlon (Highlands and Islands) (Con)

*attended

THE FOLLOWING ALSO ATTENDED:

Lewis Macdonald (Deputy Minister for Health and Community Care)
Margo MacDonald (Lothians) (Ind)

THE FOLLOWING GAVE EVIDENCE:

John Forsythe (Scottish Transplant Group)
Joe Logan (Scottish Executive Health Department)
Professor Sheila McLean (Review Group on the Retention of Organs at Post-mortem)
Will Scott (Scottish Executive Health Department)

CLERK TO THE COMMITTEE

Simon Watkins

SENIOR ASSISTANT CLERK

Tracey White

ASSISTANT CLERK

Roz Wheeler

LOCATION

Committee Room 6

Scottish Parliament

Health Committee

Thursday 8 September 2005

[THE CONVENER *opened the meeting at 14:02*]

Items in Private

The Convener (Roseanna Cunningham): I welcome everybody back to the Health Committee after the recess. We had a big event in Perth last Thursday and so, in a sense, we reappeared after the recess much earlier than today. We have received apologies from Duncan McNeil.

Item 1 on the agenda is consideration of whether to take agenda items 7 and 8 in private. Item 7 concerns the Human Tissue (Scotland) Bill. It has become our practice, as part of the process of drafting our stage 1 reports, to review in private at the end of each meeting the evidence that we have heard. Having found that that works extremely well, we intend to continue to do so. Item 8 concerns potential witnesses. Again, it is our practice to discuss the names of potential witnesses in private.

Do members agree to discuss those items in private?

Members *indicated agreement.*

The Convener: It would be useful if members also agreed to take in private our review of evidence following each subsequent meeting at which we hear oral evidence on the bill. Do members agree to do so?

Members *indicated agreement.*

Subordinate Legislation

Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No 5) (Scotland) Order 2005 (SSI 2005/379)

Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No 6) (Scotland) Order 2005 (SSI 2005/384)

Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No 7) (Scotland) Order 2005 (SSI 2005/391)

Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No 8) (Scotland) Order 2005 (SSI 2005/410)

Food Protection (Emergency Prohibitions) (Paralytic Shellfish Poisoning) (East Coast) (Scotland) Order 2005 (SSI 2005/415)

14:03

The Convener: We move to our consideration of subordinate legislation. I welcome the Deputy Minister for Health and Community Care, who is with us for the first five affirmative instruments, all of which deal with amnesic and paralytic shellfish poisoning. This may be the minister's first outing to the Health Committee on the subject, but I am sure that it will not be his last. The minister is accompanied by Chester Wood—is that right? Chester is an unusual name—of the Food Standards Agency.

The Subordinate Legislation Committee had no comment to make on the instruments. I invite the minister to make his opening statement.

The Deputy Minister for Health and Community Care (Lewis Macdonald): Thank you, convener. This is my first visit to the Health Committee and I thank members for the opportunity to address you so early in my new role, although I will be brief. This is my first appearance before the committee on the subject, but it will not be my last. However, because of the change in regime that is to come into force at the end of the year, it will very nearly be my last appearance in the present format.

I think that committee members are familiar with the format and the purpose of these orders. While I am happy to answer any questions, I intend to take up no more of the committee's time than is required to make that offer and to move the motions when asked to do so.

The Convener: Does any member wish to seek clarification from the deputy minister or his official with regard to the five instruments?

Mrs Nanette Milne (North East Scotland) (Con): I do not seek clarification, but I have a brief comment. As members know, my party group has opposed such orders in the past but, given the changes that are to happen at the end of the year, I will make no further comments on those that come between now and then.

The Convener: Does any member wish to debate the orders?

Members: No.

The Convener: Does any member object to a single question being put on the motions?

Members: No.

The Convener: I therefore invite the deputy minister to move motions S2M-3179, S2M-3180, S2M-3181, S2M-3207 and S2M-3211 en bloc.

Motions moved,

That the Health Committee recommends that the Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No. 5) (Scotland) Order 2005 (SSI 2005/379) be approved.

That the Health Committee recommends that the Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No. 6) (Scotland) Order 2005 (SSI 2005/384) be approved.

That the Health Committee recommends that the Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No. 7) (Scotland) Order 2005 (SSI 2005/391) be approved.

That the Health Committee recommends that the Food Protection (Emergency Prohibitions) (Amnesic Shellfish Poisoning) (West Coast) (No. 8) (Scotland) Order 2005 (SSI 2005/410) be approved.

That the Health Committee recommends that the Food Protection (Emergency Prohibitions) (Paralytic Shellfish Poisoning) (East Coast) (Scotland) Order 2005 (SSI 2005/415) be approved.—[*Lewis Macdonald.*]

Motions agreed to.

Mental Health (Content and amendment of care plans) (Scotland) Regulations 2005 (SSI 2005/309)

Mental Health (Content and amendment of Part 9 care plans) (Scotland) Regulations 2005 (SSI 2005/312)

National Health Service (Primary Medical Services Section 17C Agreements) (Scotland) Amendment Regulations 2005 (SSI 2005/336)

National Health Service (General Medical Services Contracts) (Scotland) Amendment Regulations 2005 (SSI 2005/337)

The Convener: Agenda item 3 is consideration of further statutory instruments. Sorry. We are moving so fast that I forgot to thank the minister—thank you, minister.

We have received comments from the Subordinate Legislation Committee on SSI 2005/309 and SSI 2005/312, which are reproduced in an abridged report in the committee papers. There were no comments on the other two instruments. No comments have been made by any member of the committee and no motions to annul have been lodged. Do members agree that the committee should make no recommendations on the instruments?

Members *indicated agreement.*

Human Tissue (Scotland) Bill: Stage 1

14:07

The Convener: Agenda item 4 is consideration of the Human Tissue (Scotland) Bill at stage 1. Members are aware that the bill was referred to us before the summer recess and that the committee called for evidence on the bill during the recess. Copies of all the submissions that were received have been circulated. Today is our first opportunity to discuss the bill in detail.

We have with us Executive officials with the relevant policy responsibility and, unusually but appropriately, given the nature of the bill, we have other individuals. I welcome Will Scott, who is responsible for the part of the bill that deals with transplantation and post-mortem examination. He will be followed by Professor Sheila McLean, who is the chair of the review group on the retention of organs at post mortem, which was set up to inform the policy that underlies the bill. John Forsythe is the chair of the Scottish transplant group, which was set up for similar purposes. After we have heard from those two witnesses, we will hear from Joe Logan, who is responsible for the part of the bill that deals with amendments to the Anatomy Act 1984. Also at the table is the deputy chief medical officer, Dr Aileen Keel. I welcome them all to the committee.

I ask Will Scott to make a brief opening statement, followed by Professor McLean, Mr Forsythe and Joe Logan. However, I ask them to be brief, because we have a lot to get through.

Will Scott (Scottish Executive Health Department): I will be as brief as possible. The bill provides a new framework for transplantation and hospital post-mortem examinations and modernises the Anatomy Act 1984. It has its origins in the distress that was caused to families by revelations in the year 2000 about the way in which organs had been retained at post-mortem examination without the families' knowledge or permission. In response, the Executive set up the review group on the retention of organs, to investigate the problems in past practice and to suggest changes to the existing legislation—the Human Tissue Act 1961. As members have heard, Professor Sheila McLean chaired that group.

