The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 24 November 2015

Session 4

Tuesday 24 November 2015

CONTENTS

Col.

CARERS (SCOTLAND) BILL: STAGE 2 1

TRANSPLANTATION (AUTHORISATION OF REMOVAL OF ORGANS ETC) (SCOTLAND) BILL: STAGE 1 31

HEALTH AND SPORT COMMITTEE

32nd Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Professor David Galloway (Royal College of Physicians and Surgeons of Glasgow)
Jamie Hepburn (Minister for Sport, Health Improvement and Mental Health)
Dr Calum MacKellar (Scottish Council on Human Bioethics)
Anne McTaggart (Glasgow) (Lab)
Dr Charles Wallis (Scottish Intensive Care Society)

CLERK TO THE COMMITTEE

Jane Williams

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 24 November 2015

[The Convener opened the meeting at 09:30]

Carers (Scotland) Bill: Stage 2

The Convener (Duncan McNeil): Good morning and welcome to the 32nd meeting in 2015 of the Health and Sport Committee. As I usually do at this point, I ask everyone to switch off mobile phones, as they can interfere with the sound system. I also note that members are using tablet devices instead of hard copies of the papers.

We have received apologies from Bob Doris, and we expect Mike Russell to join the committee at some point.

The first item on the agenda is stage 2 consideration of the Carers (Scotland) Bill. We have with us the Minister for Sport, Health Improvement and Mental Health, Jamie Hepburn—I welcome him—and from the Scottish Government's bill team Moira Oliphant, team leader; Lynn Lavery, delivery manager; Ruth Lunny, a lawyer; and Ian Young, depute Scottish parliamentary counsel.

Everyone should have with them a copy of the bill, as introduced, the marshalled list of amendments, which was published on Friday, and the groupings of amendments, which sets out the amendments in the order in which they will be debated.

There will be one debate on each group of amendments. I will call the member who lodged the first amendment in the group to speak to and move that amendment, and to speak to all the other amendments in the group. Members who have not lodged amendments in the group but who wish to speak should indicate in the usual way. The debate on the group will be concluded by my inviting the member who moved the first amendment in the group to wind up.

Given that we will not dispose of all the amendments at today's meeting, I propose to finish this item around 11 am. Any outstanding amendments will be considered at next week's meeting.

Only committee members are allowed to vote. Voting in any division is by show of hands. It is important that members keep their hands clearly raised until the clerk has recorded the vote. The committee is required to indicate formally that it has considered and agreed each section of and schedule to the bill, so I will put a question on each at the appropriate point.

Sections 1 to 5 agreed to.

Section 6—Duty to prepare adult carer support plan

The Convener: Amendment 1, in the name of the minister, is grouped with amendments 2, 3, 92, 8 to 10 and 93.

The Minister for Sport, Health Improvement and Mental Health (Jamie Hepburn): I am very happy to be here for stage 2 of the Carers (Scotland) Bill, and I place on record my thanks to the committee for all its work at stage 1.

As the provisions in sections 6 and 11 are currently drafted, they could imply that there are circumstances in which the duty to offer a person an adult carer support plan does not apply or does not have to be fulfilled. For example, if the responsible local authority or responsible authority is simply asked by a carer for direction to low-level support services that are available generally in an area, such as information and advice services, the duty to offer an adult carer support plan or young carer statement does not apply or require to be fulfilled.

Amendments 1 to 3 and 8 to 10 put beyond doubt that, once a person has been identified to or by a responsible local authority as a carer or young carer, that identification in itself triggers a separate duty on the authority to offer that carer an adult carer support plan. It is the acceptance of that offer of a support plan that triggers a subsequent duty to prepare the relevant support plan or young carer statement.

I turn to amendments 92 and 93. It was clear in the original consultation on the bill that the vast majority of respondents, including many local authorities, favoured the support plan being available to all carers. Even now, a number of local authorities do not use the test to see whether a carer offers regular and substantial care, which is the statutory requirement now, and offer the carer's assessment to all carers. Therefore, we have removed what is called the regular and substantial test in the current legislation, whereby only carers who provide or intend to provide a substantial amount of care on a regular basis are eligible for the carer's assessment.

I am not inclined to introduce another way to regulate demand, which would seem to be the intended effect of amendments 92 and 93. I understand that there will be increased demand for the adult carer support plan and the young carer statement, and that is a good thing. It is a preventive measure so that carers can be assessed early in the caring journey. Even if a carer does not require any support to meet the identified needs, the process for a good-quality, empathetic support plan or statement is beneficial in itself.

The support plan and statement process also helps to identify carers who, even if they do not need support now, may need support in future. I do not think that amendments 92 and 93 would save resources, if that is why they have been lodged. There would have to be an assessment process in order to determine whether a carer is in need of support. On that basis, I respectfully ask Nanette Milne not to move amendments 92 and 93.

I move amendment 1.

Nanette Milne (North East Scotland) (Con): Amendment 92 applies to adult carers, and amendment 93 would have the same impact for young carers. The amendments, which have been suggested by the Convention of Scottish Local Authorities, aim to construct a means of ensuring that assessment and support are targeted at those for whom caring has the greatest impact on their ability to maintain their health and wellbeing and lead a life alongside caring. They would allow councils to manage demand for assessment, with reference to the eligibility criteria that the bill requires councils to publish in consultation with carers and carer organisations. That would ensure that assessment resources are targeted at those with the greatest need and would prevent resources from being lost on applicants who cannot be granted a support plan.

COSLA reasons that, as the bill is currently drafted, prioritising comes later, in sections 19 and 22. COSLA would like another layer of prioritising to be introduced, which would come earlier, at the assessment stage covered by sections 6 and 11. It would not replace sections 19 and 22 but would sit alongside them, giving a two-stage process. That would allow prioritisation of those who will receive the full adult carer support plan or young carer statement provided for in sections 6 and 11, if amended, followed by those who will be eligible for support services, as provided for in sections 19 and 22.

Rhoda Grant (Highlands and Islands) (Lab): I have sympathy with what Nanette Milne is trying to do but I am concerned that it would stop carers getting an assessment when they require it. A real issue that is not dealt with by the bill is how to prioritise carers. We all know, from casework, that there are carers who are on the verge of breakdown. They need to be given priority, especially in the early stages of implementation of the bill. If we do not give them priority, the risk is that some carers will break down, while others, who may not have the same need, are seen first.

At the same time, I am not minded to support Nanette Milne's amendments because I think that they could be used as a loophole not to provide carers with the assessment that they may need. However, I am keen that, especially in the early stages of the bill, some kind of priority should be given to those in most need.

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): I, too, am not minded to support Nanette Milne's amendments. However, I have talked to COSLA about them and I understand its concerns. It comes down to the financial implications. Although I cannot claim to be totally on top of the twists and turns of the financial memorandum, it would be useful to have a comment on the financial implications of assessing everyone, because I think that that is pretty central to COSLA's concerns. Nevertheless, I will not support amendments 92 and 93 because they seem to contradict a fundamental principle of the bill.

The Convener: No other members want to speak but I have one small point that the minister might want to address in his response. Some carers also expressed concern that they would see a shift in priorities; it was not just COSLA and others. If you could say something about that, minister, that would be great.

Jamie Hepburn: I will pick up on what has been said. On Mr Chisholm's comments, I have been clear through the entire process that, as far as we are concerned, the financial memorandum is the most robust estimate that we can make. It was based on all available information, much of which has come from local authorities. We have established a finance group to keep looking at the assumptions that have been made thus far. I am not aware of the group having brought forward any evidence that would cause me to question the assumptions in the financial memorandum.

I accept that case loads will still need to be prioritised once we have legislated, as I hope we will, albeit with my amendments to what is in the bill. I know that carers have raised the issue as well and that you, convener, have been pursuing it. It will be incumbent on us to make clear in guidance how prioritisation should be taken forward. It is not beyond local authorities to prioritise their case loads. We are already responding to certain circumstances and later will debate some amendments regarding carers for people who are deemed to be terminally ill and prioritisation in that respect. We can respond to such concerns.

It will come down to having robust guidance and I am happy to speak to any member about their particular concerns, as that could help to influence the guidance that we propose. We will also speak to the national carer organisations and COSLA.

At the end of the day, this comes down to the fundamental point that I made at the outset and that Nanette Milne's amendments would move the bill away from, which is the importance of offering the process to all carers. That is our ethos in the bill.

On that basis, I urge the committee to support my amendments. I ask Nanette Milne not to move her amendments and, if she does, I ask the committee not to support them.

Amendment 1 agreed to.

The Convener: Amendment 70, in the name of Rhoda Grant, is grouped with amendments 71, 5, 74, 75, 13, 83, 64, 89, 66 and 67. If amendment 83 is agreed to, amendment 39 cannot be called.

Rhoda Grant: Amendments 70 and 71 would put into the bill the timescale within which an adult carer's assessment must be completed. A different timescale would be set for people who are caring for someone who is terminally ill, which recognises that time is limited and carers will be facing a quickly changing situation that will also be emotionally stressful for them. It is important that they receive support quickly and that that support changes to meet their changing needs.

Amendments 74 and 75 would make similar amendments for the young carer statement, ensuring a timeframe for an assessment and an expedited process for those who are caring for someone who has a terminal illness.

The Government has lodged alternative amendments in respect of carers of people who are terminally ill only, giving them the power to set the timescales in guidance. I would like to learn what the Government thinks those timescales should be. I would also like to know why the Government has not put down a timescale for carers of people who are not terminally ill, because there should be a maximum wait.

Amendments 83 and 89 are consequential amendments that provide a definition of "terminally ill", which is very similar to the one that the minister has proposed.

I move amendment 70.

The Convener: The minister will speak to amendment 5 and all other amendments in the group.

Jamie Hepburn: Thank you, convener, and I thank Ms Grant for lodging her amendments. I am concerned that setting timescales for the preparation of all adult carer support plans and young carer statements would result in local authorities having to use much of their resources to prepare plans within set timescales. That could limit the resources that might otherwise be available for the provision of support and there is also a risk that local authorities' focus might shift from being on the completion of good-quality plans. For some carers, the preparation of a plan will be an iterative process, rather than a one-off intervention.

The discussion that we have just had about the need to prioritise case loads is germane to the present discussion about setting hard and fast timescales. Such timescales could cause local authorities difficulties.

09:45

I understand, however, that carers want to have an indication of approximately how long it will take to prepare an adult carer support plan. Ms Grant suggests that there is nothing on the face of the bill about that. That is not quite the case: there is a provision at section 28(2)(f) that a local carer strategy must set out

> "the authority's intended timescales for preparing adult carer support plans and young carer statements".

I also agree with Ms Grant that there is merit in prioritising the preparation of an adult carer support plan or young carer statement for those carers who are caring for someone who is terminally ill. I thank Marie Curie for its suggestion about that.

I undertook in response to the committee's stage 1 report to lodge amendments to legislate for that. Amendments 5 and 13 introduce additional regulation-making powers for Scottish ministers so that timescales can be set for the preparation of adult carer support plans and young carer statements where the cared-for person is terminally ill.

Amendments 66 and 67 add the regulation-making powers to the list at section 37(2). The regulations made under that power are subject to the affirmative procedure. There are a number of significant issues that need to be resolved and set out in both regulations and guidance. It is therefore right that the regulations are subject to the affirmative procedure so that they receive due parliamentary scrutiny.

Amendments 5 and 13 also introduce a definition of terminal illness. The definition is taken from that set out in section 66(2)(a) of the Social Security Contributions and Benefits Act 1992 on attendance allowance for the terminally ill. It states:

> "a person is 'terminally ill' at any time if at that time he suffers from a progressive disease and his death in consequence of that disease can reasonably be expected within 6 months".

Ms Grant asked about how we might use the regulations. It is important that we get them right. I have not got a specific timescale in mind. It is important that the Administration consults those who will be interested in the matter, such as COSLA, individual local authorities and the national carers organisations. I am also committed to involving the committee in that process.

On that basis, I ask the committee to support amendment 5 and the other amendments in my name in the group and I urge Ms Grant to withdraw amendment 70 and not to move the other amendments in her name.

The Convener: I call Rhoda Grant to wind up and press or withdraw her amendment.

Rhoda Grant: I am grateful for the explanations given, although I am concerned that we do not have a timescale for the assessment of carers who are looking after someone who is terminally ill.

I seek leave to withdraw amendment 70. I will have further talks with the minister to try to get some reassurance on that point and to discuss the timescales for carer assessments for those who are not terminally ill.

Amendment 70, by agreement, withdrawn.

Amendments 2 and 3 moved—[Jamie Hepburn]—and agreed to.

Amendment 92 not moved.

The Convener: Amendment 4, in the name of the minister, is grouped with amendments 7, 12, 15, 18, 19, 28, 29, 31, 32, 36, 38, 45, 46, 59, 61 and 63.

Jamie Hepburn: The bill currently provides that in most cases the local authority for the area where the carer resides is responsible for preparing the adult carer support plan and young carer statement and for providing support under both.

