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Official Report

HEALTH AND SPORT COMMITTEE

Wednesday 3 November 2010

Session 3

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CONTENTS

HEALTH AND SPORT COMMITTEE
32nd Meeting 2010, Session 3

CONVENER

*Christine Grahame (South of Scotland) (SNP)

DEPUTY CONVENER

*Ross Finnie (West of Scotland) (LD)

COMMITTEE MEMBERS

*Helen Eadie (Dunfermline East) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Michael Matheson (Falkirk West) (SNP)
*Ian McKee (Lothians) (SNP)
*Mary Scanlon (Highlands and Islands) (Con)
*Dr Richard Simpson (Mid Scotland and Fife) (Lab)

COMMITTEE SUBSTITUTES

Joe FitzPatrick (Dundee West) (SNP)
Mr Frank McAveety (Glasgow Shettleston) (Lab)
Nanette Milne (North East Scotland) (Con)
Jamie Stone (Caithness, Sutherland and Easter Ross) (LD)

*attended

THE FOLLOWING ALSO ATTENDED:

Gil Paterson (West of Scotland) (SNP)

THE FOLLOWING GAVE EVIDENCE:

Dr Marion Bain (NHS National Services Scotland)
Max Barnett (Shetland Islands Council)
Dr Ross Cameron (NHS Borders)
Mark Hazelwood (Scottish Partnership for Palliative Care)
Lilian Lawson (Scottish Council on Deafness)
John Owens (Glasgow City Council)

CLERK TO THE COMMITTEE

Douglas Wands

LOCATION

Committee Room 6

Scottish Parliament

Health and Sport Committee

Wednesday 3 November 2010

[The Convener *opened the meeting at 09:32*]

Palliative Care (Scotland) Bill: Stage 1

The Convener (Christine Grahame): Good morning and welcome to the 32nd meeting this year of the Health and Sport Committee. I remind everyone to switch off mobile phones and other electronic equipment. We have received no apologies and I welcome to the meeting Gil Paterson MSP, who is here for the evidence-taking session on his Palliative Care (Scotland) Bill.

This morning we will take evidence from three panels of witnesses, the first of which comprises local authority representatives. I welcome John Owens, Glasgow City Council's head of health and community care in south west Glasgow and Max Barnett, assistant manager of community care resources with Shetland Islands Council. Before we begin, gentlemen, I suggest that when members ask questions you should indicate to me which of you wishes to answer. However, a question might well be directed specifically at one of you. I also point out that your microphone comes on automatically. Well, that is the plan, anyway.

Mary Scanlon (Highlands and Islands) (Con): Glasgow City Council's submission seems to me almost grudging and perhaps slightly sceptical. For example, it says:

> "If the legislation meets its original aims and does not dilute or sacrifice any aspect of the 'Living and Dying Well' strategy"

it might be okay. Do you think that the bill is actually necessary or do you feel that the living and dying well strategy is progressing very well and is addressing palliative care patients' needs?

John Owens (Glasgow City Council): We in Glasgow feel that the living and dying well action plan, as captured in the framework of managed clinical networks, sets out a performance framework and provides opportunities for joint working. That said, we whole-heartedly welcome this statutory framework and, indeed, should probably have elaborated on that view in our submission. I certainly think that the bill provides critical governance for actions captured in a performance and governance framework.

Mary Scanlon: I realise that the living and dying well strategy is being rolled out gradually and has not yet been fully implemented but what, from the patient's point of view, does the bill bring to palliative care treatment and support that is not covered in that strategy?

John Owens: The bill will give greater clarity to the roles and responsibilities of not only the national health service board and Glasgow City Council, but linked partners, particularly those such as our general practitioner colleagues and pharmacists who provide contracted services. Capturing those roles and responsibilities in a bill will make a great difference.

Mary Scanlon: Would the same thing not happen with good will and through joint working? Do we need legislation to get people co-operating and working together?

John Owens: Given Glasgow's recent experience of its journey towards integration. I think that legislation would definitely help.