The review group's proposals had two main aims: to ensure that people's wishes were respected after death and to make it clear that control over the hospital post-mortem examination process should rest with the family. Those aims are embodied in the concept of authorisation—a concept that we have also applied to organ donation. Concerns about the 1961 act have also been expressed by the Scottish transplant group. Both groups strongly recommended that in future there should be separate legislation in Scotland on each of the topics. That is the approach that we have adopted in the bill.

There are two different types of transplantation—from deceased donors and from living donors. Part 1 of the bill deals with both types. For deceased donors, the provisions in part 1 strengthen the existing approach to transplantation, which is one of opting in. By that we mean that people, while they are still alive, indicate a positive wish in favour of donation, usually by carrying an organ donor card or by putting their name on the national health service organ donor register. The new legislation builds on those positive attitudes by treating the carrying of a card or the joining of the register—or other expressions of wishes—as forms of authorisation. It then ensures that those wishes are respected.

If a person has left no authorisation, the bill provides that authorisation may be given by the person's nearest relative, by which we mean the person who was closest in life to the deceased and is therefore most likely to know what their wishes were.

For living donation, it will continue to be an offence—as it is at the moment under the Human Organ Transplants Act 1989—to remove an organ or tissue from a living person unless a number of conditions are satisfied. Those conditions are basically that no money should have changed hands and that the donor is acting under their own free will. However, the bill extends scrutiny of living donation to all cases, not just those in which the parties are unrelated. The Human Tissue Authority will provide scrutiny for Scottish cases so as to achieve a consistent approach across the United Kingdom.

Part 2 of the bill deals with hospital post-mortem examinations. There are two types of post-mortem examination. For examinations that are instructed by the procurator fiscal as part of his or her responsibility for the investigation of sudden, suspicious or unexplained deaths, the fiscal can instruct the examinations without the agreement of the family. The other type is hospital post-mortem examinations; they cannot take place unless the family has agreed. Part 2 of the bill sets out the purposes of a hospital post-mortem examination and provides the same system of authorisation as in part 1.

We have addressed one of the main criticisms of the 1961 act by including in part 2 an offence provision. That is intended to underline the importance that we attach to obtaining authorisation and then respecting the detailed terms of that authorisation.

Part 3 of the bill sets out a system of authorisation that will apply once tissue samples or any organs taken at a post-mortem examination instructed by the fiscal are no longer needed for the fiscal's purposes. Parts 2 and 3 both contain provisions allowing the continued use, without authorisation, of material from a post-mortem examination that is already in an archive. That continues the approach that was developed by the review group at the suggestion of the family support groups with which it was dealing.

The bill deliberately sets out a broad framework for transplantation and post-mortem examinations, but these are such complex and sensitive areas that we need to underpin the primary legislation with regulations and guidance as these can be more easily adapted to deal with changing circumstances.

Professor Sheila McLean (Review Group on the Retention of Organs at Post-mortem): Thank you for the opportunity to speak briefly today. Will Scott has covered much of the ground but I would like to say a couple of things to reinforce what he said.

I very much welcome the introduction of this bill. For us, it has been five years in the making and a great deal of effort has been put in by many people. I am particularly pleased that the bill adopts the concept of authorisation rather than that of consent; if any member is confused about why we have done that, I will be happy to explain. The concept of authorisation reflects more clearly than did the traditional concept of consent the location of the authority that we believe should be vested in people.

On the one hand, the inquiry was enthusiastic about the notion that people, including mature minor children who are legally competent to make such decisions, should have as much control as possible over their own bodies following their death but, on the other hand, it was felt that, in the case of children, the location of authority to make decisions about what happens after death should firmly be vested with the parents, who can, presumably, be expected to act in the best interests of their children.

14:15

As Will Scott said, the bill does not directly address the procurator fiscal's post mortem, in as much as that is outwith our remit. However, on behalf of the review group, I would like to say that we have been pleased with the way in which the Crown Office has co-operated with us in taking account of our recommendations.

Another important aspect of the bill is the adoption of the review group's suggestion that tissue that is stored in the way of tissue blocks and slides should become part of the medical record and, therefore, should be available for future research or diagnostic procedures. As members will know, we have made special provision for research. As Will Scott said, the importance of research was recognised by everyone who gave evidence to the committee, particularly the family groups who were involved and the clinicians.

In the long run, one of the critical features of the bill will be that, unlike its predecessor, it will provide clarity both for families and individuals and also, importantly, for the medical professionals who will be involved in the process. The 1961 act is notoriously vague and difficult to interpret and we have reason to believe that some of the problems that arose might have done so because of that uncertainty. I welcome the bill's clarity and believe that it reflects the recommendations of the review group.

John Forsythe (Scottish Transplant Group): I am a transplant surgeon involved in liver, kidney and pancreas transplants and am also the chairman of the Scottish transplant group, which is a multi-disciplinary team looking after patients who require transplantation. The group also has lay transplant recipient and donor family representation. In 2002, we drew up an organ donation strategy for Scotland and have been interested in the bill as it has developed.

In contrast to organ retention, in relation to which there are seen to be significant problems, organ transplantation is seen to be a good practice and no major problems have been identified with it. Accordingly, the bill is meant to ensure that present practice continues while improving in terms of the organ donor side.

We approve of the idea that there be two separate parts to the bill: one for organ retention and one for organ transplantation. That will help to highlight the fact that those practices are quite different.

It is generally felt by the transplant community that the bill strikes a good balance between the rights of an individual over their body and the legitimate needs of a society in which organ transplantation is seen to be a good thing that helps many people.

Joe Logan (Scottish Executive Health Department): Part 5 of the bill proposes amendments to the Anatomy Act 1984. We are proposing those amendments because the Executive received representations about perceived shortcomings in the act. A difficulty with the 1984 act is that, although anatomical examinations are possible, surgical reconstruction is not, which means that students can dissect a corpse but cannot practice surgical procedures unless they fall within the scope of anatomical examination. In addition, in England and Wales the Department of Health has repealed the Anatomy Act 1984 and the Human Tissue Act 1961 and has replaced them with the Human Tissue Act 2004. Although the Anatomy Act 1984 will remain in place for Scotland, unless it is repealed by the Scottish Parliament, the action by the Department of Health will impact on the arrangements of Her Majesty's Inspector of Anatomy for Scotland.

Another deficiency in the current legislation was identified recently when there was controversy over the public display of plastinated corpses, which had previously been dissected outwith the United Kingdom. It has been argued that the display of body parts that were dissected abroad and preserved by a process that alters their characteristics should not be regarded as being subject to the Anatomy Act 1984.

A consultation exercise on the issues and possible changes was carried out in 2004. The main provisions in the amendments seek to widen the definition of anatomical examination to allow a body to be used for any procedure for the purposes of teaching, studying, training or research; to extend the licensing arrangements so that they cover imported bodies and body parts; to revise the arrangements for the donation of bodies so that authorisation to donate can be given only in writing, signed by a person who is 12 years old or more, and witnessed; to repeal section 4(3) of the act, which allows a person in lawful possession to donate the body if they have no reason to believe that the deceased, a surviving spouse or relatives have any objection; to give ministers the power to grant licences for public display of bodies and body parts, whether or not they have undergone a process to preserve them; for the first time to introduce a right of appeal to a sheriff against the refusal of the granting of any license; to introduce a code of practice to support the amended act and regulations; and to retain the reference to Her Majesty's Inspector of Anatomy for Scotland.