During stage 1, the committee heard concerns from COSLA and local authorities that it would be difficult to consider the adult carer support plan and young carer statement alongside the cared-for person’s assessment, if the plan and statement were prepared and support was administered under them by different local authorities from those that were administering the cared-for person’s assessment. Taking that into account, I have lodged amendment 4 to amend the definition of “responsible local authority” so that responsibility for preparing the adult carer support plan will lie with the local authority where the cared-for person resides. With regard to young carers, in order to align with arrangements for the administration of the child’s plan as set out in the Children and Young People (Scotland) Act 2014, the local authority where the young carer resides, or in some cases the health board or directing authority, will continue to have responsibility for preparing the young carer statement.

Amendment 12 changes the “responsible local authority” referred to in section 11(7), which must agree and administer any support under a young carer statement, from the local authority where the young carer resides to the one where the cared-for person resides. That means that, for the small number of cases in which the young person and the person whom they care for do not live in the same local authority area, it is expected that both the responsible local authorities will work with each other to ensure a co-ordinated approach. Both amendments will enable local authorities to create complementary packages of support that meet the support needs of both the adult carer or young carer and the person whom they care for.

Amendments 7 and 15, which are consequential on amendments 4 and 12, make it clear that where the adult carer or young carer does not reside in the same local authority area as the person whom they care for, information about support will be available to the adult carer or young carer in the area where they live, and will also be included in the adult carer support plan or young carer statement. Amendments 18 and 19 are also consequential on amendments 4 and 12.

Amendments 28, 29, 31, 32, 36, 38 and 45, which make amendments to section 28 on local carer strategies, are consequential on the changes to sections 6 and 11 made by amendments 4 and 12. Those amendments will result in the local carer strategy being prepared for what are termed “relevant carers”—in other words, carers who reside in the area of a local authority, whether or not they provide or intend to provide care for cared-for persons in that area, and carers who do not reside in the authority’s area but who provide or intend to provide care to cared-for persons in that area. Amendment 46 provides the definition of “relevant carers”.

Amendment 59 has a similar effect to the amendments on local carer strategies by amending section 31(1), which relates to the information and advice service, to ensure that local authorities establish and maintain an information and advice service for relevant carers. Amendment 61 provides the definition of “relevant carers” for the purposes of section 31 by referring to the definition that I propose to insert into section 28 through amendment 46.

Finally, amendment 63 is consequential on amendments 4 and 12 and amends the definition of “responsible local authority” in section 36, which sets out how various terms in the bill are to be interpreted.

I move amendment 4.

Amendment 4 agreed to.

Amendment 71 not moved.

Section 6, as amended, agreed to.

After section 6

Amendment 5 moved—[Jamie Hepburn]—and agreed to.

Section 7 agreed to.

Section 8—Content of adult carer support plan

The Convener: Amendment 72, in the name of Rhoda Grant, is grouped with amendment 76.

Rhoda Grant: Amendment 72 gives the adult carer control over their caring role by stipulating that the adult carer support plan must indicate the hours and time that the carer is willing to commit to caring, and amendment 76 gives similar control to young carers. Carers often tell me that they have no choice about their caring role—they are expected to take it on, often to the detriment of their own work or education—and these amendments will ensure that carers have choices about their caring commitments and will allow them to continue to work or attend school, college or university.

I move amendment 72.

Jamie Hepburn: I thank Rhoda Grant for lodging amendments 72 and 76. As she has explained, they stipulate that the number of hours a week for which the adult carer or young carer

“is able and willing to provide care”

must be included in the information contained in the adult carer support plan or the young carer statement. However, section 8(1)(b) and section 13(1)(b) of the bill already provide that the adult carer support plan and young carer statement must contain

“information about the extent to which”

the adult carer or young carer

“is able and willing to provide care for the cared-for person”,

which I believe takes account of the not unreasonable concerns that Rhoda Grant has expressed. Those particular sections already allow for the number of hours for which the carer is willing to provide care to be included in the adult carer support plan and young carer statement if that information is considered to be relevant and appropriate to the individual carer.

In any case, the adult carer support plan or young carer statement is personal to the carer and relevant to their personal circumstances, which can change in respect of the nature of the care provided and the amount of time devoted to caring. There might be circumstances in which the nature of the caring role makes it difficult to quantify the amount of time that is devoted to caring, such as where a person provides care to more than one person or where the circumstances of the cared-for person are such that the hours of care that they require differ from week to week. It is therefore not appropriate for a carer to have to specify the number of hours they are willing and able to provide care in each and every circumstance.

I recognise the concerns that have caused Rhoda Grant to lodge her amendments. However, the bill as worded should take account of them, because it already provides for the need to establish the extent to which the adult carer or young carer is willing and able to provide care for the cared-for person. I therefore ask Rhoda Grant to withdraw amendment 72 and not to move amendment 76, but in so doing, I make it clear that I am happy to speak to her on this matter to see whether I can reassure her about the provisions in the bill or, if some change is indeed needed, to discuss that with her to see whether we can agree a way forward.

Rhoda Grant: I think that everyone agrees that it is really important that carers have a choice about their caring role and that they are able to continue with their lives. However, I have heard what the minister has said, and I will take him up on his offer of further discussions on the issue.

I will therefore withdraw amendment 72 and not move amendment 76.

Amendment 72, by agreement, withdrawn.

The Convener: Amendment 6, in the name of the minister, is grouped with amendments 73, 14, 77 and 60.

Jamie Hepburn: Enable Scotland and others have raised concerns that the bill as worded does not take account of carers who might, for a number of reasons such as illness, find themselves unable to care for the person who usually relies on them for support. Understandably, that can be a huge source of anxiety and concern for carers, as the safety and support of the people for whom they care is of paramount importance.

In order to address that issue, as I said I would in response to the committee’s stage 1 report, I have lodged amendments 6 and 14, which amend sections 8(1) and 13(1) respectively to provide that the adult carer support plan and young carer statement must contain information about emergency planning. That means that as part of the adult carer support plan and young carer statement process the carer will be asked whether they have in place arrangements for the provision of care that they would normally provide to the cared-for person if an emergency should arise, and that information will have to be recorded as part of the adult carer support plan or young carer statement.

Amendments 73 and 77, lodged by Rhoda Grant, seek to amend sections 8(1) and 13(1) to ensure that the adult carer support plan and young carer statement contain

> “information about whether the adult carer has arrangements in place for the future care of the cared-for person”.

I believe that that approach has some merit. The bill might already allow for it, but I certainly agree that it is worth considering further. On that basis, I ask Ms Grant to withdraw amendments 73 and 77 and to meet me so that, together, we can consider and work on the matters further, potentially with a view to lodging at stage 3 amendments with similar effect.

10:00

Amendment 60 amends section 31(2) to ensure that the information and advice service for carers provided for in section 31 provides information and advice on

> “emergency care planning and future care planning”

in addition to the other issues in section 31(2) on which information and advice must be provided. I know that emergency care and future care planning are important for carers, and I recognise that carers’ health and wellbeing can be affected if they are worried about how care will be provided to the cared-for person if, because of an emergency or other unforeseen circumstances, they are unable to provide the care that they normally provide or if they are no longer able and willing to provide care.

I move amendment 6.

Rhoda Grant: Amendment 73 ensures that the adult carer support plan includes transitional arrangements for circumstances in which the carer is unlikely to be able to continue their caring role, and amendment 77 has the same effect for the young carer statement. I support the Government’s amendments 6 and 14 with regard to emergency care planning, but I am concerned about the fact that future care planning will be left to the advice and information service.

Carers, especially elderly parents looking after offspring who are likely to outlive them, worry about what will happen to their loved ones when they are no longer able to care, and it is important that they know what will happen and that any transitions will be managed. The lives of many vulnerable people are changed beyond recognition while they deal with bereavement. Although occasionally that cannot be foreseen, it can on many occasions be planned for.

The same is true for young people who might want to go on to further and higher education; they need to know what will work for their loved ones and that they will be looked after in their absence. That is why future care planning should be part of support plans and statements. Such planning needs to be person centred and properly managed, and thought needs to be given to it.

Given what the minister has said, I am willing to withdraw amendments 73 and 77 and to discuss the matter further, but I point out that the provisions are really important and should be included in the bill.

Jamie Hepburn: I welcome Ms Grant’s comments, and I look forward to having that discussion. I am sure that we will be able to agree a way forward.

Amendment 6 agreed to.

Amendment 73 not moved.

Amendment 7 moved—[Jamie Hepburn]—and agreed to.

Section 8, as amended, agreed to.

Sections 9 and 10 agreed to.

Section 11—Duty to prepare young carer statement

Amendment 8 moved—[Jamie Hepburn]—and agreed to.

Amendment 74 not moved.

Amendments 9 and 10 moved—[Jamie Hepburn]—and agreed to.

Amendment 93 not moved.

The Convener: Amendment 11, in the name of the minister, is grouped with amendments 94 to 96, 16 and 97 to 99. If amendment 96 is agreed to, amendment 16 cannot be called.

Jamie Hepburn: I will address the two amendments that are in my name before turning to those that are in Ms Grant’s name. Several stakeholders have expressed concern about the provision at section 11(6) under which, when a young carer is offered or requests a young carer statement,

> “the responsible authority must notify the young carer’s named person.”

Members will recall that that issue was a feature of the stage 1 debate. Similar concern was expressed about section 15(2)(b), which requires the responsible authority to provide the information that is contained in the young carer statement to

> “the young carer’s named person”.

I fully sympathise with those concerns. I recognise that there will be circumstances where the young carer will wish to protect his or her privacy. Equally, I expect that, in many cases, it will be helpful for the named person service provider to know that the young carer has been offered or has requested a young carer statement and that one has been put in place.

I have considered those issues carefully, and I lodged amendment 11 to remove section 11(6). That will remove the requirement for the responsible authority to notify the young carer's named person if a young carer statement is offered or requested.

I lodged amendment 16 to remove section 15(2)(b). That will remove the requirement for the responsible authority to share with the named person the information that is contained in the young carer statement.

We do not require section 15(2)(b), because section 26 of the Children and Young People (Scotland) Act 2014 covers that area. Under that act, the information that is contained in a young carer statement can be shared with a young carer's named person service provider only if that information is relevant to or necessary for the exercise of the named person's functions. In effect, that means that the information can be shared with the young carer's named person service provider, but that sharing is by no means automatic.

When deciding what information to share, the local authority or health board with the responsibility for the young carer statement must have regard to the views of the child or the young person, while bearing in mind his or her age and maturity. The young carer's views must be sought where it is reasonably practicable to do so, and the responsible authority must have regard to those views. We will set it out in guidance that we fully expect the young carer's views to be sought. However, it might not be reasonably practicable to do that if, for example, the young carer was out of the country.

There are further protections for young carers. The responsible authority will need to respect the common-law duty of confidentiality, the requirements of the Data Protection Act 1998 and the right to private and family life under article 8 of the European convention on human rights.

We have consulted young carers' interests. They appear to support our proposal as a pragmatic way forward.

I will now respond to Rhoda Grant's amendments. Her amendments have the same intention as the Government amendments in the group, so I argue that they are not required.

The substantive effect of amendments 94, 96 and 97 would be that the responsible authority no longer needed to provide the information that is in the young carer statement to the named person. However, amendments 95 and 98 would retain the requirement for the responsible authority to notify the named person that a young carer statement or revised statement had been prepared.

Amendment 95 would duplicate section 11(6) of the bill, which the committee should note that I propose to remove with amendment 11. I have made the case to the committee that we do not require a provision that requires the named person to be notified of the preparation of the young carer statement, because that will be covered by the information-sharing provision that is set out in section 26 of the Children and Young People (Scotland) Act 2014.

Amendment 99 is a consequence of amendment 96 and would in effect reinstate as a new section provisions that amendment 96 seeks to remove. Amendment 99 would provide that the information that is contained in the young carer statement could be shared with any other person the young carer requested that it be shared with. However, the proposed new section has no equivalent of section 15(4), which requires the information to be provided as soon as practicable after the statement or revised statement is prepared.

I ask the committee to support the Government amendments in the group and I urge Rhoda Grant not to move her amendments.

I move amendment 11.

Rhoda Grant: I listened carefully to what the minister said. The difference between my amendments and his amendments is that my amendments would put in the hands of the young carer control of who has information about them. The only piece of information that they would not control would be about whether a young carer statement existed. It is important that the named person is informed that a young carer statement exists, because the named person is normally a headteacher, who needs to know that the young person is a young carer so that they can put measures in place in school to ensure that the young person has access to education. It would be very much down to the young carer to decide who had access to any other information, which would give them comfort.

My understanding of the Government's amendments is that information would not be automatically shared with the named person but, if it was deemed important to share information, it would be shared with the named person regardless of whether the young carer wished that to happen. That would improve the situation under the bill at the moment, but it would not go far enough to give the young carer full control. I ask the minister to have further discussions to see whether we could give young carers more control of who has access to the content of their statement. If I got reassurance on that, I would not move my amendments.

Dennis Robertson (Aberdeenshire West) (SNP): I am pleased that the Government has lodged amendments 11 and 16. The minister's explanation of them shows respect to young carers and shows that the amendments will give them more control. As I said, his interpretation is respectful to young carers.

Jamie Hepburn: I think that we are all on the same page on the issue. I reassure Ms Grant that I share her perspective, because it is important that the named person is informed that a young carer statement exists. The provisions under the Children and Young People (Scotland) Act 2014 that I set out should allow for that.