Mary Scanlon: Mr Barnett, in your submission you seem to feel very strongly about the use of the term "reasonable" in the very first sentence of proposed new section 48A of the National Health Service (Scotland) Act 1978 as inserted by section 1 of the bill, which says:

> "The Scottish Ministers shall provide, or secure the provision of, palliative care ... according to ... reasonable needs".

Why are you asking the committee to delete "reasonable"?

Max Barnett (Shetland Islands Council): We very much believe that people have individual needs; indeed, any services that we supply through the council or the NHS are based on assessed individual need. When I spoke to health board colleagues about the issue, we agreed that, in the situations that we are talking about, an individual's needs change sometimes daily, sometimes hourly. Moreover, there are many views on what is or is not reasonable. After all, what I see as reasonable might not be seen as such by the people for whom we are providing care and indeed might not be reasonable with regard to service delivery.

Mary Scanlon: That brings me on to my second question about your submission. With regard to one of the indicators in the schedule, you ask:

> "What does constitute psychological, social and spiritual help and support"

and suggest that the indicator is "nebulous in nature". Do you think that it is difficult to define those terms?

Max Barnett: It is not difficult to define the various types of support, but what does this indicator actually mean? Does "spiritual ... support" mean that a chaplain or minister of the individual's faith is supposed to visit the individual once, twice or however many times? I should point out that the strategy that has been devised by the council and the health board very much takes a holistic approach to support. We were also not quite sure what the bill means by "psychological ... support". Does it mean that individuals would have to have psychologists present or could that support be administered by, say, Macmillan nurses or the trained counsellors that we have on our staff?

Mary Scanlon: Thank you.

Ross Finnie (West of Scotland) (LD): In highlighting Glasgow's belief that the statutory framework in the bill is essential, John Owens has raised an interesting point of principle. As you will be more than well aware, all health services are generally provided for under the 1978 act and, because there is no specification, they depend on directions given by ministers and in various documents. One might say that, as a result of that system and the many reports, particularly the Audit Scotland report, that have been critical of the delivery of palliative care services, the Government responded with the living and dying well strategy.

You have stated that you believe that there would be a difference under the bill because, among other things, GPs and other partners would feel some statutory obligation that they apparently do not feel under the 1978 act. Does that extend to the idea that, if it is good enough for palliative care, it has to be good enough for other services? Is there, therefore, a possible principle to be discussed here? Should we move away from the general provisions of the 1978 act and have a raft of legislation covering the provision of separate care services? Is that really necessary, or is the important thing the quality of the specific directions that are issued by any Government—I am not attacking the current Government—in which case we should take "Living and Dying Well" on its merits?

John Owens: I take your comments on that. The 1978 act is in place, but it can be strengthened, and the bill provides an opportunity for a sharper focus on the area of work. "Living and Dying Well" is almost beginning to make that inroad in terms of better practice and joint working. I am not convinced that we should have a raft of specific, disparate legislation for a range of other conditions or requirements. I would not advocate that and nor would the council. However, we would welcome the opportunity to have a refreshed framework for palliative care, given its critical nature for individuals—patients, citizens or clients.

Ross Finnie: Can I press you slightly on that? I do not wish to be insulting, but you gave me your reasons why you would advance the particular option, then you smiled and said, "We would not necessarily propose that raft of legislation." Will you elaborate on why you draw that distinction?

John Owens: If we can harmonise other legislation, that would make a great deal of sense. Palliative care does merit that particular, sharp focus, given the demography and the needs of the ageing population.

Ross Finnie: That is helpful. Thank you.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I still find that difficult, Mr Owens. It is not about ageing. Palliative care is about the last stage to death, and the number of deaths in Scotland has been falling steadily. Ultimately, we all die, so why should palliative care be promoted above everything else? In a time of austerity, why should I as a person with a disability be likely to have my resources constrained because we have decided to promote one particular area above all others? Are you really comfortable with that? If we pass the bill, you, as a local authority, will be required to ensure that palliative care is given primacy above everything else—above all other forms of care that you offer. Are you saying to us, "Yes, I am happy to discriminate against all these other groups"? The only other group that is included in the 1978 act is mothers and children. Society has agreed that that group should be promoted, so we have made one such decision. Are you saying that we should make a second decision?