The Convener: Thank you. Before we open up the discussion to questions from committee members I ask the four witnesses what they think are the real issues of controversy in the bill.

Will Scott: As John Forsythe said, there have not been public concerns about transplantation but there are people who would like a complete change in the system on which transplantation is based. They would like it to be turned upside down and switched to a system of opting out, so that the assumption would be that unless someone had registered an objection to their organs or tissue being used after death, retrieval could take place. We have discussed that in the policy memorandum.

The Convener: You think that that is the issue of most controversy.

Will Scott: I think so, in that part of the bill. In relation to the post-mortem provisions, the review group worked closely with all the key parties. The consultation suggests that there is a strong measure of support for what we are intending to do.

The Convener: Professor McLean, from your perspective are there any areas in which we may find ourselves stumbling into controversy?

Professor McLean: The only likely area is an historical one. Will Scott is right that we have worked with health care professionals and with most of the family groups, and they are all on board with this. In fact, practice has changed, very much in line with our broad recommendations. There may still be some historical concerns among certain individuals or groups, but the bill should be largely uncontroversial—if that is not a hostage to fortune.

John Forsythe: I underline what Will Scott said about the transplant side and consent: opting in versus opting out, and authorisation. Those issues are debated across the world where transplantation has any impact. The bill also provides for preservation of the body or parts of the body for the purposes of transplantation. That is another advance, if you like, but that is the only other part that I would point to.

Joe Logan: There are no real issues of controversy in the modernisation of the Anatomy Act 1984. There may be some concerns around the new licensing arrangements that are being introduced with respect to the public display of bodies. However, generally the response to the consultation that we carried out was supportive of the changes.

The Convener: It is helpful to get a feel from the four of you about where you think the most likely areas of controversy lie.

Janis Hughes (Glasgow Rutherglen) (Lab): The Human Tissue Act 2004 is a recent piece of Westminster legislation. Although the legislation here is slightly different, the Executive has made the point that it has actively sought to ensure consistency throughout the UK. I wonder why it is felt that we need different legislation here. Could you outline the reasons for that and say why our legislation will be different?

Will Scott: The parts of the bill that I have been dealing with address subjects that are devolved to the Scottish Parliament, so it was felt that it was appropriate to consider legislation in the Scottish Parliament. Part of the reason for that was that we had already been doing quite a lot of work to develop Scottish solutions to those problems, through the review group and through the important work that NHS Quality Improvement Scotland has done in developing standards for hospital post-mortem examinations. As you heard from John Forsythe, the Scottish transplant group was already examining those issues.

We thought that we could get the best of both worlds by having separate Scottish legislation, bearing in mind the important recommendation from both the groups that there should be separate legislation on each of the subjects. As you will know, the 2004 act takes a different approach, by weaving all the different strands together. I would like to think that the approach that we have taken has enabled us to focus and fine-tune the provisions for transplantation, as opposed to post-mortem examinations, and to reflect the different starting points for the legislation.

It is terribly important, however, that there should be a broadly consistent approach across the United Kingdom, and all the health departments have been working closely together on the primary legislation and, even more so, on the regulations and codes of practice that underpin them. That is important in relation to living transplantation, where we want the Human Tissue Authority, set up under the 2004 act, to discharge that function for Scotland. It did not make sense to set up a separate body in Scotland, given the numbers involved.

Janis Hughes: I understand the point that was made about the bill relying more on authorisation than on informed consent, which I think is in the 2004 act. Are you saying, in effect, that the Scottish bill will go further than the 2004 act?

Will Scott: No. I think that informed consent and authorisation are different terms for trying to ensure that people’s wishes are expressed and, having been expressed, are respected.

Professor McLean: There is another underpinning set of reasons why Scotland should legislate on its own. First, as Will Scott said, it is important that we separate transplantation and organ retention and removal, which the initial English report did not do. Secondly, the review group on retention and removal had a much bigger remit than its equivalent for Bristol and Alder Hey. We were also invited to consider adults, so it was likely that there would be a different set of solutions.

On a slightly more legalistic point, because the law is quite significantly different in Scotland and in England in respect of older children, it is important that account is taken of Scots law’s approach to the mature minor. That would be quite difficult to achieve in national legislation.

Finally, there was an opportunity to modify the basis on which people opted into the system. I would go slightly further than Will Scott and say that authorisation is a significantly different concept from consent. I was delighted when the British Medical Association withdrew its concern that we should have absolutely the same approach throughout the United Kingdom and endorsed the notion of authorisation, because that does make a difference.

The Convener: We now live in a world of what we might call surgery tourism. We are talking about trying to achieve some similarities for the whole of the UK, so that we do not have a situation in which things are terribly different in Scotland. Does that go for the European Union as well? Is there a broad general agreement in EU countries? There might be some minor differences about the issue, but are we moving towards a general agreement? That is probably about as far as I can take the question, because there is not much that we can do about surgery any further away from us, but I wondered about that wider scope. We are now in a world in which people are signing up for package tours that involve surgery.

Will Scott: I will have a go at answering that, but John Forsythe, who is not only chair of the Scottish transplant group but president of the British Transplantation Society, will be more able to talk about the European dimension. Certainly, there are arrangements within Europe for the exchange of organs and tissue in accordance with the general rules governing health matters in the EU. John Forsythe will say something more about the specifics of that in the context of transplantation.

14:30

John Forsythe: The laws across Europe are quite different from country to country, with some countries requiring people to opt in and others requiring people to opt out, which can be either a so-called soft opt-out or a hard opt-out. There is quite a bit of variation, but there is some capacity for the movement of organs in particular. Organs that will not be used within the local area or nation can be moved around. That is not very common but it happens, with close co-operation. For patients who require a transplant, it was felt after discussion that it is fair for such patients to be able to move around by opting to be on a waiting list in another area, but they can be on only one waiting list at a time. That is probably a fair compromise in the circumstances.

Shona Robison (Dundee East) (SNP): The Human Tissue Authority, which was established by Westminster under the Human Tissue Act 2004, has been the subject of a couple of comments already. It was mentioned that the authority will have a role in Scotland in monitoring transplants involving live donors and that the small number of such transplants was one reason why it was not felt necessary to have a separate body for Scotland. In that case, which authority will monitor and oversee the other aspects of the bill for matters other than live donation? How is that envisaged?

Will Scott: Do you mean which authority will monitor those aspects in Scotland?

Shona Robison: Yes.

Will Scott: For post-mortem examinations, oversight will be by NHS Quality Improvement Scotland. NHS QIS has already had a go at assessing performance against the standards that it developed; indeed, it published the results of that assessment—the publication is mentioned in a cross-reference in the briefing from the Scottish Parliament information centre—back in February of this year. That report provides a good overview of the current state of Scotland's post-mortem services, which reflect many of the changes that, as Sheila McLean said, have taken place as a result of the work of the review group that she chaired, and public concern about past practice. In the context of post-mortems, NHS QIS will have a monitoring responsibility.