I am happy to discuss the matter further with Ms Grant, and that offer is open to any committee member at any time as we move towards stage 3. In having that discussion with her, I hope that I can reassure her that the approach that we are taking through amendments 11 and 16 will address all the concerns that she expressed.

Amendment 11 agreed to.

Amendment 12 moved—[Jamie Hepburn]—and agreed to.

Amendment 75 not moved.

Section 11, as amended, agreed to.

After section 11

Amendment 13 moved—[Jamie Hepburn]—and agreed to.

Section 12 agreed to.

Section 13—Content of young carer statement

Amendment 76 not moved.

Amendment 14 moved—[Jamie Hepburn]—and agreed to.

Amendment 77 not moved.

Amendment 15 moved—[Jamie Hepburn]—and agreed to.

Section 13, as amended, agreed to.

Section 14 agreed to.

Section 15—Young carer statement: provision of information to carer etc

10:15

Amendments 94 to 96 not moved.

Amendment 16 moved—[Jamie Hepburn]—and agreed to.

Amendments 97 and 98 not moved.

Section 15, as amended, agreed to.

After section 15

Amendment 99 not moved.

Sections 16 to 18 agreed to.

After section 18

The Convener: Amendment 78, in the name of Rhoda Grant, is grouped with amendment 90.

Rhoda Grant: The amendments would ensure that all public authorities had to identify carers and would mean that, if a carer was identified by a general practitioner, a hospital, a school or a nursery, the authorities had to act to ensure that the carer was getting the support and the healthcare that they needed. We hear too often of GPs who are caring for a cared-for person not being aware of who looks after them and whether the carer is getting the support that they require. All our local authorities need to take a holistic approach to the people they deal with, to look below the surface and to take responsibility for carers. We need to make sure that a referral is made and that carers receive support. Amendment 90 is consequential to amendment 78.

I move amendment 78.

Jamie Hepburn: Rhoda Grant's amendment 78 aims to introduce a new regulation-making power about how public authorities should refer an adult carer or a young carer to a responsible local authority or a responsible authority. Many public authorities are listed in schedule 1 to the Freedom of Information (Scotland) Act 2002. They include health boards, national health service trusts and primary medical services—including GPs—and many other bodies such as procurators fiscal and the National Library of Scotland. On the face of it, it would not make sense to impose such a duty on many of those public authorities.

The bill sets out provisions that relate to carer identification. Section 28(2)(a) provides that local authorities must set out their plans for identifying carers in the context of their local carer strategy and must consult health boards before preparing that strategy. Government amendments are being lodged to place a duty on each local authority to prepare a local carer strategy for its area jointly with health boards. That is the appropriate way forward, rather than conferring a general power on all public bodies to identify carers. I ask the member to withdraw amendment 78 and not to move amendment 90.

Rhoda Grant: I did not really receive comfort from the minister's comments. The issue that has been raised in evidence is that the NHS is quite often at fault. Last week, some MSPs met a group of carers who talked about the NHS involving carers when someone was about to leave hospital, to ensure that they were referred to services and were receiving support. That made a huge difference to the lives of carers, and that was contrasted with the position of carers who had not received that level of support.

I am really concerned that what the minister said does not address that problem. However, I take on board the point that some of the organisations listed might not deal with carers, so I will withdraw amendment 78. However, I may come back at stage 3 with an amendment that would put a duty on at least the NHS, because that is sometimes where things fall down.

Amendment 78, by agreement, withdrawn.

Section 19—Duty to set local eligibility criteria

The Convener: Amendment 100, in the name of Rhoda Grant, is grouped with amendment 101.

Rhoda Grant: The committee took conflicting evidence about whether eligibility criteria should be set nationally or locally. COSLA was concerned that that should be done locally and cited the lack of funding to implement the bill. My understanding is that the funding for the bill, other than that for replacement care, is around £3 million. Carers believe that the criteria should be set nationally, as there would otherwise be a postcode lottery for the support that they get.

Amendments 100 and 101 would strike a balance between those two conflicting concerns by giving the Scottish Government the power to set a level of need at which carers would be entitled to support. The form that that support took would be decided locally, but carers would know that they would receive support. Carers who are at risk of having to give up their caring role should be in that category; they need support before their caring role breaks down, so they must have a nationally set entitlement to support.

I move amendment 100.

Jamie Hepburn: I thank Rhoda Grant for lodging her amendments. I recognise that, as she said, this has been the subject of much debate. Members will know that the arguments on local versus national eligibility criteria are finely balanced, and I think that I am right in recalling that the committee's stage 1 report reflected that, although it did not make a recommendation either way.

There is an argument for national eligibility criteria. However, individual local authorities, as democratic bodies that are accountable to their own electorates, should be able to make decisions that are based on the needs of their caring population and the resources that they have available to meet those needs. I want to ensure that there is consistency across the country, which I believe can be achieved through the national matters that we will set out in regulations and which will underpin local eligibility criteria.

The issue is of paramount importance for carers and for the national carer organisations, which I thank again for their input. I assure them and the committee that the work that they have undertaken will be fully considered as we develop the regulations on national matters. As we move towards that position, I am inclined to include in the regulations the specific indicators that are set out in those organisations' draft framework. That approach would mean that a local authority had to have regard to the importance of those indicators in assessing the impact of caring on a carer's wellbeing and day-to-day life and in deciding whether it was required to provide support, although the local authority would retain control over the exact level of impact that would lead to a duty to provide support and the nature of the support to be provided. That would encourage the setting of local thresholds for support that are creative and take into account similar factors across the country.

I draw the committee's attention to the fact that the intended effect of amendment 100 is not entirely clear. It is not linked to the duties to provide support to meet carers' eligible needs, which are set out in section 22, so it is not clear whether the amendment would introduce a requirement for the local authority to support the types of carers covered by the amendment. Regardless of the issues that relate to the amendment's practical application, I am persuaded that the eligibility criteria for supporting carers should be determined by individual local authorities but with consistency brought to that approach through the national matters set out in regulations that will be produced in partnership with the national carer organisations, COSLA, local authorities and health boards. I expect and appreciate that the committee will take an interest in what might be in those regulations.

I remind committee members that the committee asked clearly about how we will monitor the efficacy of local eligibility criteria. I responded clearly that we will monitor how effective that approach is. We have the provision in the bill to introduce national eligibility criteria by way of regulation if that is felt necessary in the future.

Neil Findlay made the point in the stage 1 debate that what is important is not whether there are local eligibility criteria or national eligibility criteria but whether the approach on the ground for carers is effective. The committee can be assured that we will take the greatest interest in the approach that is taken and that, if it is not effective, we will respond accordingly. I therefore ask Ms Grant to withdraw amendment 100 and not to move amendment 101.

Rhoda Grant: I am glad that the minister acknowledged that the issue is about resourcing and that local authorities are really concerned about the resourcing of the bill. I believe that carers who are in critical need of support should get that support, which should be a national entitlement. I will therefore press amendment 100.

The Convener: The question is, that amendment 100 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For

Chisholm, Malcolm (Edinburgh Northern and Leith) (Lab)
Grant, Rhoda (Highlands and Islands) (Lab)
McNeil, Duncan (Greenock and Inverclyde) (Lab)
Milne, Nanette (North East Scotland) (Con)

Against

Keir, Colin (Edinburgh Western) (SNP)
Lyle, Richard (Central Scotland) (SNP)
MacKenzie, Mike (Highlands and Islands) (SNP)
Robertson, Dennis (Aberdeenshire West) (SNP)

The Convener: The result of the division is: For 4, Against 4, Abstentions 0.

The vote is tied. I will use my casting vote against the amendment, on the basis that the committee has not made a specific recommendation on the matter. I do that in the hope that further, meaningful discussions can take place with members who support the proposal, to get a resolution to this difficult issue.

Amendment 100 disagreed to.

Amendment 101 not moved.

Section 19 agreed to.

Sections 20 and 21 agreed to.

Section 22—Duty to provide support

The Convener: Amendment 17, in the name of the minister, is grouped with amendments 102, 20 to 23, 79 and 68.

Jamie Hepburn: I will address the amendments in my name first before I turn to the amendments that were lodged by Nanette Milne and Rhoda Grant.

Section 23, on “Provision of support to carers: breaks from caring”, was included in the bill, as introduced, in order that the local authority must consider in particular whether the support that is provided to a carer should take the form of or include a break from caring. We also introduced a regulation-making power principally to deal with the issue of the waiving of charges for replacement care that meets the identified needs of the carer. I made it clear to the committee that the requirement to waive charges will be made through minimal amendments to the existing regulations on the waiving of charges, and that remains the case. My clear policy intention is that neither the carer nor the cared-for person will be charged for what we called replacement care meeting the carer’s assessed needs. Members will recall that, in stage 1 evidence, Mr Lyle in particular was interested in pursuing that issue with me.

Amendment 20 means that the terminology “replacement care” will no longer be used in the bill. I thought that it was confusing; instead, I prefer the wording “provision of care for the cared-for person”, which is provided to enable the carer to have a break from caring. That describes exactly what is being provided to enable the carer to have a break from caring.

Amendment 17 provides that the power and duty to provide support to a carer do not apply where the carer’s needs can be met through the provision of services or assistance to the cared-for person. Therefore, if a carer’s needs could be met by, for example, a bath hoist for the cared-for person, that should be agreed through the community care assessment for the cared-for person. However, there is an exception to that rule in circumstances in which care is provided to the cared-for person in order to give the carer a break from caring.

Amendments 20 and 21 give further effect to that policy by amending the regulation-making power so that it focuses specifically on circumstances in which care is provided to the cared-for person in order to give the carer a break from caring.

Amendment 22 removes section 23(2)(b)(ii), as it is no longer necessary given the other amendments to sections 22 and 23.

10:30

Amendment 23 corrects a technical problem in the drafting of section 23(3) to make it clear that any support that is provided to a carer in order to provide a break from caring is provided under section 22 and not under section 23. Support is provided under section 22, albeit that it is provided following specific consideration of whether the carer requires a break from caring, which is required under section 23.

A further policy intention is to secure the involvement of the cared-for person in relation to decisions about the provision of care to the cared-for person to enable the carer to have a break from caring. I believe that that is important, as it would be inappropriate for a cared-for person to be forced to receive care that could involve personal or intimate care without being involved in that decision-making process.

There are, however, a number of practical issues to be considered regarding the involvement of the cared-for person in decision making about the provision of care that enables the carer to have a break from caring. Those include, in particular, whether the cared-for person should have to provide their express consent. I propose that regulations on those matters will be made using the powers at section 23(2)(b)(i). I want the procedure for those regulations to be affirmative. Amendment 68 gives effect to that.

Turning to amendment 102, in the name of Nanette Milne, I fully understand just how beneficial breaks from caring are in supporting carers. A break from caring can allow the carer to get some rest and recharge their batteries. Those breaks can make all the difference for carers being able to maintain their caring role. Through the bill, the outcomes that carers would like to achieve and the support that is required to meet those outcomes will be identified. That is the core purpose of the bill. In many cases, that will include a break from caring.

The intention behind amendment 102 appears to be that carers should have access to a market that provides a range of short breaks to meet the individual needs of carers. However, existing provision, under section 19 of the Social Care (Self-directed Support) (Scotland) Act 2013, already requires local authorities to promote a variety of support and support providers to deliver short breaks. As a result of amendments that are being made by the schedule to the bill, it is clear that the reference to support in that section covers support to both adult and young carers under this bill.

Amendment 102 appears also to place a duty on local authorities to ensure individual carers are provided with sufficient short breaks. The person-centred approach to adult carer support plans, young carer statements and subsequent support will ensure that individual carers are provided with adequate support to meet their needs. That would include short breaks. However, I would like to get a better understanding of the issues underlying the amendments in the name of Nanette Milne. On that basis, I ask her not to move amendment 102 and to meet me to discuss the issue ahead of stage 3. If necessary, the issue can be returned to then with a similar amendment.

I do not believe that amendment 79, which was lodged by Rhoda Grant, is required to section 23(1). It already makes it clear that support may be provided in the form of a break from caring where that is to meet the carer’s identified needs rather than those of the cared-for person. The framework of the adult carer support plan and young carer statement schemes—in particular the personal outcomes approach and obligation to identify the nature and extent of caring—should make it easier to identify whether support is to meet the needs of the carer or the cared-for person. I ask the member not to move amendment 79.

I move amendment 17.

Nanette Milne: The first part of amendment 102 provides for an obligation that must be fulfilled by the local authority in the context of thinking about the services that a person may or must receive. The second part specifies short breaks. Overall, the amendment provides a sufficient duty to ensure that short breaks are used not just as a crisis intervention. It promotes collaborative working between local authorities and other stakeholders to provide more capacity and choice, taking into account available resources. However, having listened to the minister, I would be happy to meet him between now and stage 3 and, on that promise, I am prepared not to move amendment 102 at this stage.