John Owens: Palliative care is a critical area. As resources are stretched and there is greater prioritisation, it is a key area for specific attention. That brings an opportunity for greater integration and co-ordination of services at a critical point. I hope that we can retain that within a partnership arrangement and a collaborative approach under "Living and Dying Well", but I have concerns that that might not always be deliverable.

Dr Simpson: In your first answer to Mary Scanlon, you talked about a managed care network. Is there a specific managed care network in respect of palliative care?

John Owens: There is a managed clinical network, which has an action plan. Its role is to encourage best practice and the use of a joint framework and co-ordination. I almost criticise myself, but that approach almost gives strength to those who are growing frameworks for planning performance within the proposal for refreshed legislation.

09:45

Ian McKee (Lothians) (SNP): I would like to get back to the word “reasonable”. The bill states that palliative care should be provided

> “according to the reasonable needs of such person or persons”.

That includes their spiritual and psychological care, and so on. Who best decides what is reasonable? Is it the Scottish ministers, you, or the person who is receiving the services? How would you interpret that provision if the bill became an act?

Max Barnett: We see it being done through a single shared assessment framework. Within the strategy that the council and the health board have developed, we co-ordinate roles for all palliative care cases. At the end of the day, the co-ordinator would assess the person’s needs in conjunction with district nurses, Macmillan nurses, GPs and any consultants that were around. As I said earlier, the needs of people who are in an end of life condition can change daily, and hourly in the later stages. The assessment would also have to involve the person and their family, and it would be a holistic assessment with agreed needs, and an agreed goal and plan of care at the end of it.

Ian McKee: In your experience, is there always consensus between the person receiving the care and those who are giving it on whether certain needs are reasonable?

Max Barnett: As a practitioner, I would have to say that there is not always a consensus. Individuals vary, and families can be desperate to prolong the person’s life as long as possible. Others have said, “Make me comfortable. I need to die and I want to die at home.” There can be differences between what family members and kin want and what the individual wants. That then becomes a difficult decision to make, and makes for difficult working conditions for the professionals who have to offer support to the family. Ultimately, we take our lead from the person who is in the palliative care state.

Ian McKee: But at the end of the day, it would be an outside body that would determine reasonable needs, rather than the person who needs the care.

Max Barnett: Yes, but as I say, the decision would be based on assessments and discussions with everyone involved.

John Owens: I want to amplify the centrality of assessment in the process. There is a growing practice of building in the user’s voice and the carer’s voice through the talking points approach of the Government’s joint improvement team. That approach is now built in to a standard shareable assessment process, as we now describe it, rather than single and shared. We use a process of early diagnosis, prognosis and assessment, and advanced care planning for those who we anticipate will reach a critical stage, and we gather as much information about their views and needs on that journey as we possibly can.

Ian McKee: But, at the end of the day, it is you who decides what is reasonable, rather than the person.

John Owens: Yes, I concur with that.

Rhoda Grant (Highlands and Islands) (Lab): My understanding is that very little information is currently collected about who is in need and what palliative care is available. It seems that we need to gather information to show that while there is good palliative care in some areas, in other areas it is almost non-existent, but Shetland Islands Council’s submission expresses concern about the indicators and the reporting requirements in the bill. How should we amend the bill to ensure that we get the information that we need without putting too much of a burden on the authorities?

Max Barnett: When we discussed the bill and considered our submission, our initial thought was that we had been told that reporting to Government was going to decrease, whereas the bill will put an onus and a burden on the NHS and councils to report. I have no objection to the collection of statistics, provided that it is guaranteed or we are given some assurance that the information that is reported will be used to improve the services. I do not think that any of us round the table want statistics to be collated so that at the end of the year we can simply say that a certain number of people had certain experiences.

Our main concern is about the survey and the quality assurance. We have no objection to the quality assurance; it is more the way in which the bill talks about a survey of people who have received palliative care. We must remember that the time when a survey is issued and we are seeking people’s opinions on the quality of their palliative care is an extremely emotional time for people. I am not sure that the information would be as accurate as it could be.

I agree that if the survey highlights areas of first-rate service around the country, we can all use that knowledge and the people we are looking after can benefit from it. However, we are concerned whether the survey information will be accurate and of any value.