For transplants, although it might look from the Human Tissue Act 2004 as if the Human Tissue Authority will have a lot going on, the authority will in fact take quite a light touch in its monitoring of transplantation involving deceased donors. Certainly, it has no intention of introducing any licensing or inspection system. That was made clear to us at the outset, when we were trying to work out how the position in Scotland would match up to the position in the rest of the UK. Another body—UK Transplant—oversees organ matching and allocation arrangements and carries out an audit function. That is probably as much oversight as is needed.

Perhaps John Forsythe will comment from the transplantation perspective.

John Forsythe: Transplantation is heavily audited and is subject to data collection perhaps more than any other type of health care in which I have been involved. Allocation policies and so on are overseen. If I may hark back to my previous point, I would say that transplantation has not been seen to get things wrong or to have anything other than good practice in the past. The task is simply to facilitate the continuation of good practice rather than to stop some previous difficult or bad practice.

Shona Robison: We understand that, should one be required at a later date, the bill provides for a suitable body to be established for monitoring purposes. Is that the case?

Will Scott: It is more the case that we are leaving our options open. The bill contains a power for the Scottish ministers to ask any other public body anywhere in the UK to take on any of the bill's functions, which is one of the reasons why section 1 includes a statement of the functions of the Scottish ministers.

If it turns out in the future that the arrangements prove to be untenable or if, given that our aim is to increase the number of living donations, the numbers are sufficient to justify a separate Scottish body, we could do that, in time. Keeping our options open is part of trying to future-proof the bill as much as possible

John Forsythe: Given that oversight now applies not only to unrelated transplants but across all living donor transplants, our slight concern is that there could be a swamping of the mechanism. It is important that the mechanism responds in a timely fashion; we need to keep an eye on that.

Mike Rumbles (West Aberdeenshire and Kincardine) (LD): I understand that organ donation has been in rapid decline in recent years. The bill should arrest that decline and make transplants easier. I have my old and rather battered NHS organ donor register card with me—some of my colleagues might like it to be used sooner rather than later.

I am surprised to find no reference to the NHS organ donor register in the bill, which refers only to authorisation by an adult or to an existing written request. I assume that a massive Executive campaign to encourage the use and carrying of donor cards will be linked to the introduction of the eventual act. However, the change in the law will make the card meaningless if it can be overridden by the wishes of a relative. Why was the Executive not a bit more forthright by including the donor card in the bill?

Will Scott: We made a deliberate decision not to include in the bill reference to the NHS organ donor register. We cannot be sure what will happen in 20 or 30 years—the register might have served its purpose and some other mechanism have been put in its place. We thought it best to establish the general principle without expressing it in terms of a specific mechanism. The decision was made for no other reason.

We run regular organ donation publicity campaigns to encourage people to carry the card, to join the register and, crucially, to tell their nearest and dearest of their wishes because people need to make their wishes clear. We thought that to include a reference to the register would be too prescriptive. The register is, however, central to plans for implementation of the legislation.

Professor McLean: The major difference between the legal regime in the bill and the previous one is that a relative will not be able to veto a donor's wishes. One of the problems with the Human Tissue Act 1961 is that it appears—either from the face of the act or in practice—that relatives are allowed to veto. The review group's recommendations on the locality of the authority were taken into the transplantation arena as well, which means that, if someone has registered their wishes, the card that they carry will have more weight in the future than it ever did in the past. The obligation under the bill is to discover only whether the person has changed their mind; there is no obligation to ask spouses and distant relatives whether they agree.

Mike Rumbles: Is it necessary to have section 8—"Existing written request: adult"—and section 6, "Authorisation: adult"? Surely, when the bill comes into effect, section 6 will cover people like me who carry a donor card and have registered their wishes. What is the need for section 8?

Will Scott: Section 8 makes it absolutely clear that people who carry a card or who have joined the register do not need to do anything more. When the act comes into operation, all those authorisations will be automatically sorted out—people will not need to go through the process again.

Section 6 will apply to people who have not carried a card or added their name to the register. They will start from scratch. The bill preserves all the names that are already on the register and all the donor cards that people already carry. They will become the authorisation, with the effect that Sheila McLean just explained.

Dr Jean Turner (Strathkelvin and Bearsden) (Ind): My question is for Professor McLean, who commented on the age of 12 for a competent minor and why that age was decided on, which many submissions discussed. Your submission says:

> "It is not clear why authorisation for transplantation requires only one witness, whereas for a post-mortem examination two witnesses are required"

and

> "Nor … is it clear why authorisation must be in writing."

The submission also says that the Age of Legal Capacity (Scotland) Act 1991 gives a young person the right to give permission for medical treatment but does not stipulate a chronological age.

When I read through the bill, I wondered why the age of 12 was chosen. People who have worked with children who are younger than 12 will know that some of them are competent to make such decisions. Having read something from parents, I know that some people are worried about the age of 12 having been chosen. I think that a pathologist also expressed concern about it in a submission. Will you expand on that?

Professor McLean: I am happy to do so. I do not know why the age of 12 was selected except that, historically, a girl reached the age of minority at 12—boys did so two years later. At that age, increased legal status was recognised; a child stopped being a pupil and became a minor. That might have permeated the drafters' consciousness.

As you know, I have some concerns about section 9, because it is unclear why a competent minor should be constrained from making decisions that he or she would be allowed to make if they were chronologically a little older. It occurred to me after I submitted my evidence that genuine problems may arise with domino transplantation—John Forsythe may want to pick up on that—whereby a competent child would undergo a transplant and is giving to another child. If they were precluded in law from making such a donation, they would not be allowed to participate in such a transplantation process. There could be practical reasons for being concerned about the proposal.

The Age of Legal Capacity (Scotland) Act 1991 was referred to because we in Scotland have felt superior to our colleagues south of the border, because our legislation makes it clear that if a child is deemed to be competent—a doctor normally judges that, as Dr Turner knows—he or she is entitled without parental intervention to consent to involvement in medical treatment. The act also refers specifically to medical procedures. The presumption on the part of the academic community at least has been that that means that young people who are competent could consent to a non-therapeutic event such as donation of an organ. If that interpretation is not right, many people in England will be pleased, because we have told everybody how superior our position is. It is strange that we will constrain the situation.

As for Dr Turner's first point, it is unclear why a difference should be made in witnessing a competent request because of what is being requested. Little evidence exists about the long-term effects of organ donation on children, because we have not traditionally done that. That might be a reason why the transplant community was concerned about using mature children. However, our law has always said that once a minor is competent, he or she is entitled to make decisions of any sort, so the bill goes backwards a little.

John Forsythe: The subject is difficult and everyone is trying to get it right. It seems to be right that a competent minor should be able to decide, for example, to give a portion of his or her body to help a sibling to survive or have a better quality of life. We would all be comfortable with that if a piece of skin was being transplanted, but we might be a little less comfortable if a kidney was being transplanted—a procedure to which significant morbidity and mortality rates are attached. We might be talking about a person who was only 13 or 14, which would mean that they would live with only one kidney for a long time. Would that be right for them? Beyond that, would it be right to remove a portion of liver from a live donor of that age, so that it could be given to someone else?