Rhoda Grant: Amendment 79 makes it clear that the break from caring has to be for the needs of the carer, and indeed has to be to the benefit of the carer. Too often, we have heard that carers are given a respite break to allow them to attend to their urgent medical needs. That should, of course, be catered for, but it should not be about somebody’s entitlement to a short break. The minister said that the bill says that the short break is about the carer’s identified needs. That could be for the carer to go to work or hospital and the like. We should make it clear in the bill that this is a break from caring for the carer. It is not for them to attend to something else; it is for them to have some time off in which to rest and recuperate.

I hope that the minister will discuss that further before stage 3. If he is willing to do that, I will not move amendment 79 but will come back with another amendment at stage 3. It should be clear that the break is for the carer’s benefit so that they can have a rest and do something different from attending to other identified needs.

Dennis Robertson: Could the minister indicate that there is already clear legislation to protect carers and to provide the breaks that Rhoda Grant is referring to? If we go ahead with her amendments, would it not create a complicated situation for the health and social care joint boards when they are progressing their local needs and identifying what works best for carers and the people for whom they care? If the minister can outline existing legislation, there will be no need to pass Rhoda Grant's amendment.

Jamie Hepburn: On Mr Robertson's point, in my opening remarks I made the point about the provisions that exist in the Social Care (Self-directed Support) (Scotland) Act 2013. On top of any legislative provision, we have invested a considerable amount in the provision of and support for short breaks. I hope that that indicates the great importance that we invest in ensuring that carers are provided with a short break.

Rhoda Grant's point about it being necessary to make it clear that a break is for the benefit of the carer rather than the person who is being cared for should be taken account of in the way in which the bill is drafted. However, I hear her point and I am happy to meet her, as I have already agreed previously, to discuss this further issue.

I also thank Nanette Milne for providing clarity about her thinking on where she wanted her amendment 102 to take us. We can use that as the basis for discussion in advance of stage 3.

Amendment 17 agreed to.

Amendments 18 and 19 moved—[Jamie Hepburn]—and agreed to.

Section 22, as amended, agreed to.

Section 23—Provision of support to carers: breaks from caring

Amendment 102 not moved.

Amendments 20 to 23 moved—[Jamie Hepburn]—and agreed to.

Amendment 79 not moved.

Section 23, as amended, agreed to.

Section 24 agreed to.

After section 24

The Convener: Amendment 80, in the name of Rhoda Grant, is grouped with amendment 91.

Rhoda Grant: Amendment 80 will allow a carer who has had an assessment to appeal the outcome of that assessment. The timescales are different for carers who are looking after terminally ill people, which acknowledges that their time is limited. The timescales are shorter than the time taken to carry out the assessment—which was covered in amendment 70, which I withdrew—because the work will already have been done. It is a shorter review period. It is important that carers have the ability to appeal the outcome of their assessment if they do not agree with it. That is in line with other legislation that deals with assessments.

I move amendment 80.

Jamie Hepburn: Carers and carer organisations are concerned about circumstances in which the local authority determines that the carer does not have eligible needs and therefore the duty to provide support does not apply. As Rhoda Grant set out, amendment 80 seeks to introduce a separate decision review mechanism for carers who face that situation.

I do not believe that it is necessary for carers to have a separate, specific method for raising a complaint that is distinct from existing systems. We are in the process of changing the complaints procedures that apply to social work decisions. The changes that are being made to complaints procedures will benefit all service users, including carers, in order to improve accessibility and deliver real outcomes. We are consulting on a draft order for social work complaints that will extend the role of the Scottish Public Services Ombudsman to investigate complaints involving the professional judgment of social work staff, as well as maladministration.

If agreed to by Parliament, the changes to social work complaints will mean a shorter, more person-centred complaints procedure. No matter who a person complains to, their complaint should be handled in a joined-up manner. The person who is making the complaint will receive a co-ordinated response. The ombudsman will have the power to make recommendations to a local authority on a decision that has been made, and it will be able to lay a special report to the Scottish Parliament should its recommendations not be acted on. We aim to have the new procedures for social work complaints up and running by early April 2017, when this bill's provisions will come into effect.

As Ms Grant set out, amendment 91 is a consequence of amendment 80. Again, I say that I would be happy to meet Ms Grant to reassure her that what we have in mind with the order that we are consulting on takes account of her concerns. On that basis, I ask her to withdraw amendment 80 and not move amendment 91.

Rhoda Grant: I would like more detail about what the minister is proposing. My understanding is that the ombudsman currently looks at procedure. The minister said that the ombudsman will also look at professional judgment. It is not clear whether that means that decision making and the outcome of decision making will be looked at. It is also not clear whether the ombudsman will be able to overturn an assessment decision and entitle a carer to support. The aim of amendment 80 is that, if a carer does not agree with the level of support that they are being given, they will be able to appeal and overturn the decision.

Given the offer of further discussion, I will seek to withdraw amendment 80 and I will not move amendment 91. It is important that someone reviews decision making. Given the financial situation surrounding the bill, there is concern that decisions will be driven by finance rather than need, so we need robust systems in place to ensure that carers get the support they need.

Amendment 80, by agreement, withdrawn.

10:45

The Convener: Amendment 81, in the name of Rhoda Grant, is grouped with amendment 69.

Rhoda Grant: Amendment 81 seeks to bring services for carers under the inspection regime of the Care Inspectorate. It is right that an independent body can review the services and ensure that they are fit for purpose. The Care Inspectorate carries out that role for services for the cared-for person, so it is familiar with the situations that carers find themselves in and would be best placed to inspect services for carers. It is important that such services are high quality and that carers receive the support that they require.

I move amendment 81.

Jamie Hepburn: I thank Rhoda Grant for introducing amendment 81. My officials have been in contact with the Care Inspectorate, and I agree that there might indeed be merit in amending schedule 12 to bring more services that support carers into the registration regime. However, there are significant policy considerations to be resolved before doing so at present. Services that support carers caring for cared-for persons because of age, disability or drug and alcohol dependency issues have to be registered with the Care Inspectorate. Those services might cover training or other support that is focused particularly on the vulnerability of the cared-for person—for example, a service that trains carers in how to lift the elderly or a support group helping those with alcohol-dependent partners.

I therefore want to consider the implications for service providers and, indeed, the impact on the Care Inspectorate in terms of its resources and expertise before deciding whether it is appropriate to make all such services subject to registration requirements. The Care Inspectorate has made recommendations to Scottish ministers about a number of changes that it considers could be made to the scope of care services under the bill. I have agreed that that should be considered as part of the wider review of care services that the Care Inspectorate has been considering. If it is decided that more services to carers should be brought within the definition of care services, it will be possible to do that using order-making powers in the Public Services Reform (Scotland) Act 2010. In my view, amendment 81 is therefore not required, so I ask Ms Grant to withdraw it at this stage. I would be happy, of course, to discuss the matter further with her to set out in greater detail the work that will be under way.

Scottish Government officials have also discussed amendment 69 with the Care Inspectorate. I have introduced amendment 69 to add functions under the bill to the list of social work service functions in schedule 13 to the 2010 act. I want to ensure that any services provided by a local authority in undertaking the functions listed in schedule 13 and any service that is provided with others, such as third sector providers, in connection with arrangements with a local authority will be social work services and social services within the meaning of part 5 of the 2010 act.

Amendment 69 will give the Care Inspectorate a power to inspect services that are provided by, or on behalf of, local authorities in the exercise of functions under the bill, most significantly the adult carer support plan and the young carer statement, the local carer strategy and information and advice service functions. Amendment 69 will also require local authorities to provide information to the public on request about the services that are provided in the exercise of those functions. I hope that the committee will agree that those are sensible arrangements.

Rhoda Grant: I will wait to find out more information about the minister’s thinking on that. Perhaps he can give me some written thoughts ahead of a meeting, because otherwise it will be a very long meeting. It would be good to have those thoughts before a meeting so that I can discuss them with stakeholders and then discuss with him the best way to take the issue forward.

Amendment 81, by agreement, withdrawn.

Section 25—Duty to involve carers in carer services

The Convener: Amendment 103, in the name of Nanette Milne, is grouped with amendment 24.

Nanette Milne: Amendment 103, on hospital discharge, would strengthen the bill by focusing on patient outcomes. It would mean that patients would be consulted and involved in designing the patient’s care plan and would ensure that adequate time was taken to design the care plan so that it was in place before the patient was discharged from hospital. That would result in the avoidance of the sort of dreadful experience that I heard about just last week from a carer whose husband was discharged, on oxygen, with only two hours' notice. The gas cooker in their home had had to be disconnected and the family was without cooking facilities for a week after his return home. Such appalling situations should not be allowed to happen. They would not happen with proper discharge planning while the patient was in hospital.

My amendment aims to cover the general carer involvement. It differs from Rhoda Grant's amendment to section 8, which would require information about hospital admission and discharge to be discussed in an adult care support plan.

I move amendment 103.

Jamie Hepburn: Amendment 24 is a minor drafting point that removes an unnecessary "of" from section 27.

I thank Nanette Milne for her points on amendment 103. I fully support the involvement of carers in hospital admission and discharge processes, as I also support taking account of carers' views when making decisions about the discharge from hospital of the people they care for. I agree that planning for discharge should begin as soon as it is reasonably practicable to do so after a person's admission to hospital. Carers can then be supported when the patient is back home.

I have considered this important issue carefully, but I am not inclined to support amendment 103 for two reasons. First, we cannot delay hospital discharge. Evidence clearly demonstrates that delaying discharge when someone in hospital is ready to go home is harmful to their wellbeing and that is why we are investing considerable effort in improving the effectiveness of discharge arrangements in local systems. Amendment 103, which would require carers to be identified and consulted in every circumstance, could inadvertently cause some delays in hospital discharge. That would not do anyone any good. Secondly, this Government will take forward a comprehensive package of measures that is intended to tackle carer identification and carer involvement in hospital admission and discharge processes.

We agree on the issues, but not on how to deal with them. From 2016, we will implement project work with the aim of changing attitudes and culture, and adopting positive practice in the health workforce. The work will be locally led and will involve carers and other key stakeholders, with local solutions shared nationally. The work will be developed within the living well in communities portfolio led by Healthcare Improvement Scotland, which is about reducing hospital bed days and delayed discharge. That will benefit from working in partnership with carers to find the best way forward.

In 2016, we will update and reissue statutory guidance on hospital discharge, with a particular emphasis on carer identification and involvement in hospital discharge. We will follow up with integrated joint boards the role for carers in the strategic planning of services and discussions at local level, in localities acknowledged as the engine room of the integration reform agenda where the greatest impact and outcomes can be achieved. It will include discharge from most in-patient hospital services.

In 2017-18 and 2018-19 we will continue and enhance the work with further workforce development.

In 2017, before commencement of the bill's provisions, as part of the statutory guidance on the Carers (Scotland) Bill, we will include sections on the content of the adult carer support plan and the young carer statement concerning the circumstances in which the plan is to be reviewed. If individual carers want the adult carer support plan or the young carer statement to be reviewed when the cared-for person is discharged from hospital, then that will happen.

In light of the substantial effort that we are making, I invite the member to withdraw amendment 103.

Rhoda Grant: I want to speak in support of Nanette Milne's amendment 103. I was at the meeting when the situation she mentioned was discussed. It was not only the gas cooker but the gas fire that was disconnected, so the family had no heating or cooking facilities for a fortnight. They were given only two hours' notice about the disconnection. You would not want anyone to return home to that situation, far less to have a carer having to deal with the matter.

We have heard about situations arising when vulnerable people have been sent home in the middle of the night in a taxi without it even being checked whether a carer is at home to meet and look after them. It is important that a duty is placed on health services to ensure that admission and discharge planning is carried out properly, and especially to ensure that needs are met and adaptations are in place. There are far too many horror stories going around. We need to do something about the situation.

Dennis Robertson: I believe that the duty is already there and I am not sure that amendment 103 would change what is perhaps bad practice.

I acknowledge that the integrated joint boards and the work that they will do with the health and social care services will address the particular issues that Nanette Milne and Rhoda Grant raised. I suspect that the situation that they identified was more to do with poor practice than something that can be addressed through legislation.

The Convener: Minister, you have an opportunity to respond to what members have said.

Jamie Hepburn: That is very kind of you, convener. It is obviously very difficult to speak about individual circumstances without having all the information. Clearly, the specific case that Ms Milne and Ms Grant referred to was not acceptable, but the point that Mr Robertson made is germane to our discussion. There is already a set of procedures out there that should be adhered to. We have ahead of us a range of work: I have set out what we will do in the coming months and years to further improve performance on the ground.

I assure the committee that I think that it is essential and vital that carers are involved as far as they possibly can be in the admission and discharge process, but we cannot do anything that would inadvertently exacerbate delayed discharge, because that would have a negative impact on the person who has been admitted to hospital.

On that basis, given the range of work that is under way and the reasonable point that Mr Robertson made, I ask Nanette Milne to withdraw amendment 103.

Nanette Milne: There are far too many cases of bad practice, as we heard from Rhoda Grant. I feel strongly that there should be a real emphasis on discharge planning almost as soon as the patient is admitted to hospital, when that is possible. Many of the problems with delayed discharge are a result of the fact that that discharge planning does not get going soon enough.

Although I hear what the minister says, I feel quite strongly about the issue, so I will press amendment 103.