We are also concerned about how the survey would be carried out. The thought of sending out survey forms at a critical time in families’ lives seems a bit insensitive, and it could be done in a slightly better way. I have no objection to doing it afterwards.

Rhoda Grant: Would it be possible to use the survey as a tool during care to assess the patient’s expectations and whether they felt that the service was meeting their reasonable needs? I understand that it is a horrendous and sensitive time, but it is almost too late if you find out after the person has passed away that you got it wrong. Palliative care is about how comfortable people are and how much support they get. Would there be a way to incorporate the survey into a review of the patient’s care pathway and get their views while they are receiving care?

Max Barnett: Yes, I think that that would be possible. The concern for us, more than anything, is the timing of what is being asked for. There should be a way—I have not come up with one yet—to collect and collate the information that you require in a way that is accurate and meaningful, and that would allow it to be used to improve services throughout the country. Our discussions covered the question whether the information that you seek could be accurately gathered at a time when things are very critical for people. I question whether anyone who was given a form at such a critical time would even answer the questions.

The Convener: That is interesting, because I had not read “survey” as being a matter for close relatives, but I can see that it could be read in that way. I was thinking more along the lines of professionals being asked to compile the data. The bill says that the survey is

“on the standard of such care”,

so perhaps we need to consider that further, as you have raised a relevant issue.

Max Barnett: If you are doing a survey, it needs to involve the people who receive the care, because it is ultimately those people who will tell you whether it is of good quality or not.

The Convener: I believe that Gil Paterson wants to ask a question, as the member in charge of the bill.

Gil Paterson (West of Scotland) (SNP): I should point out that I have decided to take a self-denying ordinance and not ask questions of witnesses; I just want to sit and listen.

The Convener: But you are breaking it now.

Gil Paterson: No. I just want to say, for the sake of accuracy, that the bill does not require any surveys to be conducted.

The Convener: No, it just says that the Scottish ministers should report on

“the number ... who have completed a survey”.

The survey is not obligatory, but it is provided for. It is still an interesting point, though, so thank you very much.

Michael Matheson (Falkirk West) (SNP): When we discuss palliative care, we can get too focused on the medical aspect, such as the management of pain and so on. However, as Mr Owens suggested earlier, palliative care takes a holistic approach that involves people from not only the health service, but services such as social work and the social care sector. The bill, however, amends only the 1978 act, which of course involves health services. The provision of the side of palliative care that involves social care would relate to duties that are in the Social Work (Scotland) Act 1968 or other NHS community care legislation, but the bill does not touch that legislation.

Mr Owens, your comments suggest that the bill could help to improve joint working between health and social care. Why do you think that that is the case and why do you think that there is a need to create a greater focus on improving joint working between the health and the social care sides? If the bill does not place an explicit responsibility on the social care side of things, why would a local authority feel obliged to meet some of the requirements that might arise from the implementation of the bill?

John Owens: Section 12 of the 1968 act controls the promotion of the welfare of and the provision of support to vulnerable individuals. That would underpin our on-going commitment to working collaboratively with other partners.

With regard to the reporting and the performance framework, we would co-operate with others in the roll-out of Liverpool care pathways, which would clearly have an explicit role for social care within that end phase. There is an explicit requirement for the provision of on-going personal care and social care.

The reporting aspect also moves us towards the adoption of a gold-standard framework across not only health but social work. That framework is already in place, but—without criticising anyone in particular—I think that it is variable across the country. The bill will allow a strengthening of performance in that regard.

Max Barnett: Presently, Shetland Islands Council and NHS Shetland have a joint strategy. We are equal in terms of the care that we deliver. Obviously, health board staff have a far greater role in terms of the provision of medicine and the application of expertise, but that works within a joint strategy that was developed by the two agencies in a strategy group that also had lay members. That strategy is currently being rolled out across Shetland.

Michael Matheson: Although the bill places a legal duty on health boards, you would have to follow the route that the health board took to meet the requirements that are introduced by the legislation.

John Owens: Yes, because of the joint planning framework.

Michael Matheson: Why do you feel that legislation is required to make that happen? Why is it not happening effectively just now?