I and some of my colleagues feel some discomfort because we are worried that there could be coercion. Although that might not take the form of the family saying to a child, "You must do this," the child may have the feeling that he or she has to go through a particular procedure to save a family member. There is a great deal of concern about that. The issue is difficult and could be debated for a long time, so the committee must recognise the problems that might be opened up if the proposal were agreed to.

14:45

Shona Robison: Surely that would come down to the individual child. The same concerns apply whether the child is 12, 13 or 14. Surely it is important to ensure that the system and procedures that are put in place prevent such coercion as much as possible. I hear what you say, but I am just not sure that the provision that the child should be aged 12 or more would stop coercion.

John Forsythe: That is right. The difficulty is that people's views mature as the years go by, so there is always a worry that it is easier to coerce a younger person, even if one does not mean to, than it is to coerce an older person. That may be wrong, but we probably all feel that innately.

Professor McLean: The problem is that a person who is 16 can do anything they like with their body, but can be coerced just as easily as someone who is 15 years and 11 months old or even someone who is 14. The real question is about what we think we mean when we talk about legal competence. If we are saying that a person is competent to make health care decisions, it seems to be inappropriate to second-guess them. If there was evidence of physical harm or it was likely that there would be physical harm in the long term, we would have a different set of reasons for questioning a young person's decision but, in the absence of such evidence, if we genuinely mean that we as a legal community regard certain young people as being legally competent, it is difficult to justify second-guessing their decisions.

Dr Turner: I want to return to the issue of witnesses. One of the submissions spoke about avoiding having medical people as witnesses. I think that it stated that, in relation to children, the two people who would be required to act as witnesses must not be medical people. I assume that that means nurses or doctors. Would anyone like to comment on that?

Will Scott: As Sheila McLean has not been directly involved in drafting the bill, I should have a stab at dealing with that.

There was a theme running through the written evidence, which was about the formalities of authorisation and all the provisions for signing and witnessing. The main point is that the provisions in parts 2 and 3 are more stringent than those that relate to transplantation. That was a conscious decision that reflected public concern about the whole business of authorisation of hospital post-mortem examinations. We recognised that there was a need for everyone involved to be clear about what had or had not been agreed to.

In the past, one of the problems was that people just signed a simple form. Many things would be said that families were in no condition to take in. We want to have a form that sets out all the options that have been made available to a family and which has boxes for ticking so that there is a clear record of what has or has not been agreed to. The family will get the top copy to take away so that they can think over what they have agreed to. Another copy will go in the medical records and the pathologist who will do the post-mortem will get a copy.

The aim is partly to try to reassure everybody that we are trying to re-establish a system in which everybody can have confidence that all the options have been properly examined and that there is a clear, properly witnessed record of what has been agreed. There is a lighter touch in the transplantation part of the bill. Everything will be much clearer when people have the forms in front of them. Fairly complicated-looking provisions in the legislation should translate into a series of tick boxes and people will be able to see clearly whether something has been agreed.

Mike Rumbles: I want to return to the previous exchange about the age of 12. I am a little confused. Section 9 of the bill, which is entitled "Authorisation: child 12 years of age or over", and sections 10 and 11, which refer to that age, come under the heading,

> "Use of part of body of deceased person for transplantation, research etc."

but the discussion was about the appropriateness of live transplants. I cannot find what I am looking for in the bill.

Will Scott: Two different sets of provisions apply to children. The provisions on mature children who are aged from 12 to 16 relate to children who have died and for whom the question of donation arises. Those provisions are in section 9 of the bill, which relates to children who are 12 years or over. Section 15, which deals with transplants involving live donors, will make it an offence to remove

> "an organ, part of an organ, or any tissue … from the body of a living child".

A child is defined in the interpretation section as being someone who is under the age of 16. There are two different sets of circumstances.

Mike Rumbles: So, am I right in saying that transplants are not allowed for people under 16 and that the age is 16 and not 12?

The Convener: The age is 16 for live transplants.

Will Scott: Yes. We erred on the side of caution for living children because of the risks and pressures that John Forsythe has talked about. Removal of regenerative tissue, such as bone marrow, is the sole exception—that should still be possible with safeguards.

Mike Rumbles: So the age of 16 relates to live transplants.

Will Scott: Yes.

The Convener: We are basically saying that people who are aged 12 and over can make a decision about what will happen if they die, but people must be 16 or over before they can make a decision about live transplants.

Will Scott: Yes—that is right.

The Convener: That is clear enough. A slight air of confusion was rippling around the committee.

Janis Hughes: I want to return to the issue of ages, particularly with regard to post mortems. The independent review group gave a lot of consideration to disputes between parents. The bill proposes that only one parent would be allowed to give authorisation—both parents do not need to do so. There will potentially be contentions if a parent who is not looking after the child objects. How can we deal with such situations?

Professor McLean: As you know, the review group's recommendation was that a post mortem should not go ahead if there was such a dispute. The bill has not taken that recommendation on board. Will Scott may be able to explain why. We certainly thought that there was scope for considerable contention if parents were in dispute.

Will Scott: Following the review group's work, we consulted on the matter because it raises all sorts of tricky issues. As you say, the bill makes it possible for one parent to give authorisation, but that does not preclude the other parent from agreeing to give authorisation, too. That will be reflected in the authorisation form.

If there is a dispute, the issue boils down to the nature of the relationship between the parents. Nowadays, after all that has happened, I am sure that a post-mortem examination would not go ahead if the pathologist who was going to carry it out thought that the nature of the dispute between the parents was such that it would be unwise to rely on the authorisation of one of them.

We have left open the possibility of going ahead with authorisation by one parent because there may be circumstances in which that is perfectly appropriate. The bill would force nobody to go ahead if there was only one signature and if it was known that there would be a great deal of opposition or if it would cause distress to the other parent. That would be left as a pragmatic decision for clinicians.

Janis Hughes: If clinical opinion was that a post mortem was necessary, perhaps for diagnosis, but one parent objected while the other felt strongly that a post mortem should go ahead, how would that be dealt with?

Will Scott: We have tried very hard not to skew the legislation either way. You will have seen from one of the submissions that there are concerns even now that hospital staff may put parents under undue pressure to agree to post-mortem examinations. The review group's thinking, as embodied in the legislation, was that this had to be a process of discussion and agreement; there is no place for any kind of coercion.

Although we are very keen to position the post-mortem examination as part of the continuum of care that the NHS provides, we cannot go so far as to say that the bereaved should be forced to agree to a post mortem. That would be a failure to learn one of the main lessons of the past: if parents are in any way unhappy at the prospect of a post mortem, the legislation leaves it open to the clinicians concerned not to go ahead.

Mrs Milne: I suppose that I ought to declare an interest as the mother of a transplant recipient, which was successful, I may say.

I want to ask one or two questions about authorisation and the consistency of requirements for valid authorisation. I notice that the British Medical Association is concerned that the different requirements could lead to uncertainty and that people could inadvertently breach the law. The law should be kept simple, so what should the standard criteria be in order to keep it simple?