The Convener: The question is, that amendment 103 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For

Chisholm, Malcolm (Edinburgh Northern and Leith) (Lab)
Grant, Rhoda (Highlands and Islands) (Lab)
McNeil, Duncan (Greenock and Inverclyde) (Lab)
Milne, Nanette (North East Scotland) (Con)

Against

Keir, Colin (Edinburgh Western) (SNP)
Lyle, Richard (Central Scotland) (SNP)
MacKenzie, Mike (Highlands and Islands) (SNP)
Robertson, Dennis (Aberdeenshire West) (SNP)

The Convener: The result of the division is: For 4, Against 4, Abstentions 0.

We have a tie, and I have a casting vote. I recall that our stage 1 report recommended

> “that the Scottish Government responds to the calls from carers and carer organisations to include provisions in the Bill that place a duty on health boards to involve carers in hospital admission and discharge procedures.”

On that basis, I support amendment 103.

Amendment 103 agreed to.

Section 25, as amended, agreed to.

Section 26 agreed to.

Section 27—Care assessments: duty to take account of care and views of carers

Amendment 24 moved—[Jamie Hepburn]—and agreed to.

Section 27, as amended, agreed to.

The Convener: I previously indicated that we would not conclude our consideration of amendments today, and I think that this would be an appropriate point at which to break.

I thank the minister and his colleagues. We will continue our stage 2 consideration of the bill next week.

10:58

Meeting suspended.

11:04

On resuming—

Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill: Stage 1

The Convener: Agenda item 2 is our second oral evidence-taking session on the Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. I welcome to the meeting Professor David Galloway, president elect, Royal College of Physicians and Surgeons of Glasgow; Dr Charles Wallis, intensive care consultant and organ donation representative of the Scottish Intensive Care Society; and Dr Calum MacKellar, director of research, Scottish Council on Human Bioethics.

I should make our witnesses aware of the fact that Anne McTaggart MSP, the member in charge of the bill, has joined us. I welcome her to the meeting and will give her an opportunity to ask questions at the end of the session.

As there are no opening statements, we will move to the first question, which is from Richard Lyle.

Richard Lyle (Central Scotland) (SNP): I note, Professor Galloway, that in the submission from the Royal College of Physicians and Surgeons of Glasgow, the response to the question whether you supported the bill was “Unsure”.

Professor David Galloway (Royal College of Physicians and Surgeons of Glasgow): We came down heavily on the fence.

Richard Lyle: When you were asked

> “Do you think the bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland?”

your response, again, was “Unsure”. If the RCPSG is unsure about the bill, what does that convey to the general public?

Professor Galloway: Perhaps I can attempt to answer that question by explaining the mechanism behind our indecision. Initially, we put consultations to the council of the college, which is a reasonably large representative group of both physicians and surgeons, and we also pull in some expert opinion where that is necessary and relevant. To be honest, we had a mixed economy of views on each element of the questions that were put to us. Some were of the view that moving to a presumed consent or opt-out type of system, which is the thrust of the bill, would be desirable and have the intended effect. However, others were very uncertain about that and thought that if there were such a benefit it might be marginal or might even work in a counterintuitive way against the bill’s objective. For that reason, there was no strict consensus and hence our response as a college was, “We are not sure.”

Richard Lyle: May I ask your personal opinion about the bill and how you would have voted?

Professor Galloway: You certainly can ask me that on a personal basis. Perhaps, though, I should declare a potential conflict of interest. From about the late 1970s to the mid 1980s, I was very involved in the much earlier stages of developing the renal transplantation programme at the Western infirmary, and I have therefore had direct involvement in speaking to relatives and dealing with organ donation as part of an organ retrieval process. Furthermore, during a spell in neurosurgery, I was frequently dealing with patients who were diagnosed as brain dead, and the question of organ donation came up time and again.

No one, not even within our collegiate system, will disagree with my personal view that there is clearly a gap between supply and demand in relation to organ donation, and it would be wonderful if we could find a sure-fire way of closing it. We might never close it completely—I suspect that demand will always outstrip supply.

In any event, having looked at the evidence, I personally am unpersuaded that moving from the current situation, which is effectively a soft opt-in, to the soft opt-out enacted in the bill will produce any significant effect, and I think that any benefit is likely to be marginal. There are many more factors that are relevant to the supply of organ donors than simply the issue of making a legislative change with regard to presumed consent. It comes back to education, public awareness and a whole raft of things that I am sure that the committee is well aware of and for which there is now quite a bit of evidence.

Having read almost all the submissions that various groups have made to the committee, I note that a frequent reference point that comes up time and again is the work by Abadie and Gay, which is a 40-odd page document that dresses the whole thing up in mathematical jargon. The bottom line is that the authors are not persuaded that the change that would be produced by a bill such as this would have the desired effect on organ donation nationally. We should therefore stay where we are right now instead of adopting the change that the bill would make.

The Convener: How would staying where we are increase organ donation?

Professor Galloway: There are various ways of tackling that, including public awareness, getting the message out in schools and so on. The trend in the past five or six years from 2009 shows that the rate of deceased organ donation in the UK has virtually doubled from around 12 per million to more than 20 per million. There is no doubt that there has been an increase, which has clearly occurred without any legislative change, and that there are lots of ways of enhancing that.

The Convener: You are saying that the bill would not bring any gain, but that still presents us with the challenge of bridging the gap.

Professor Galloway: That is right.

The Convener: So why has there been an increase? Is it because more people are available, or is it because we are taking organs from older people? Is it because of an education programme, a communications programme or a legislative drive? We are all as one in agreeing that organ donation and transplant programmes are good and that we would all like to increase the number of donations to give people a better quality of life. If we do not do that through this bill, how do we do it?

Professor Galloway: There are two points to address. First, we do not have a crisp answer to that question. The important issue is public awareness. The public seem to have a great deal of sympathy with the idea of acceding to the request for people to be organ donors, but the number of people who sign up for donor cards and make a positive decision to opt in is much more limited.

Secondly, I am slightly concerned that a change such as the one proposed in the bill might be counterproductive; indeed, two or three transplant surgeons have articulated the same concern. We can envisage a situation in which a family in the depths of a crisis is faced with a question that, for them, might come from left field and might be a source of uncertainty and disagreement for family members. When that kind of thing leaks out, it can lead to bad press. That is exactly why such a bill can be counterproductive.

I am sure that the committee is aware of other national examples. In Brazil, a legislative change to an opt-out was enacted and then repealed because it had the opposite effect to that which was intended. The issue is a complex one.

The Convener: I am conscious that Dr MacKellar and Dr Wallis have not yet had the opportunity to speak. If you wish to respond to some of the earlier points, you may do so, and then I will bring in Malcolm Chisholm.

Dr Calum MacKellar (Scottish Council on Human Bioethics): I agree fully with Professor Galloway.

Dr Charles Wallis (Scottish Intensive Care Society): The increase in the number of organ donations since 2008 followed the publication of a task force document by NHS Blood and Transplant that improved the systems and processes behind organ donation and also increased public information. That multi-pronged attack has led to the almost 50 per cent increase in donation, but there is still a shortfall of organs.

The Convener: Yes. Compared with Spain, for instance, our figures are not great.

Professor Galloway: We need to consider the Spanish figures in context. Interestingly, Spain has almost no live donors. Clearly, living donation applies to some organs, but not to others; we have a very reasonable proportion of live donors for renal transplantation, whereas in Spain such donors are virtually non-existent. That is just a comparison.

11:15

The Convener: You are correct to say that Spain does not have many live donors, but overall it has significantly higher donations—

Professor Galloway: From deceased donors.

The Convener: —and a smaller opt-in of people signing up for donor cards. Are there some lessons for us in that?

Professor Galloway: It is interesting. One lesson that might be pertinent to this discussion is that, to my understanding, the Spanish legislation has not changed during the process.

The Convener: We know from speaking to practitioners that it is part of the process. Malcolm?

Malcolm Chisholm: I think that everyone accepts that, as has been said, there is no panacea and a range of measures are necessary. Whether people support or oppose the bill, I think that everyone accepts that.

I suppose that there are two issues that I would like to start by highlighting. In a sense, the first one—the gap between supply and demand—has already been highlighted. That is what drives people to think about the range of measures we should adopt. However, the even more striking gap is the one between the 40 per cent of the population who are on the register and the 90 per cent who say that they support organ donation. I feel that the proposals in the bill, to some extent, have that gap as their starting point.

Having read your evidence, all of which is useful, it seems to me that there are moral objections in Dr MacKellar’s submission but more pragmatic objections from the two clinical people who are here. Let us deal first with the moral objections from the Scottish Council on Human Bioethics. Is it your position that the only thing that matters is whether an individual has said that they want their organs to be used? Do you feel that relatives should never give consent if the person has not already opted in to the register that exists at present?

Dr MacKellar: I think that there are three cases. The first is where the person has made known their wish to opt in or out of the register. The second is where the relatives know the wishes of the deceased but the deceased has not registered either in or out. That, again, would be acceptable: when it is clear that the relatives know the wishes, they can say either no or yes to organ donation.

The problem is created when the relatives have no idea and no information about the wishes of the deceased. When that happens, it is a difficult decision for the relatives. It is just guesswork, and we believe that organ donation should not take place in that situation. The fact that it is taking place in Scotland shows that, at present, we have a soft opt-out situation.

There is an awful lot of confusion in all the documents that I have read over the years. In 2005 and 2006, I was involved on behalf of the Scottish Council on Human Bioethics in the Human Tissue (Scotland) Act 2006. Section 7 of that act, which is in force, enables the soft opt-out system to operate when deceased persons have not made any wishes known. As the Scottish Parliament information centre report says, there is an assumption that organs and tissue are available for transplant if the deceased has left no instructions about what to do with them. I do not really understand why we are having this debate when the soft opt-out situation already exists in Scotland.

Malcolm Chisholm: I asked the question because in your submission you said that the SCHB is

> "very concerned that over the five year period 2008-2013, in Scotland, 62% of donations have come from donors who were not on the register at the time of their death."

I suppose that my concern is that your proposal would dramatically reduce an already inadequate number of organs, if you object to 62 per cent—

Dr MacKellar: Amongst that 62 per cent of people, there will be quite a number of people who had told their relatives what they wished in a discussion over a meal or whatever, so the relatives would know that.

Malcolm Chisholm: I understand that.

Dr MacKellar: A proportion of that 62 per cent would have relatives who had no idea, and their organs would have been taken even though no one knows whether that would have been what they wished. Many people are disengaged in our society and do not know what the present system is. That has to be taken into account.

Malcolm Chisholm: The reality is that, under both the current and the proposed systems, relatives will be consulted. That is why I took particular exception to your reference to the scandal at Alder Hey, where parents were not consulted.

The Scottish Intensive Care Society has said, in a much softer way, that the proposal would

> "Lead to loss of goodwill and confidence in organ donation from the public".

Again, if the relatives are still to be consulted, that loss would not happen because the relatives would still have the final say.

What the proposal will do is to change the nature of the conversation between the specialist nurses or clinicians and the relatives. In the vast majority of cases, the relatives will still have the final say—or, in a minority of those cases, a proxy will have that say, which is an issue that we may want to consider later.

How could that approach lead, in the extreme case, to an Alder Hey, or even to the more moderate concern of a loss of goodwill and confidence?

Dr Wallis: The flowchart on page 16 of the policy memorandum states that the clinician must

> "Ask the nearest relative whether they are aware of any objection expressed by the person."

If all the preconditions are met, it says to go ahead with donation.

It is difficult to see how the proposals would change the current situation, in which we already ask the relatives. The bill says that we will do the same thing. How will that improve organ donation rates? That is our concern.

Malcolm Chisholm: The conversation would be changed—but the more you say that the proposed system is similar to the present one, the less effective are what I would regard as the exaggerated objections to it.

I accept that your critique is not nearly as extreme as that of the Scottish Council on Human Bioethics, but you are still raising very serious concerns at the same time as saying that, in practice, the proposed system might not be very different from the present one.

Dr Wallis: Most of my concerns are about the practicalities because, as clinicians in intensive care, my colleagues and I are the people who approach families in that very difficult situation. We are almost always the first people to raise the question of organ donation, with or without the specialist nurse for organ donation present. We know what it is like. In my nearly 20-year career, I have seen lots of very distressed families going through the process, and it is very difficult for them. I would not want to be in a situation in which I am forcing a family to accept organ donation because the person has not opted out.

Malcolm Chisholm: We are all very respectful of your experience. The scenario you have outlined is not the intention of the conversation. However, your point goes to the heart of the bill, and we will reflect very seriously on what you have said.

Although it attracted headlines in Sunday's newspapers, the Alder Hey analogy did not seem to be appropriate, given what is proposed in the bill.

Dr MacKellar: I agree that the Sunday headlines were inappropriate. We mentioned Alder Hey because we mentioned it in 2005 and 2006 in relation to the Human Tissue (Scotland) Act 2006, which was trying to address the issues related to it. There is an ethical principle that, when someone does not say anything, that is not consent. That is why in our report we did not talk about presumed consent but about an opt-in or an opt-out system. That was the problem in Alder Hey: nothing was said, and it was presumed that the staff could go ahead and use the organs from the dead children for research.