10:00

John Owens: I am not sure that I have got all the answers to that, but I think that it is variable and that there is a need to create a more robust framework. In my own patch, we were very slow in engaging our GP colleagues to buy into the roll-out of the Liverpool care pathway. We now have 26 out of the 27 practices buying into that and 12 out of the 27 practices buying into the national gold standard framework. There needs to be a greater push towards that. In my current role as head of health and community care, where I have joint responsibilities, I am passionate about and committed to ensuring that we have total buy-in from all our partners. We have done some excellent work with some of our pharmacists on a demonstration project whereby 70 community pharmacy practices are now routinely reviewing. That was not happening before.

More can be done, and creating a statutory framework allows us to move towards excellence.

Michael Matheson: I understand why you feel that the statutory framework can help in driving up the level of buy-in, but if I am to understand it more fully, it would be helpful to know why you were slow in getting the Liverpool care pathway sorted out. Why were you slow in getting that moving in the way in which it should have been moving and why has there been variation in service provision? Until I understand those issues, it is difficult to know whether the bill will address them.

John Owens: Indeed. The situation is complex and there are competing priorities. As we state in our written submission, it would be useful to have clarity on the definitions from generalist to specialist. I believe that there will be buy-in from generalists, but it could be an awful lot better. We worked hard with our GP community for that buy-in and we are beginning to deliver on it, but it took a great deal of time and effort. The hard work was worth while because we now have that base, which I want to protect.

Michael Matheson: I am afraid that it is still not entirely clear to me what the barriers have been in the policy's implementation.

John Owens: Some of the barriers have been down to confusion about roles and who sets the agenda. Why is a manager setting an agenda for a clinician? Such tensions always exist in the constructs that we have created for service delivery.

Michael Matheson: Do you think that that situation would be helped by clarification of the fact that health has the lead role in this area?

John Owens: I do.

Michael Matheson: You do. That is helpful.

The Convener: There are no further questions, so I bring this session to an end. Thank you, gentlemen, for your evidence.

10:03

Meeting suspended.

10:04

On resuming—

The Convener: I welcome Lilian Lawson, director of the Scottish Council on Deafness. I apologise to Ms Lawson for the little bit of kerfuffle last week, which she took very well—I thank her for that.

Ms Lawson sat through the previous evidence session, so I simply invite members to ask questions. Rhoda Grant has a question—at last.

Rhoda Grant: I am not usually first off the mark.

What will the bill do to improve palliative care services for people with disabilities? It is difficult to deliver health care services when people have difficulties in communicating. How would the bill ensure that people receive the services that they require?

Lilian Lawson (Scottish Council on Deafness): *(simultaneous interpretation from British Sign Language)* It will and will not. The bill should be able to improve services but it does not say how. It does not mention the communication needs and culture needs of deaf people.

Let us take for example a profoundly deaf person who is critically ill and needs care. Their first language is British Sign Language. Are staff members able to communicate with that person? If the deaf person is emotionally upset and critically ill, how do they manage that communication and the care that the person gets? How can they contribute to that care? I am concerned that there is nothing on that in the bill.

It is the responsibility of the people who provide the service to provide communication support services and to give their staff some deaf awareness training, deafblind awareness training and training in communication tactics—just basic signing—to make the patient feel that they are receiving good care. It is not good enough just to bring in an interpreter. It is not possible to have an interpreter present in the ward all day, so it would be good if some staff had some training in how to communicate with deaf people.

It must also be acknowledged that not all deaf people use British Sign Language as a means of communication. Some are happy to rely on English. They will happily receive and respond in written English. If a loop system was present and working, they could use that. Deafblind people have a totally different manual alphabet from British Sign Language. There is no mention of that, and no clarity about it, in the bill. It is the responsibility of whoever provides the care to match the patient’s communication and cultural needs.