Will Scott: I am probably not the right person to answer that question. We had developed a carefully calibrated system of authorisation to take account of different circumstances, whether transplantation or post mortem, adult or child.

I realise that the bill can seem to be confusing; however, it will ensure that the transplant co-ordinators revamp their forms, which at present are headed in bold block capitals, "Lack of Objection". We want to replace that rather wishy-washy phrase with something much more positive.

We will have to sit down with the co-ordinators and with UK Transplant to work out what the requirements mean for the post-mortem form. If John Forsythe was about to perform a transplant he would check which boxes had been ticked on the form. Only when he was sure that the right boxes have been ticked would he go ahead with an operation.

The form will be much simpler and easier for people to use than is suggested by the bill. All the requirements will be on the form when the transplant co-ordinator is going through it with the family.

Professor McLean: Some clarification comes from other sections in the bill; for example, there will be a list of who is entitled to authorise if the deceased has not made authorisation. The common law would cover people who had made their own declarations and the list of next of kin will explain who else is given the power of authorisation.

Personally, I would like the bill to contain a definition of authorisation. In the past, the lack of clarity has left us in difficulties. The clearer we are about precisely what triggers authorisation, the better.

Mrs Milne: I have read through the submissions and it seems to me that there is some confusion and uncertainty.

John Forsythe: You are absolutely right. It is important that from the words in the bill are drawn forms that are relatively easy to use in practice in the specific situation that you are talking about. UK Transplant is well organised and it is likely that the forms will be produced relatively quickly. Teams from England and Wales visit Scotland—rarely, but it happens. Likewise, my team from the Scottish liver transplant unit sometimes makes visits. It is, therefore, important that we are aware of legislation in other parts of the UK. That requires good forms and proper training.

15:00

Mrs Milne: Do you think that what is in the bill is sufficient to ensure that that will happen?

John Forsythe: Yes. The text is fine, but we need to ensure that any codes that accompany it and any forms that follow from it are clear. Generally, it is felt that "authorisation" is the correct term to use in trying to establish the primacy of the deceased person's views.

Mrs Milne: I have one or two other questions on whether it is ethical for a person to give authorisation if the individual who has died has not left any indication of their wishes. Is it ethical for someone else to assume that authority?

Professor McLean: The position that has been adopted in the bill is much more in accordance with ethics than was the previous position. The principal purpose of these provisions is to make inquiries into what the deceased would have wanted.

We know, for example, that 90 per cent of the public say that transplantation is a great thing that they really approve of; yet, only 20-something per cent bother to register for it. We are trying to ensure that the next of kin or the people who knew the person best in life, instead of being given a right of veto, are asked not what their views are on whether the donation should go ahead, but what they can tell us about the deceased person's view. That follows through on our commitment to ensure that the authority that is vested in the individual now remains there, as much as possible, afterwards. The proposed situation is more ethical than the situation that we had before.

Mrs Milne: That would cover a friend of long standing and that sort of thing as well.

Professor McLean: Yes. We specifically included either a spouse or a partner as the first person who would be approached in the expectation that they would know better than anyone else what the person would have wanted, as they would be more likely to have had a discussion with them about it. A friend of long standing is included at the bottom of the list in section 45; nonetheless, it is there.

The Convener: Shona Robison has questions about part 3 of the bill.

Shona Robison: Yes—my questions are about the procurator fiscal. It is probably pretty obvious why you have decided that there cannot be authorisation for a post mortem to go ahead, as the procurator fiscal has that responsibility in the event of sudden, unexplained or suspicious deaths. However, what happens to the organs and tissue after the fiscal has finished the post mortem seems to be an area of contention. Perhaps you could say something about that. For example, why has it been decided to include

> "a person who had a longstanding professional relationship with the adult"

in the hierarchy in the bill? I understand that there was disagreement about that. It would be helpful to hear the bill team's reasons for including that provision and to hear from Professor McLean why there are concerns about it.

Will Scott: The hierarchy of nearest relatives for part 3 includes a person who had a long-standing professional relationship with the deceased on the basis of the advice that we got from the Crown Office and Procurator Fiscal Service, which deals with these cases. In quite a large number of cases, the deaths that the service investigates are of people who had no known relatives and no friends. The provision is included to take account of that and to open up the possibility that somebody such as a social worker or general practitioner with whom the person had had a long-standing professional relationship could be approached to give authorisation. That was the thinking behind the provision, which was introduced subsequent to the review group's discussions—the thought emerged during the process of developing part 3.

Professor McLean: As Shona Robison may know, I raised that issue in my submission, as well as an issue that goes hand in hand with it: the question whether local authorities should be allowed to give authorisation. The intention to maximise the potential of post-mortem examinations to provide quality education and research opportunities is good. However, I am slightly uncomfortable about the extent to which the drive in that direction might be at the expense of the requirement for intimate knowledge of what the person wanted, on which we founded our recommendations. A general practitioner may be well aware of what a person would have wanted in respect of post-mortem examinations. However, there is a balancing act between the individual's right to make certain disposals and the extent to which the requirement for a certain quality of information about their wishes is met. My concern is that those two agencies—the GP or the local authority—may not have the level of knowledge that I would want.

Shona Robison: So in a case in which there are no known relatives, what would the alternative be?

Professor McLean: The alternative would be that the organs or tissue that had been retained could not be used. That is the balance. Is it in the interests of society to proceed to use organs or tissue in those circumstances, or should we stick to one coherent ethical position?

The Convener: Helen Eadie is interested in that issue, but that discussion probably answers her questions on it.

Helen Eadie (Dunfermline East) (Lab): Yes, it does.

The Convener: She also has a question about part 5, which will be for Joe Logan.

Helen Eadie: My question is about the definition of anatomical examination—I was worried in case I might not get my tongue round that. Will the proposed definition satisfy the expectation that a broadening of it will facilitate training opportunities in the procedures for all the relevant professionals, not just for surgeons?

Joe Logan: Yes. We took into account the responses to the consultation exercise that asked us to consider that, for example, technicians are involved in retrieving organs from bodies for transplantation and that they should be allowed to practise the procedure. Our definition will widen the scope and will allow other professionals to use the facility for training.

The Convener: Jean Turner has a question about verbal authorisations in relation to part 5.

Dr Turner: The provision on verbal authorisation for the donation of one's body for anatomical examination seems to be different from the provision on authorisation for organ donation and hospital post mortems. A person will not be able to state verbally that they want their body to be used for the purposes of anatomical examination. However, at present, people can authorise the donation of their body in front of two witnesses. Will you explain the reason for that difference?

Joe Logan: Again, in the response to the consultation, there was support for tightening that part of the 1984 act so that witnessed written authorisation is required. However, we will seek to standardise the authorisation forms. At present, the authorisation forms that the various anatomy schools use differ. We feel that the measure is justified, as there may be a desire to retain body parts, which could be used in the interests of education and information and could be put on public display. For example, that could be done to show healthy lungs and to demonstrate the effects on lungs of long-term smoking. It seemed appropriate to concentrate on written authorisation and clarity around that written authorisation in establishing what individuals were prepared to have their body used for after their death.

The Convener: That exhausts our previously intimated questions, but do any committee members wish to pursue anything else arising from what they have heard?