Another problem is that, for an opt-out system to be ethical, everybody in the country should know about it. I would be surprised if a great majority of the people in countries in Europe that have an opt-out system know that they have such a system and that there is a possibility that if they said nothing their organs would be removed.

In the soft opt-out countries, the relative will always be asked what they think—but first the deceased person has to have relatives. It is always assumed that we have a family, with brothers and sisters who are close to us, but a lot of people do not have that. I have nobody in the whole of Scotland who would be considered a relative; I just have friends of long standing, who I have probably never talked to about organ donation. That is the first problem: who are the relatives? We have heard that in Scotland even someone's landlord has given authorisation for the removal of organs for transplantation.

Before we go down the opt-out route, it would be useful to know how many people are aware of such systems in countries where they already operate and how much relatives, who could just be friends of long standing, know about the wishes of the person who might wish to donate their organs. That is quite easy research to do, and we believe that it should be done before we consider going down that route.

The Convener: Mike MacKenzie wants to ask about the ethics, but we need to come back to the two extremes—one is that we already have a soft opt-out system in practice and the other is that, if we introduce it, there will be all sorts of consequences. We are getting confused with the evidence about the serious consequences of enacting this bill. I will bring in Mike MacKenzie to ask his supplementary question, after which Rhoda Grant can come in.

Mike MacKenzie (Highlands and Islands) (SNP): I would like Dr MacKellar to confirm whether I am right in my understanding of the position set out in his written evidence. It is inevitable that, if the bill were to pass, a substantial proportion of people would be ignorant of it. Some of them might be quite happy with presumed consent, but a proportion of them would be unhappy with it. Your position is that that would create a situation that is unethical, which I understand.

My problem with that position is that with regard to the rest of our law—certainly our criminal law—ignorance of the law is no excuse. If I committed a crime and said in court, "I'm sorry, your honour, but I just didn't know about that law", that would not be an excuse. It seems to me that your argument runs the risk of ethically undermining our whole body of law, and it is invalidated as a result. What are your comments on that?

Dr MacKellar: The whole aim of ethics is to make any legislation scandal proof. There was a scandal at Alder Hey, which we have talked about already. I am sorry to come back to that, but the problem was that something was done without asking people what they wanted.

Nobody in this room would want a scandal to arise with either the current legislation or future legislation. That is why it is extremely important to make sure that what is done to a deceased person's body is in accordance with his or her wishes. If that does not happen and relatives find out that it did not happen, or a journalist carries out an investigation and finds out that a lot of organs have been taken from people who had no relatives or friends, that would undermine confidence in the system.

On the bill, we want the general public to have really strong confidence in the system, so that there is no possibility of things happening that should never happen, which would result in a scandal.

Mike MacKenzie: With the greatest of respect, you have merely reiterated your position as I understood it. The question that I hoped you would address is whether those same principles would apply to the rest of our law. Do you not agree that it is important that the public have confidence in our criminal justice system?

I am struggling to see how you can apply ethics and turn them on and off as it suits, in a pragmatic fashion. That also relates to the six months' residency part of the bill. It is important that we consider ethics in their wider context and not just pick and choose to apply them willy-nilly. Why should ethical consideration be applied to this bill and not to other bills?

11:30

Dr MacKellar: In a way, ethics are more important than law. Laws are based on ethics; they are not just drafted out of thin air. Ethics are more of a foundation than law.

We are not talking about crime in the financial sector or whatever; we are talking about something that involves everybody in the whole of Scotland. It is extremely important that everybody in Scotland knows the system, because it is really important for them. They might not be interested in some financial bill, but they will be interested in this bill.

Rhoda Grant: The Alder Hey issue was about organs for research, whereas the bill is about organs for donation. It is a bit like comparing the gift of life to medical research. Both things are laudable, but they are poles apart. The comparison does not really work.

I will turn your arguments on their heads. We know that almost half the people who are on the donor register will have their wishes rejected by their family at the point of death. That is an ethical issue as well, and the bill seeks to do something about that. I have belt and braces: I am on the register, I carry an old donor card, and I told my husband about my wishes—I have done almost everything that I can. However, if my husband was not there when I died and another member of my family was there, they could reject my wishes. Where are the rights of the person? We are losing half the available organs at the moment because people's rights are not being taken into account.

Dr MacKellar: It is a bit like writing a will before you die. Normally, a person's wishes should be respected, but, as we have been saying, it will be very difficult to respect a person's wishes if the family opposes them. You cannot wheel out a person in front of a relative to remove their useful organs when the family is so distressed. Normally, however, the last wishes of a deceased person should be respected.

Professor Galloway: It seems there is a bit of difference between members of this panel regarding their understanding of the current situation. Dr MacKellar referred to it as a soft opt-out system; I would think of it as a soft opt-in system.

Whichever way we look at the issue, it seems that, since we will involve the family in making the decision, there is not a huge difference between the two options. The question seems to turn on this point: would changing the legislative framework to one of presumed consent make such a difference to the conversation that would be had with the family, which Malcolm Chisholm talked about? Would that change the nature of the conversation such that we would enhance the number of organ donations? That seems like an enticing prospect, but I do not know the answer to the question.

The Convener: Dr Wallis, you mentioned your practice and your involvement in the area. If you change the question and change the people who ask it of a distressed family, will that make a difference? Will that increase organ donation?

Dr Wallis: I suspect that it probably will not. The reasons that people cite for not wanting to go ahead with organ donation are commonly things such as the time factor, which I alluded to in my written submission. Currently a donation takes about 21 hours after cardiac death and nearly 30-plus hours after brain death. That length of time is unacceptable to many families and is often cited as the reason for not wanting to go ahead. It is not necessarily that they disagree with organ donation in principle. I do not think that changing the law or changing the conversation will change how families perceive that problem.

The Convener: What question do you ask of the families at this point?

Dr Wallis: The first and most important thing is to explain to the family that their loved one is either brain dead or about to die, and that conversation has to be quite separate from the discussion about organ donation. Once the family have accepted the inevitability of death or impending death, you can then move on to a separate conversation about organ donation. You can introduce the subject in a variety of ways, depending on the family. If you know that the person is on the organ donor register, you can open that conversation by saying, "We know that John is on the organ donor register and we'd like to talk about organ donation."

The Convener: Does that mean that the clinician who has been working to save or extend the life of that person in the intensive care unit, and who comes to the conclusion that the person is brain dead and has that discussion with the family, is the same person who begins the discussion about organ donation, or is that handed over to a different person?

Dr Wallis: Quite often it is the same person, but increasingly we involve the specialist nurse for organ donation. NHSBT likes the specialist nurse for organ donation to be involved at that initial approach.

The Convener: There is a complete division in Spain. The clinicians who are working to save the person’s life do not in any way begin the discussion about organ donation. It is a completely separate process and there are established clinicians and doctors in each of the major ICUs to take on that discussion; they become involved only when it is accepted that the person is brain dead. That is the situation as I understand it. Would it be the same here?

Is there a clinical process to establish whether somebody is brain dead?

Professor Galloway: Yes.

Dr Wallis: Yes.

The Convener: Is that well respected and recognised?

Professor Galloway: Yes, internationally.

The Convener: So there is an international standard. Maybe it is just a question of changing some of the systems that we have.

Dr Wallis: I would like to comment on that, if I may. One of the strengths of the ICU team approaching the family is that the family already know them and have respect for them, because they have seen that team working hard to save their relative. I think that it would be quite difficult to bring in a new person whom the family have never met before.

The Convener: It works to great effect in Spain. Going back to Dr MacKellar’s idea, if somebody who is fighting to save a person’s life starts to talk about organ donation, I would have thought that it raises a contradictory point about trust. People would say, in that situation about organ donation—

Professor Galloway: With respect, convener, there is no contradiction at all. In practical reality, you get to a point where a decision has already been made and it is clear, on internationally accepted guidelines, that the patient is brain dead, and that is the end of the story. It is only then that there would be any discussion or that the subject would even be broached about the possibility of the individual becoming an organ donor.

Malcolm Chisholm: Further to what Dr Wallis said, and we appreciate his knowledge and experience of the subject, irrespective of whether we change the system, the length of time—whether it is 21 hours or 32 hours—being a negative thing for a lot of families is an issue that has been raised. We picked that up when we spoke recently to families who had a relative who donated. The specific point that they made was that they had been asked a vast number of medical questions and wondered whether some of that information could have been found out from the medical notes. That is one aspect of it, but is there any way in which the length of time could be reduced in terms of the involvement of the families? You seem to be highlighting that as a major obstacle to donation for a lot of people.

Dr Wallis: It is really a logistical problem. The initial conversation with the family about organ donation typically takes about an hour. If I introduced the subject to the family and they gave an initial positive response to organ donation, we would bring in a specialist nurse for organ donation—if he or she was not already there—and the authorisation process would then take about an hour. That is not actually very long. What takes a long time is all the other logistical things, such as tissue typing, blood typing and virology checks—to ensure that the patient does not have hepatitis, HIV or other viruses—and then we have to find a potential matching recipient. Only then, when we have the okay to proceed, do we call the surgical team, who come and retrieve the organs. There has to be time for that team to be mobilised and time to find a slot in the operating theatre, as well as the time that the procedure itself takes.

Malcolm Chisholm: But most of that does not involve the family.

Dr Wallis: That is right.

Malcolm Chisholm: So why is the time that it takes a negative for the family? I know that one hour is bad at such a moment, but are you saying that that is all the time it takes to ask all the questions?

Dr Wallis: Oddly enough, it is less of a problem in brain death cases, because in those cases you have already told the family that their loved one is dead—brain dead—and they have accepted that point. The difficulty is with donations after cardiac death, which account for about a third of our donors. In those cases, the person is not dead until right up to the point of donation—we keep them hanging on, and the families find that difficult. Often, they have been through days, if not weeks, of a very distressing illness when they come to that point, so they are utterly exhausted.

The Convener: I again hark back to what happens in Spain. The big difference is that in Spain they spend a lot of their time not on cardiac death but on brain death, and they get big results. The specialist comes in to take over the burden from the clinician. They establish whether the person is a viable donor or whether there is any infection, cancer and so on, and they deal with the legal issues. There are also specially trained doctors and nurses who support the family. The results indicate that the approach in Spain is effective. When we were in Spain, we were told that the family refusal rate among expats—Brits in Spain—was 10 per cent, in comparison with the 40 per cent rate in the UK. There seems to be a gain as a result of the practice in Spain.

Professor Galloway: I accept that. It is difficult to understand exactly why the difference exists, and we do not know whether it is a result of the changes of the sort that the bill would introduce.

The Convener: We spoke to the practitioners—the transplant doctors—in one of the biggest hospitals in Madrid, who said that they felt that the legal framework allowed them to ask whether there was any objection, and the conversation started at that point. They do not cross that line. They described situations similar to those described by Dr Wallis, when there are differences within families—between brothers and sisters, or whatever. Spain has highly trained clinicians whose job is to do that on a daily basis—whereas we have the SNOD nurses, Spain has clinicians.

Dr Wallis: In this country, the role that you describe is done by the SNODs—nurses who are paid for by NHSBT. They work in teams across the UK and are highly experienced in all the things to which you refer. They pretty much do the job done by the Spanish team that you describe.

The Convener: We all know about the hierarchy in our hospitals. Unfortunately, clinicians sometimes have more clout than nurses. By how much have the nurses increased organ donation?

Dr Wallis: They are absolutely pivotal. Without them, the system—

The Convener: What has been the outcome of the introduction of the specialist nurses? What increase has there been in organ donation since specialist nurses were introduced?

Dr Wallis: I could not possibly say. Back in the 1980s, there were people called transplant co-ordinators. As time went on, their role evolved, and the name was changed to SNOD about 10 years ago or so. There has been an evolutionary process, during which organ donation has increased. There is no one point about which you can say, “We introduced this person and look at the effect.” That is an impossible question to answer.

The Convener: In Spain they can point to such a moment. They can point to a significant increase in organ donations when specialist people were introduced in their hospitals, but we cannot do that.

Professor Galloway: There are so many confounding variables that the question is impossible for us to answer.

11:45

Dennis Robertson: Good morning. The Scottish Intensive Care Society’s submission says that the situation is already very complex. It also suggests that the bill would not increase organ donation. It is difficult for me to understand why the society would state that.

I return to the issue of complexity. Is there a way to make the conversation with families easier? For example, by running sufficient tests beforehand, some of the questions that are asked by the specialist nurse may not need to be asked. You have the patient in and you know their blood type and whether they are suffering from any virus. You do not need to do all the significant checks or ask extremely personal questions on issues such as drug use, HIV and sexual activity. How many families walk away from the specialist nurse at that point because the questions that they are being asked are too hurtful or concern matters that are too sensitive?

Dr Wallis: I am not aware of any families walking away at that point. The questions do not come until a little later on. You start off with the initial approach about organ donation and you get a clear steer pretty quickly as to what the family’s views are. If you get a provisional positive, if you like, you get into those much more detailed questions. The families are warned by the specialist nurses that the process will involve some questions of the nature that you describe.