Rhoda Grant: In previous inquiries, we received evidence about how deaf people did not receive mental health support. There were big issues about where they could receive specialist mental health care. I suppose that palliative care is no different from any other health care. Are there examples of good practice that we could pick up on and incorporate into the bill to make it more responsive?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* I have one good example, which is from the Highlands and concerns a deaf man who wanted to go to Donaldson’s college. He was poorly educated. He did not have learning difficulties, but he had complex difficulties and when he left school he was moved into the local hospital because his family could not cope with him. When the hospital closed down, he was moved into the community and received support from the social work department. He went on to get married and got a job. He worked well, controlled things well and looked after himself well. He did not use sign language as such; he was more a gesture person and used his artistic ability to communicate.

One day, that man discovered that he had a lump on his neck. He went to his GP along with his social worker and an interpreter. The lump was found to be cancerous and the decision was that it needed to be removed. The doctor explained that to them through the interpreter and also explained it through artistic means. From the explanation, the deaf man thought that his face was going to be cut off, so it had to be explained more that the root of the cancer had to be removed from his neck. He accepted the explanation, but he wanted to blame others in his work situation, because it was explained to him that the lump possibly came from contamination in the atmosphere. He was a heavy smoker, too. The social worker was able to explain through sign exactly how this had happened and exactly what the procedure would be for the operation. Through that, he was able to agree to the treatment; he gave informed consent.

Sadly, he went downhill and was transferred to the hospice. The same social worker was there to provide support and that social worker informed the staff how to work with him. The social worker explained that he was not a profound BSL user but used more gesture and artistic signing. The social worker explained to the staff how to talk about food, care and medication. The patient died with dignity, because there was good joint working with a specialist social worker who could communicate with him, the family and the health service. The hospice staff also went through deaf awareness training and training on basic communication tactics.

That is one good example of partnership working, but sadly it is not happening elsewhere. Some areas have no partnership working of that kind. That is the one good example that I can give you.

Dr Simpson: My question is the same one that I put to the first set of witnesses. Only one area in the 1978 act separates out any specific group—mothers and children. Are you comfortable with promoting palliative care above support, care and treatment for all other groups?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* I am not looking for extra services for deaf people. They should get exactly the same services and have exactly the same access to them. We are asking for deaf people to be able to communicate and for the staff to be able to communicate to the patient what is happening to them. That is extremely important if people are to understand and give consent. I do not think that that will involve an awful lot of money.

Mary Scanlon: An existing strategy and action plan—it is called “Living and Dying Well”—is currently being implemented across Scotland. Witnesses have commented favourably on it in written and oral evidence. Does anything in the action plan address the needs of deaf people, or do we need legislation to do that?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* I do not think that we are asking for more legislation. We just want to ensure that deaf people have access. You could perhaps make it mandatory for all staff who provide the care to undergo deaf awareness training or deafblind awareness training and to learn basic signing communication. That is only a small thing, but it should happen.

We have done some research by asking hospices what they have done for deaf patients. The results have been very varied. Macmillan cancer nurses in the Scottish Borders have undergone some basic training and they have a good working relationship with the local social worker for the deaf. If any situation arises, the social worker is in the area to provide support. That is good if staff have not had deaf awareness training. If such training was available, staff would be sent on it.

10:15

If a loop is available, that will do and will be enough for someone who wears a hearing aid, but what about other people, such as deafened people, who rely on written and spoken English, or deafblind people? A huge variety exists.

Local authorities and health boards provide funding to care providers. If providing training was mandatory, a portion of money would have to go towards training for all staff to have more communication ability with patients. That would make the whole situation more comfortable.

Michael Matheson: You gave us a good example of service provision in the Highland region. I take it from your comments that you feel that the bill can help to give a greater focus to improving the quality of services that people receive, particularly by promoting more training of staff. Why do you believe that some service provision for people who are deaf or deafblind is inadequate? How would the bill assist in addressing that and improving the service?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* Some areas have a poor service because they do not have specialist services for deaf people. For example, as members know, Edinburgh has a good voluntary organisation—Deaf Action—that has a service-level agreement with the local authority to provide interpreting services and social work services. That means that any deaf person who lives in the Edinburgh area knows that a specialist service is available for them. That is fine, but other areas, such as Perth and the Western Isles, do not have that.

My concern is about parts of Scotland that have no specialist service and where no specialist organisation is based. Local authorities in those areas have no specialist service or service-level agreement, so deaf people there suffer.