Shona Robison: I have a general point that goes right back to the start and the debate around the opt-in and opt-out possibilities. I would like to get more of a flavour of that debate. John Forsythe might be able to tell us what the balance is in the EU between countries that have an opt-in system and those that have an opt-out system of organ donation.

John Forsythe: I am trying to do a quick calculation. I think that more countries in Europe have an opt-out policy, rather than an opt-in policy, although I cannot be absolutely certain. It is interesting that Spain is always cited as being the country with the best practice, with a donor per million rate of more than 30, in comparison with a rate of 13 for the UK. There is opt-out legislation in Spain.

However, I have spoken to the main architect of the system in Spain, and he has been quoted as saying that legislation in itself has not brought about the high rate. He has said that what happens in Spain is in fact very similar to what is proposed in the bill with respect to relatives being consulted—mainly to be asked what the views of the deceased were. The Spanish may have an opt-out system according to the strict definition of the law, but it is used slightly differently in practice.

Shona Robison: Have there been any projections of what we can hope for by way of an increase in the level of donations, should the bill be passed?

John Forsythe: It is difficult to know. There is no really good evidence to say that changing legislation in itself produces a major change in the level of donations. We hope that it will produce such a result and that the refusal rate among relatives, which a few years ago used to be about 30 per cent in the UK as a whole, but which is now about 46 per cent, might change. We can only guess why the refusal rate has risen but, following the events at Alder Hey children's hospital and Bristol royal infirmary, there has been a slight loss of trust between those who deliver care and those who receive care. It is important that what we put in place does not damage that trust any further.

Professor McLean: There are systems known as required request systems. I think that there was some research carried out in Flanders, where one hospital adopted such a policy and another one did not. The rate of donation went up significantly where a soft required request system was in place, under which the clinicians in charge of the deceased person had an obligation to raise the question of transplantation with relatives. It seems from the research that I have seen that such a system can make a difference to the donation rate.

Dr Turner: I might have missed something—Nanette Milne may have touched on this point—but I wish to refer to the General Medical Council's submission on live donation. The submission states:

> "Section 15 precludes the removal and use for transplant of organs and tissue, other than regenerative tissue, from living children. While we agree that measures should be in place to protect children's interests, we do not believe that it is appropriate to make the removal of organs or tissue from a living child an offence without exception, since exceptional circumstances can be envisaged (for example, where the child is the only suitable donor for a sibling with acute kidney failure). We propose therefore that the Bill be amended to require that where such situations arise, a court ruling should be sought on whether it is appropriate to proceed."

John Forsythe: Was that from the GMC or from the BMA?

Dr Turner: That was from GMC Scotland.

The Convener: This subject would have been covered by our earlier discussion about age limits.

John Forsythe: Yes.

Dr Turner: I was not sure whether the point that I have just highlighted came under that discussion.

Professor McLean: That is indeed where some confusion arose, and I was hoping to get the opportunity to come back to this subject. We were discussing live donations by 12 to 16-year-olds because the bill does not permit such donations at all. However, consider the provisions on post-mortem examinations for 12 to 16-year-olds. I know that the BMA also feels that there should be some way of overseeing decisions in this area for those between the ages of 12 and 16. To have an outright ban not only precludes domino transplantations but rejects the notion of competence.

Will Scott: My reading of the BMA's submission was that it does not want living children to be involved at all in donation, other than when it comes to regenerative tissue.

Professor McLean: I must have seen an earlier draft of that submission.

The Convener: I am sure that we will be able to take evidence directly from the BMA. I thank all the witnesses for coming. I hope that you did not find the experience too painful. No doubt you will be watching the committee's progress on the bill with interest.

I propose to take a five-minute break before we move on to agenda item 5—and I really mean five minutes. I will reconvene the meeting at 3.20, so do not go far.

15:15

Meeting suspended.

15:21

On resuming—

Care Inquiry (Participation Event)

The Convener: Item 5 on the agenda is a brief discussion about the care inquiry participation event that took place last Thursday in Perth under the auspices of the Health Committee. I welcome Margo MacDonald, who wanted to join us for this part of our discussion.

I invite members to comment briefly on what they consider to be the key issues and themes arising from last Thursday's meeting. We will agree the remit of the inquiry at the committee meeting on 27 September, so we are a considerable time away from a final decision on the matter, but we need to have a brief discussion today to help to inform the preparation of a draft remit for consideration at that meeting.

Mike Rumbles: I was at the free personal care session in which two issues predominated. First, although there was complete agreement that the legislation is good, there are problems with implementation with regard to funding, which is key. Some of the evidence that was given in the general session was also quite moving. The other issue was whether free personal care should be extended to all people who would benefit from it, not just the elderly.

Kate Maclean (Dundee West) (Lab): In the workshop that I was in and in the main sessions, implementation seemed to be more of an issue than the legislation itself. One of the main concerns that came out of all the workshops was the effect on fees of the care commission being self-financing. We should consider that.

I agree with Mike Rumbles that we need to consider extending the scope of personal care to cover other adults who have special needs. Care must be geared up to meet the needs of the individual, and the people who receive care must be far more involved in the strategic planning and focus of the care that they receive.

Shona Robison: I was at the regulation workshop. The key point that came out of it was about the duplication of regulation, which causes some providers to feel that they are being reviewed and regulated by a number of bodies at different times in different ways for different purposes. Cost was also an obvious issue.

The fees issue also came up. In the light of our discussion, it is interesting to see in the papers for agenda item 6, on the budget process, a proposal for savings to be made from the care commission.

There was also a sense that local authorities were doing their own thing or implementing the legislation in different ways. We felt that that issue should be examined.

Mrs Milne: I was in the joint working group. The key point that came out of it was the need for honesty and to manage people's expectations about what is available. It is important not to kid folk on that they can get everything that they need in the way of care and to be realistic about what can be provided.

There was also some talk about breaking down professional barriers, which has been a bit of a problem in getting joint working going. It was said that there is a need for funding to come together—ideally in one particular body, whether through community planning, community health partnerships or whatever. The point about honesty came up again and again.

The Convener: We were all very moved when we heard from Pam Duncan about the ridiculous trap that she was in, which opens up the issue of extending free care to under-65s. As it happens, shortly after the event a constituency case raised with me the negative impact on respite day care of the registration fees that the care commission requires for each activity. Some care homes are in effect withdrawing certain aspects of what they do, which might well have a negative impact on the number of respite day care places.

When we talk about the care commission, the costs and all the rest of it, it is important to explore the potential impact on delivery of the service. The matter is not just a bureaucratic, administrative issue for the care commission; it is about what happens on the ground. The care commission must be self-financing. If we take money out of its budget, it will try to get the money from somewhere else. What does that mean for the provision of care? People may decide that they are not able to afford it. All those issues are connected.

Margo MacDonald wants to comment on the matter.

Margo MacDonald (Lothians) (Ind): On the last point that you raised, I am horrified to think that the care commission might be self-financing, but that is just a personal comment.