We have to ask those questions because we cannot rely on blood tests alone. For example, when someone catches HIV, it takes a while before they develop the antibody that comes up in a blood test. Let us think of the hypothetical situation in which we have a 40-year-old man who is dying in an intensive care unit. We need to know a little bit about what he has been up to. That might include recent travel. If it turns out that he has recently been on a trip to the Philippines for uncertain purposes, he may have caught HIV out there and it may not yet show up in the blood test. We need to know these things; if we did not and took those questions out, we would increase the risk to the recipient of catching something. You may have heard about a case in Wales where two recipients died of an extremely rare worm infection that got into their brains. The infection came from the donor. While the centre had screened the donor thoroughly, it had not picked up that the donor had a down-and-out lifestyle and was an alcoholic. Nobody knew him very well—that was a real problem. He had died of that infection but it was not diagnosed at death and the infection killed two recipients. That is quite unacceptable.

Dennis Robertson: But the bill would not alter that scenario, would it?

Dr Wallis: Let us say that that patient had not opted out—which he probably would not have done because he was disengaged from mainstream society—the bill would make it more likely that we would take presumed consent. As it happened, within the current system, the donation still went ahead. I should point out, however, that all other centres in the UK had declined those organs. I am giving you publicly available information, by the way.

Dennis Robertson: Rather than the opt out proposed by the bill, is your preference to retain the opt in, but to make the public more aware of it? I am trying to understand why you feel that the bill would result in no significant increase in organ donation.

Dr Wallis: Are you asking me as a representative of our society or as a doctor?

Dennis Robertson: Both.

Dr Wallis: The answer for the society is very similar to that from Professor Galloway. Initially, when we spoke about the issue, we were split roughly 50:50. We had further discussions more recently, when some more of the bill's detail came out. Most of the discussion was on concerns about the practicalities of the proposals, such as those on the authorised investigating person, which we have not discussed yet, and the proxy. Those two things, which I think came up in many other submissions, were major causes of concern.

As an individual, I am happy with the current system and am not sure that the bill would necessarily increase the number of organ donors. However, I am just one person, and I do not want to influence things.

Dennis Robertson: But your submission states that it would not do so.

Dr Wallis: My submission is essentially based on our concerns about the practicalities and their effect. The most important thing to say is that the Scottish Intensive Care Society is extremely supportive of organ donation and always has been. We will continue to be extremely supportive of it.

Dennis Robertson: Does either of the other witnesses have an opinion on whether we should try to raise awareness of the opt-in system, as opposed to what is proposed in the bill? Do they favour something like that?

Professor Galloway: Raising awareness is almost a guaranteed way to increase organ donation. We could argue that a range of opportunities have not been fully exploited. It would be possible just to increase the role of education, even in schools, to get the importance of organ donation into the public mindset at an early stage. Ultimately, that would be likely to have a very beneficial effect on organ donation in adult life.

Although I cannot prove any of that, there is certainly plenty of evidence in North America and even in the Arab world, where there are religious issues that apply, of course. People have looked at a whole range of issues that relate to education, religion and public awareness—they have even linked it to driving tests, for example. All those opportunities have been considered to be extremely beneficial.

It is important that we maximise those easy wins in Scotland. Despite having heard the discussion around the table, I am still not convinced that making an adjustment such as that which the bill would make would achieve the hoped-for benefit. It would be nice, but I am not convinced.

Dr MacKellar: I agree. I used to be responsible for organ transplantation at the Council of Europe in Strasbourg. We used to go to Spain and Russia, for example, to try to understand what was happening in those places. Even 12 years ago, Spain was the best country in the world for transplantations. People there said that they worked with all sorts of different sections of society, including the churches. They tried to encourage priests to preach about organ transplantation in Sunday services, for example, and to remind people that the Catholic Church is very supportive of organ transplantations.

I welcome the meeting that the committee had with all the faith groups. I know that faith groups have programmes in place to try to encourage people such as ministers in the Church of Scotland to talk and preach about transplantations and to make people aware that their faith is in favour of transplantations.

I see only two differences when I look at the bill and at what is happening right now. Those differences relate to the provision of proxies and the development of authorised investigating persons. Otherwise, I do not really see what the bill, with its soft opt-out system, will achieve that is not already in place. I do not see the advantage of the bill.

Dennis Robertson: Does the bill not give us two options, in a sense? People can still opt in if there is a register, and they can have an opt out as well. Given that, through the bill, there will be heightened awareness through education, which could obviously refer to an opt in, there is the possibility of having a double option that is not currently present.

I take the point about the complexities of introducing AIPs and so on. I think that that would exacerbate situations that are already fairly complex and difficult for families.

Dr MacKellar: I believe that we already have both an opt-in system and an opt-out system in Scotland. As I said even in 2005 and 2006, I believe that we have a sort of hybrid system. What we have right now in Scotland is the best system available to provide the maximum number of organs without going down the route of having hard systems, such as a hard opt-out system. The system that we have at present, with both an opt in and an opt out, will provide the maximum number of organs.

The Convener: Does the rest of the panel agree that we are maximising the number of organs that are available in Scotland?

Professor Galloway: I do not agree that we are maximising the number. I would hesitate to say that the bill would allow us to maximise the number. Public awareness and education are the key to maximising the number. We have a soft situation now, and we need to change the background default legislative framework, without necessarily changing dramatically the practical realities of the conversations that are had with families, although attitudes might be changed to some degree. That is the level at which the bill would make a difference.

The Convener: We have referred to the situation in Spain. It is true that there is national pride in Spain that it has the highest number of organs available in the world. From that flow a number of attitudes and cultural change. However, the question remains whether we are happy with the situation here. Are we happy that all potential organ donors are being identified in the first place? If not, how do we increase the number of potential donors who are identified?

Dr Wallis: I am happy that we are identifying the vast majority of potential donors. Some are missed, but NHSBT looks at that closely. We have a process called the potential donor audit under which every death in intensive care is looked at to see whether the person could have been a potential organ donor; if they were not, that is fed back to the teams in the unit as a learning process.

The Convener: I am aware of the importance of the ICU in all this, but we have had information that shows that levels of organ donation are higher in some areas—perhaps it is bigger hospitals against smaller hospitals and so on. What is the gap between doing all that we can to identify those who could donate organs and doing the nearly all that you have described?

Dr Wallis: Even if we did absolutely everything that we could, there would still be huge differences between hospitals, because the figures depend on the case mix and the type of patient that comes into the hospital. For example, I work in the Western general, which has a specialist neurological and neurosurgery unit, so we get all the patients from south-east Scotland with major, traumatic brain injuries or bleeds into the brain from which they can die. They all come to the Western general, so we have a very high rate of organ donation. However, another hospital—such as the Royal infirmary, which is just up the road from here—will have a much lower rate of donation because it does not have that type of patient. It all depends on the case mix, and we cannot compare organ donation rates from hospitals unless they have the same case mix.

The Convener: So we cannot compare donation rates in different regions or in similar hospitals in, say, Grampian, Aberdeen and Glasgow. Are they all doing equally well?

Dr Wallis: I would not say that, because there are differences. However, we look at the issue all the time and are doing our best to optimise donation rates.

The Convener: Why are there disparities, then? What has your research found to explain the disparities between similar hospitals with similar case loads?

Dr Wallis: That might be partly down to how units work and—dare I say it—to the attitudes of clinicians, which can have an effect. Some clinicians are very pro organ donation—I am—but others are less so. That can have an effect. As time has gone on, organ donation rates have improved, as we have discussed. All places are steadily coming on board.

The Convener: If we start from a lowish rate, there is an improvement. We then start to look at comparisons and how we can do better.

You just said that the prospect of identifying a donor can depend on whether a senior clinician supports the programme. If that is one of the reasons, it is quite shocking.

12:00

Dr Wallis: That is just one of many factors. We also have to ask the question of the family.

Professor Galloway: I have never come across senior clinicians who are against organ donation. I do not have any research that can answer the question of why hospitals that have a similar case mix but are in different parts of the country might have different organ donation rates. We have not looked into that.

The Convener: Dr Wallis alluded to regular studies of the outcomes.

Dr Wallis: I did. The potential donor audit is continuous and we look at it all the time. The information is constantly being fed back to clinicians.

The Convener: There is evidence, Professor Galloway.

Professor Galloway: All that I am saying is that I am not aware of it.

The Convener: You are not aware of it.

Mike MacKenzie: I have a couple of brief questions, the first of which is for Professor Galloway. I take your point that we can do lots of things short of legislation to increase awareness and the donation rate. I dare say that you would welcome the bill because of the increased media coverage, which would also serve to raise awareness.

Despite our best efforts, no legislation is perfect. Surely you are not saying that the current legislation is perfect. I am interested to hear your thoughts on how we could improve it.

Professor Galloway: That is an interesting question. Is the current legislation perfect? No, it is clearly not. It would be great if we had a system whereby we could genuinely maximise donations and everyone was onside, not just the enthusiastic people who are around this table and those who have proposed the bill to narrow the gap between supply and demand and so on. However, there is a range of variables that are open to attack. Short of legislation, those ought to be exploited.

I take your point about the publicity that surrounds such a bill. Of course, publicity can work both ways, and it depends on how elements of the media might represent your best intentions.

The current system is good. My personal view is that the changes that the bill would enact would have a marginal effect. It would be difficult to measure and define that effect in the fullness of time, because those measurements would be made in a fluid and dynamic situation in which there are all sorts of other factors that are as likely to have as significant an effect as making the adjustment for presumed consent is, for want of a better phrase.

Mike MacKenzie: I have one more question, convener, which is for Dr MacKellar on ethical considerations. I accept your argument that there will be a proportion of people whose views we cannot know. It would be unethical to introduce compulsion, because some of those people will have a disinclination to offer the gift of life. I understand that such a consideration is on one side of the ethical scales. How do you balance that with the other side—that the gift of life can be given through organ donation, perhaps to two or more people?

Dr MacKellar: You cannot. In a way, that is what Parliament does. It measures the risks against the advantages of any procedure. That is what ethics is all about. On the one side are the disadvantages that everybody recognises and on the other, we have the advantages—in this case, that is the saving of life. In a way, it sounds wrong that, because some persons have decided not to say anything through registration or by talking to their relatives, their organs cannot be taken to save two or three lives. That sounds wrong.

Mike MacKenzie: It certainly does, if you do not mind me saying so.

Dr MacKellar: It does. I recognise exactly where you are coming from. My job is always to try to find out how other people think and what their arguments are.

However, there is a very strong principle that is enshrined in European law that means that strong wishes about a person’s body should be respected, be they alive or dead. The body of a person is extremely important. The house or the car of a person may be less important, but the body of a person is extremely important.

That is why a person cannot own their body. There is no law in England, Scotland or anywhere else that says that a body belongs to somebody. People have responsibilities for their body. We are our bodies, but we do not own our bodies. If we did, we could sell our bodies—we could even sell our organs. The ethical principle that we do not own our bodies says that we cannot do that. Bodies are extremely important, and what happens to a body is extremely important because it belongs to the person. In a way, the person is the centre of ethics—it is because we have persons that we have ethics and the idea of respecting the wishes of the person.

If we want to save lives, we can do so in all sorts of ways that are completely unethical. Just because something can save a life, it does not automatically become ethical.

Rhoda Grant: I will move on to the proxy and the authorised investigating person. It seems to me that those two aspects of the bill are what the Scottish Intensive Care Society and the Royal College of Physicians and Surgeons of Glasgow are concerned about. As I understand it, you had a split decision on the bill until you looked at those two aspects. What are your concerns about them?

Dr Wallis: It was not clear from our reading of the bill who the authorised investigating person would be or what kind of background and training they would have. We already have the SNOD—the specialist nurse for organ donation—who deals with all the aspects that I spoke about earlier. Is it proposed that we have an additional person? If so, who would they be? They would have to be available 24/7. Those were our concerns. We were worried that the proposal might complicate and prolong the process.

Rhoda Grant: If the SNOD was the authorised investigating person, would that allay those concerns?

Dr Wallis: Initially, I thought that the roles would rest with the same person, but the Scottish donation and transplant group suggested that that might not be the case, although I am not sure where it got that idea from. If the authorised investigating person and the SNOD were the same person, that would probably be better, so why bother with the proposed provision?

Professor Galloway: Some of the same concerns were voiced in the college. In relation to the proxy, we were a little unsure about the tensions that might exist if the proxy were not the nearest relative and there was a conflict between the family's view and the proxy's view, and about how the proxy would know in any event. The definition of that seemed a little vague to us, so we were hesitant about the proxy's position.

Dr MacKellar: We would have concerns if the specialist nurse for organ donation was the same person as the authorised investigating person. There could be a conflict of interest. At the moment, the SNOD does not authorise organ removal for transplantation; it is the nearest relative who does so. The SNOD is there to ask the nearest relative whether the transplant can go ahead.

If the bill were to go ahead and the specialist nurse for organ donation was the authorised investigating person, it would be the authorised investigating person who, in some cases, authorised the removal of organs for transplantation. If they were the same person as the person who was trying to encourage transplantation, there would be a conflict of interest.

If there was no proxy—if no relative was contactable—the authorised investigating person would authorise the removal of organs for transplantation. That would involve going down the road of a hard opt-out system, whereby the relatives would not be asked. That is another concern that we have about the proposal.