I do not want to go back in time, but the funding cuts mean that local authorities might consider that specialist services are no longer needed, that a general service should be provided and that they can ask other local organisations to provide a service.

Ian McKee: The bill says that palliative care should be provided

“according to the reasonable needs”

of the people who will receive it. I would have thought that everyone would agree that a reasonable need was to be able to communicate with the people who provide such care. Does the bill not give you enough reassurance, without requiring a specific provision on the needs of profoundly deaf people?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* What do you mean by “reasonable”? My definition might differ from yours. If a deaf person was happy with the quality of the care that they received, that would be reasonable for us, but we do not know whether they have received good-quality care.

Ian McKee: I totally agree that the definition of “reasonable” is subject to a degree of interpretation, because people have different views about what is reasonable, but I would have thought that most people would consider the meeting of someone’s reasonable needs to include the provision of some degree of communication. If some degree of communication were not provided, I think that even the courts would agree that that was not reasonable. Do you agree?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* That is a difficult question. The Disability Discrimination Act 1995 used the term “reasonable adjustment”. It is an area for argument.

Ian McKee: So you would like more certainty.

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* Yes, that would be better. Perhaps there should be a definition in the bill of what the word “reasonable” would mean for different categories, such as the groups in the deaf community and ethnic groups. That would give us a measurement.

The Convener: It would be possible to amend the bill so that it gave a list of considerations in the context of reasonable needs, which need not be exclusive. For example, it could say that account should be taken of things such as ethnicity and the requirements of various groups of disabled people. Would the inclusion of such a provision assist?

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* Yes, that would help.

The Convener: Thank you very much indeed for your evidence. It was delayed but highly pertinent.

Lilian Lawson: *(simultaneous interpretation from British Sign Language)* Thank you for allowing me to come back again.

The Convener: It was a delight.

I suspend the meeting for two minutes before we move on to the next panel.

10:21

Meeting suspended.

10:23

On resuming—

The Convener: Our final panel consists of witnesses who represent the health boards and the palliative care sector. I welcome Dr Ross Cameron, medical director of NHS Borders—hello Ross; Dr Marion Bain, medical director, NHS National Services Scotland; and Mark Hazelwood, director, Scottish Partnership for Palliative Care. As you sat through the sessions with the previous panels, you will know that the microphones come on automatically. If you wish to answer a question, just indicate to me.

I invite questions. I am looking away from Mary Scanlon, but no one else is indicating so, despite my efforts, she will go first.

Mary Scanlon: When I came to read the submissions for today's meeting, I wondered whether I should bother reading that of NHS National Services Scotland because I thought that it was bound to agree with everything in the bill. However, I was quite surprised to find that it is quite critical of the bill. It says that palliative services

> "should be integrated into all services provided by the NHS. Singling out a particular entity for legislation in a universal health service risks unbalancing the service."

That is the point that Richard Simpson made eloquently. The submission also states:

> "where NHS policy appears to be unsatisfactory, this should be debated and fed back to the NHS to change policy rather than producing complex laws."

Can I take it from all that that NSS believes that the bill is unnecessary and that it could in fact be detrimental to holistic care?

Dr Marion Bain (NHS National Services Scotland): It is worth saying that National Services Scotland does not have a role in providing palliative care, so that is a general opinion.

Mary Scanlon: I appreciate that.

Dr Bain: I believe that it is consistent with the views of others in the NHS to say that it does not make sense to single out a specific area. That is the context in which that response was made. Palliative care should be integrated into what is done generally in the NHS. That is the reason for that part of the response.

Mary Scanlon: To say that the bill "risks unbalancing the service" is a very strong criticism. You also say that

> "It is clinically very difficult and divisive to establish whether the progress of a patient's disease cannot be reversed by treatment",

and that

> "The NHS should be treating patients, not specific diseases."

I was surprised by how anti the bill your submission is and how critical it is of the proposals. Will you further explain what you mean by saying that the bill "risks unbalancing the service" and your points about treating patients rather than a disease?