I ask the committee whether it will examine the position of care homes. I am sure that members are aware that there has been a huge amount of publicity recently about negative aspects of care in some homes. I have been approached by various groups and trade unions in Edinburgh, which has a particular problem because of house prices, land prices and so on. When the gap between what voluntary sector and private sector homes consider it costs to provide the service that they provide to the required standard and the per capita payment that they receive became bigger than it was before—to the best of my knowledge, a gap has existed for at least 20 years—many businesses and voluntary organisations found that because of land prices and house prices their books balanced much better if they got out of the business of providing care and went into some other business. Therefore, there is a tremendous shortage of care homes in and around Edinburgh, which in turn feeds back into hospital bed provision—I do not need to bore the committee.

For that reason, as the committee is going to conduct an inquiry, I am anxious that the committee should examine the position of care homes. I would also be grateful for an objective overview of any real or perceived differences in the quality and standard of care that is provided between the private sector and the public sector and of whether the standard of staff training—and, ultimately, the quality of personal service that is offered—is better in the public sector. There is usually a greater awareness in a local authority bureaucracy of the necessity for staff training.

15:30

The Convener: Thank you. We heard quite strong views about announced versus unannounced inspections, which is not quite the issue that you are talking about but which relates to standards.

There was a pretty big difference between the priorities of the service users and those of the service providers, who had very different views about what is important. It will be for the Health Committee to juggle those priorities when it comes to setting the remit of the inquiry.

Mrs Milne: The funding of cares homes is a huge issue. Joe Campbell of Scottish Care was not well on the day of the meeting but we would have heard a lot more about that if he had been there. We should consider it because it is a massive issue.

Margo MacDonald: We must try to depoliticise the issue. The committee is a political body, but the members are the people who can depoliticise the remit.

Dr Turner: Top-up fees and direct payments were mentioned, although not in my group. Finance does come into the picture.

I was in the carers group and everyone agreed that the legislation was a good idea; it is implementation that is difficult. Finance is behind many of the problems.

It is true that many homes are going out of business or are struggling to stay in business because they are not getting enough money to provide services. Often they do not provide the services that are shown in the glossy brochures. Some people live in homes that have no money at all; everything has been taken away and their families have to fork out extra cash.

An important point about carers is that a huge number of them look after people in their own homes. As has been said, respite is most important and if funding for that is cut, the burden is greater and people become patients in the NHS. Carers do not want much; Pam Duncan who was in our group said the same. I am not really asking for much. I know from my previous occupation that getting respite care was always difficult, but it is becoming very difficult.

There are two types of respite: the kind that gives the carer a holiday and the kind that is needed every day. Convener, you seemed to be saying that you know of people who need daily respite but are not getting it.

The Convener: I am exploring the issue separately but it does impact on the inquiry and contact might have been made because of the publicity for the inquiry.

Kate Maclean: Qualifications and training were also raised. Again, there were two sides to the issue. Service users and the groups that represent them welcomed the fact that there is a benchmark for training and qualifications, but care home owners felt that the benchmark is just an unnecessary financial burden. I was not very happy about the attitude of one care home owner, who said that a person does not need qualifications to learn how to change an incontinence pad. In fact, they would need to be trained in how to change incontinence pads—I am someone who changed incontinence pads in a previous life—and it is worth exploring the level of training and qualifications. The matter is not in the legislation but it is in regulations and we should consider it.

I guess that training could be a financial burden on care home owners, but it is important for people’s safety and dignity that carers have appropriate training. However, the qualifications that are being asked for should be necessary and appropriate and it would be worth considering what appropriate and necessary training is.

The Convener: Training is also important for staff, especially if they are to avoid injury to themselves. That issue has been raised in the past.

Shona Robison: I am sorry to come in again, but I forgot to mention that, in our workshop, one of the relatives pointed out that what happens post-complaint must be monitored. Perhaps this evidence is anecdotal, but I have certainly been told on enough occasions that when a complaint is lodged there can sometimes be perceived repercussions. In fact, the perception that there might be repercussions stops relatives making a complaint in the first place. I have certainly come across cases in which constituents did not want to use official channels because they were worried about repercussions for their affected relatives. Whether those repercussions are perceived or actual, we need to take the matter seriously and consider it in our inquiry.

Helen Eadie: I do not know who organised last week's business, but it would not be exaggerating to say that everyone to whom I spoke was ecstatic that the committee had chosen to consult on the remit of the inquiry. It was certainly an example of best practice. Whoever in the team of clerks had the idea, it was first class, because it really struck a chord with the public. Indeed, perhaps other committees could learn from our experience, because it proved to be very popular with care people and professionals.

The Convener: An evaluation form has been e-mailed to all members. I have certainly filled mine out and sent it back and I encourage everyone else to do the same, because it might well play back into the rest of the committee system. As I said to one or two folk, politicians—perhaps surprisingly—do not always have all the answers right at the start. It is sometimes useful for us to say so and to ask people to help us to find some of the right answers.

I do not want this item to go on any longer. Members have the capacity to communicate directly with the clerk. We will draft a paper that will lay out some of the ideas for the remit. We will kick that around for a while, because we do not have to reach a final decision until the end of September.

Budget Process 2006-07

15:37

The Convener: The sixth item on the agenda is consideration of the budget process 2006-07. I do not propose to spend a huge amount of time on this. A paper has been circulated to all members. I should point out that, this time, our approach is slightly different; I want members to take a view on the recommendations on page 2 of the paper and to agree them. Do members have any strong views otherwise? Is everyone happy with the proposed approach?

Members *indicated agreement*.

The Convener: I realise that it marks a change in the way in which we normally do things, but this is not a normal year as far as budget scrutiny is concerned.

The clerk has just pointed out that we need to give a steer on two or three specific issues that we want to focus on.

Mike Rumbles: With regard to

"Efficiency Savings in the Care Commission",

which is programme 10 in the paper, one problem that we have already identified is that the commission has to be self-funding. I think that we should pursue that issue.

The Convener: That is one issue. Do members have any other suggestions?

Janis Hughes: Given the changes in health care provision, one important issue must be information technology. In the paper, it comes under the heading of

"Programme 3—NHS Logistics Reform",

which takes in technology, procurement and so on.

The Convener: We do not want to have any more than two or three issues.

Mrs Milne: I wanted to flag up four issues in the paper, two of which have already been mentioned. The other two are prescribing, which represents a huge part of health service expenditure, and inappropriate hospital admissions. I think that prescribing is programme 4 in the paper.

The Convener: Do members have any other suggestions?

Mike Rumbles: We should just stick with those issues.

The Convener: We will focus on three issues: efficiency savings in the care commission; logistics and IT; and prescribing.

Mrs Milne: I think that, if we had room for four issues, inappropriate hospital admissions would come in with the Kerr report anyway.

The Convener: The danger is that our list could be endless. I suggest that we stick with and work on the three issues that have been identified. Are members agreed?

Members *indicated agreement*.

Shona Robison: Can I ask a technical question?

The Convener: If it is too technical, I will have to defer it.

Shona Robison: There has been talk in the media today of what have been termed time-releasing savings. I assume that they form part of the 2006-07 budget, but it might be only fair to ask the clerk to have a wee look at where such savings fit into all of this. After all, many assertions have been made about what they will deliver.

The Convener: We will seek clarification of what time-releasing savings are, as opposed to any other kinds of savings.

That ends the public business. I ask members of the public to leave the committee room.

15:40

Meeting continued in private until 15:57.

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