The Convener: Would the role address the point that clinical enthusiasm for organ donation varies? Would the authorised investigating person help with the situation where there are clinicians who are more enthusiastic about organ donation and those who are less enthusiastic about it?

Professor Galloway: I do not know how to answer that question. I do not know on what data or evidence we would base any answer.

The Convener: My question is based on the evidence that we heard from Dr Wallis earlier. That might be one of the factors in the variance in organ donation rates between one area and another.

Professor Galloway: Are you asking whether—

The Convener: I am asking whether the authorised investigating person would help.

Professor Galloway: In changing clinicians' attitudes?

The Convener: If that person was there and there was an expectation.

Professor Galloway: It seems that the authorised investigating person would be there simply to fulfil a legislative process and establish various facts, and not to influence clinicians' attitudes about whether transplantation is desirable.

The Convener: The person would be there to ensure that the bill was—

Professor Galloway: I guess that, if the bill was passed and there was a soft opt-out scenario, that person would probably push gently in that direction, in making sure that the law was followed. In that sense, I suppose that the role might have a positive effect.

Rhoda Grant: My understanding is that the proxy is required where there is no next of kin or where the next of kin might not share the views of the person who is on the register. What happens at present when you cannot find a next of kin? I heard someone say that a landlord had been asked for permission. I would sooner have the authorised investigating person than a landlord making a decision about what happened to my body after my death. What happens now?

Professor Galloway: Are you asking whether a clinical team would ever proceed with a donation if the person was on the donor register and the family were throwing up their hands in horror? From my experience, the answer would be no. The family would carry the day.

Rhoda Grant: That was not my question. My question was about what happens when there is no next of kin or loved ones but the person is on the donor register. Someone said that, in one instance, a person's landlord gave permission.

Dr Wallis: If the person is on a donor register, it is clear. We would go ahead because the person had expressed that wish. The difficulty arises if they are not on the register. We would then try our best to find someone who knew the person enough to be able to say whether they would have wanted to be an organ donor.

Rhoda Grant: One reason for having a proxy is that there is no next of kin. I think that it was the Scottish Youth Parliament that mentioned looked-after children and said that people who do not have next of kin would very much want a proxy. You are saying that, if they are on the register, they do not need a proxy because their views and their having signed up to the register would be sufficient to allow them to donate.

Dr Wallis: I am just telling you what we do at present. I thought that the intention was that everybody would have the option of appointing a proxy and that most people would have one. Is that right?

Rhoda Grant: No. My understanding is that, if someone does not have any next of kin, they can have a proxy, and if they think that their next of kin will not agree to the donation and they very much want to donate, maybe for religious reasons, they can have a proxy who will fight their corner at that stage and say what their wishes were. My understanding is that people will have a proxy only in the rare circumstances where they think that there will be conflict or they do not have any next of kin to say what their wishes were.

Dr Wallis: Our concern is that there will be the family and also a proxy.

Dr MacKellar: The concerns that have just been raised are the concerns that we had in 2005 and 2006. In those days, people could not register their opposition to organ donation. That option has been available only since July this year. Again and again, we tried to raise the matter in the Parliament, saying, “What happens if someone does not trust their relative or does not have any relatives?”

In those days, the only way for someone to record their decision was to ask for it to be put in their GP notes, which were written on paper, so it would have been a big problem for people to know exactly what the person who wanted to donate their organs had done to state that. Since July 2015, however, it has been possible for a person to register their position.

You would also have to register that a person had decided to have a proxy. As we just heard, once organs become available and there is a green light for organ removal, there is not much time. Whoever was responsible for taking the organs for transplantation would have to know straight away that there was a proxy, so the proxy would have to be registered somewhere. The question is whether there would be any advantage in having a proxy system when someone can already register directly in the register that has existed since July 2015.

12:15

The Convener: Richard Lyle will ask our last question.

Richard Lyle: There are concerns that two sections of our community may not have their wishes dealt with correctly: vulnerable groups and adults with incapacity. In your opinion, how would vulnerable groups and those with limited capacity be treated under the bill if they failed to opt out or were unable make their views known? How would the bill support vulnerable people and those with limited capacity to express their views? What would happen if adults with incapacity had difficulty in opting out of organ donation? We must respect people’s views, and people in faith groups may have concerns about how their views would be met. In your opinion, what is the situation regarding vulnerable groups and adults with incapacity?

Dr MacKellar: Personally, I would not have a problem with their donating organs after death. Some time ago, there was a lot of discussion about whether children and persons with severe mental disorders could participate in biomedical research. Some drugs or treatments can be tested only on children or people with severe mental disorders because the drugs that are being tested are for those people, so they should be able to participate in that biomedical research. The situation that you describe is exactly the same.

People with severe mental disabilities should be able to donate their organs after their death, because they should be considered as persons like you and me. They have a right to donate their organs after their death and that right should be respected. However, if they were unable to make a decision, their welfare attorney or guardian would have to make the decision as best they could. That is the only situation in which somebody else should be able to make a decision on behalf of a possible donor when they have no information about the person’s wishes.

Those people have a right to help others in the same way as anybody else; therefore, they should have a right to donate their organs after their death. Nevertheless, I would be opposed to their being living donors. In 2005-06, we brought in the rule that a person with mental incapacity or a child should never be a living organ donor.

Professor Galloway: I think that, after death, if a person has no supporting relatives, proxies or whatever, in as much as you have any note of the level of understanding of the individual, that should be respected; otherwise, one would be comfortable with a presumed consent scenario.

Anne McTaggart (Glasgow) (Lab): I thank the panel and all my colleagues around the table for their evidence this morning. Some of it was sore in my ears and in my heart, but I have got to where I am.

I want to clarify, from the outset, that I have not introduced the bill as a silver bullet. Ultimately, all of us round the table agree that we need to increase organ donation rates. As we sit here, 571 people in Scotland are awaiting organ transplants. I do not need to tell the panel that, because they will probably know it. It was mentioned earlier that the organ donation rate is increasing but, in this year’s figures, we are looking at a 10 per cent decrease—we are sitting at a 7.5 per cent decrease and that will go to 10 per cent if the figures continue as they have been going.

Ultimately, we all want an increase in organ donation. That is why the bill has been introduced and why the convener and some members have been to look at international evidence. We know that the Welsh system will start on 1 December. Why should we be any different? Why should people awaiting organ transplants in Scotland be any different from those anywhere else in the UK? There are a lot of queries and decisions to be made about the proxies, but that proposal would actually just bring us in line with the current system in the rest of the UK—only Scotland is not doing that.

Sorry, convener—I will get to a question. Dr MacKellar from the Scottish Council on Human Bioethics mentioned that the changes are insufficient and may be open to challenge under the European convention on human rights. What article would that be under?

Dr MacKellar: It would be article 8, if I remember rightly, on respect for private life and choices.

Anne McTaggart: Would the same article not cover someone’s choice about what they want to happen to their organs when they die?

Dr MacKellar: That is right, but the problem arises when the person has said nothing and we do not know what their real wishes are, and then something happens that is against their real wishes.

Anne McTaggart: As the panel will be aware, more than 80 per cent of us agree that organ donation is a good thing and would do it. However, only up to 40 per cent have got around to registering. How do we target that other 40 per cent?

Dr MacKellar: I agree entirely. There is a difference in ethics between intentions and decisions. People can have the intention to do something good and never do it. That is the problem right now with organ donation. We have to do as much as we can to try to bring that 40 per cent figure down. I agree with all the things that have been said about trying to increase donation.

To come back to something that I said earlier and that I should perhaps have qualified more, the present legal system is the one that will enable us to maximise the number of organs. Of course, it is not just the legal system that will do that—we will also need all the programmes that have been discussed. However, as Professor Galloway said, I do not believe that we will ever have enough organs. There will always be problems.

Anne McTaggart: So that is okay then, and we should just rest on our laurels.

Dr MacKellar: No—I am not saying that. I just put that out there as a comment.

Anne McTaggart: What is ethical, then? We have a toolbox and we have used most of the tools in it, but more than 500 people are still waiting for transplants. We have tried those tools, and they are not working.

Dr MacKellar: The tools include the soft opt-out system that is suggested in the bill. We already have that system. I have been saying that again and again for the past 10 years.

Anne McTaggart: It is not working.

Dr MacKellar: Why bring in new legislation? The only thing that I can see in the bill is the appointment of a proxy—we do not have anything against the proxy—and the system of the authorised investigating person, about which we have quite a lot of concerns, especially because, if that person did not have enough time to ask the proxy or nearest relatives, they would make the decision themselves. That would be a hard opt-out system, which I believe nobody in this room wants.

Anne McTaggart: There is nothing—

The Convener: Let the other witnesses respond, if they wish to. This is not a conversation between you and Dr MacKellar.

Professor Galloway: I do not have anything to add on that specific question.

Anne McTaggart: I was about to go on to say that there is nothing ethical about resting on our laurels and not doing something when there is something that we can do. We can implement this bill.

Dr MacKellar mentioned earlier that the bill would make no difference compared with the current legislation. The difference is that the convener and one of my other colleagues have been to Spain and have done that research, gained that knowledge and know that it can happen—that donation rates can increase.

Of course we do not know the exact figures. We never will. However, the approach in the bill has been proven to have led to a 15 to 20 per cent increase in donation rates. It is absolutely right that that would not happen just because the bill is passed and the law is changed. What the witnesses have said about education is absolutely right. We have to get out there and speak to people, and we have to look at that 40 per cent of people who do not register to donate. That happens with education. However, as the convener mentioned earlier, the evidence from Madrid is that they needed that backbone. Then a different type of conversation could happen.

You are right at the front edge of this practice. Surely it is an easier conversation to have with the family if you know that a person wished to donate their organs. It is a different conversation. You are not going to the family to ask for their permission, because the person has already given their permission.

Dr Wallis: Can I answer that? Currently if somebody is on the organ donor register, that is true—it is a much easier conversation. What I am not sure about is how changing the law in the way that you have proposed would make things even easier.

Anne McTaggart: The culture will be different. It is the culture that was mentioned earlier, that was found in Madrid. As my colleague Mike MacKenzie mentioned, ignorance is not bliss in the eyes of the law. It would be the responsibility of us all to know what laws were in force in this country. That is what would be different.

Dr MacKellar: I am struggling to understand how changing the law will change the conversation. The present law already states that, if the deceased has given no wishes, their organs can still be donated, so from a legal perspective—which is the Parliament's job—I do not see how the bill would change the conversation.

I agree, though, that we have to change the conversation in society, but we do not need to change the law to do that. We have to encourage more people to discuss those issues with their relatives, their friends and even their landlords, if need be. We have to encourage the discussion, but you do not need to change the law for that.

Anne McTaggart: Then why has it not happened to date?

Dr MacKellar: Maybe that is another discussion.

Anne McTaggart: Seriously, I cannot just shrug my shoulders at 571 people who are waiting for transplants.

The Convener: This is your last question, Anne.

Anne McTaggart: Mr Wallis mentioned the conversation—I am sorry, I have lost track, because you said that this is my last question, convener.

The Convener: Well, you are doing a good job—

Anne McTaggart: The part of the bill concerning adults with incapacity would not change the current law. We have talked about education. Somebody mentioned Brazil earlier. To put it on the record and to make everyone aware, the *BMJ* article that was mentioned put the failure of the opt-out in Brazil down to failures of publicity, lack of public understanding and lack of public support. It was not just because the legislation was changed.

My final point is that we need to change the law and we need to change the culture. It has happened in other places and there is evidence to show that that led to a 15 to 20 per cent increase in donation rates—I would love for it to be a 100 per cent increase, but unfortunately it is not going to be that. Let us try to make a difference for the people who actually need it. Let us make a difference.

What we are doing now is not working. Let us change that. It has not worked to date, so why should we just sit back and think, "Oh well, with a wee bit more education and a wee bit more publicity, it will be fine"? No—it will not. We have to change the culture within—that is what I was going to say earlier.

Dr Wallis mentioned that some clinicians and CLODs are for transplantation and some are against it. I am well aware that Dr Wallis pulled himself back from stating that. It is reality, though; that is the truth. Some people are for it and some are against it. Convener, I am not going to have it that some hospitals do it and some do not. It is people's lives that we are talking about.

Dr Wallis: I was going to suggest that we wait and see what numbers the Welsh legislation brings us.

Anne McTaggart: Why would we wait up to another four years when we could do something now? Why do we need the Welsh evidence when we have international evidence?

Professor Galloway: On the train this morning I looked at a graph showing international donation rates. Comparing countries that have presumed consent with those that do not shows that the range is right across the board. It is not the case that countries with presumed consent always have high donation rates.

Anne McTaggart: Eight out of 10 of the top performing countries for organ transplantation have an opt-out system.

Professor Galloway: I will leave as evidence to the committee the document that the official reporter asked me to provide. I have the reference here.

The Convener: Thank you for your attendance and for the written and oral evidence that you have provided.

12:30

Meeting continued in private until 12:42.

Published in Edinburgh by the Scottish Parliamentary Corporate Body

All documents are available on
the Scottish Parliament website at:

www.scottish.parliament.uk

Information on non-endorsed print suppliers
Is available here:

www.scottish.parliament.uk/documents

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000
Textphone: 0800 092 7100
Email: sp.info@scottish.parliament.uk