Dr Bain: The response came mainly from our clinical or public health community in NSS. Their view, which I share, is that singling out one thing potentially suggests that other things are less important. That is the reason for the point about unbalancing. You probably interpreted it a bit more strongly than we would have said it, but our view is that the bill risks making other services less of a priority, when all patients have a right to be treated according to their needs.

Mary Scanlon: Another witness has made the point about what would happen to asthma, diabetes and other services if palliative care became a priority. I must say that I only quoted your words.

Dr Bain: I appreciate that.

Mary Scanlon: I maybe emphasised them differently from how you would have done, but I simply quoted.

I turn to the gentleman from NHS Borders. The only thing that the NHS Borders submission talks about is the cost—it does not mention anything else.

Dr Ross Cameron (NHS Borders): The first paragraph in our submission points out that we support the Scottish Partnership for Palliative Care submission. Our lead clinician feeds into that organisation and we were in agreement with its submission. The rest of our submission is a repetition of our response to the request from the Scottish Government for a financial assessment of the financial memorandum that goes along with the bill. We repeated that just for completeness.

Mary Scanlon: You feel that the costs in the financial memorandum are grossly underestimated. Are there hidden costs? As a medical director, are you concerned that the bill would require much more money than is outlined in the financial memorandum?

Dr Cameron: The detail in our submission came from my financial colleagues in the health board. As with most financial people who are involved in health today, they are thoughtful about the future. They want to get as clear a view as possible of new costs that are ahead of us. Some aspects of the initial information left room for doubt as to what the actual cost would be. In some places, the memorandum says that the bill is expected to be cost neutral to boards, but elsewhere it says that we do not yet know the full impact. My financial colleagues were being cautious and were seeking clarity.

Mary Scanlon: That is helpful.

Ross Finnie: Having listened to the responses, it seems to me that my question is more a supplementary to Mary Scanlon's questions. Dr Bain articulated the issue that I pursued earlier this morning about the principles in the 1978 act, under which care is currently provided in a general sense. With the single exception of mothers and children, we do not specify particular care delivery.

I am anxious to tease out from Dr Cameron and Mr Hazelwood exactly where they stand on the matter of the principles as opposed to the finances, and whether, in the provision of palliative care, they think that the current strategy document, "Living and Dying Well", has any deficiencies or areas that they are concerned about. More particularly, what benefits, if any, do they believe would be accrued by introducing this primary legislation?

10:30

Dr Cameron: Perhaps I could kick off. As an executive director of a health board, I am only too aware that we have a responsibility to every patient in our patch, regardless of their needs. Anything that curtails decision making or flexibility in one area leaves us less room for flexibility in others.

There are groups who probably require more focus, such as vulnerable adults, children and mothers. You could keep adding to that list for ever and you would end up back with the position that, if everything is a priority, nothing is a priority.

My concern is that so much of medicine now overlaps with palliative care proper that it is quite difficult to draw lines round it. For example, there are elements of the strategies on dementia and long-term conditions that cover areas within palliative care. It is not as easy to define the population as some people may think it is. It would give me cause for concern at the practical level, with front-line clinicians, if we had a strict legal framework set against what can be the quite complex medical needs of individuals.

Ross Finnie: I want to press you on that. The Scottish Government's strategy, "Living and Dying Well", has been mentioned. Is your preference to pursue a strategic approach or do you fancy the statutory approach that is now being considered?

Dr Cameron: I would prefer the strategic approach. I can give you a practical example. There are some patients for whom the decision to move to a palliative care stance is extremely clear cut. You can date it to a day—perhaps a conversation with an oncologist, when some test results have come back and it is clear that we have to move to a palliative care stance with the individual. There are other people who may have a chronic disease, such as organ failure, chronic obstructive pulmonary disease, heart disease or dementia—a whole range of conditions—where, even in retrospect, it is difficult to look back and pin down the exact point at which we moved to a palliative care stance. A one-size-fits-all approach does not feel comfortable in that environment.

Mark Hazelwood (Scottish Partnership for Palliative Care): The partnership's position on the principle that you ask about is that we are not convinced that the legislative route would lead to faster improvements in palliative care provision than would otherwise be the case. We did not consult our members on the idea of whether in principle you should legislate for specific areas. It could be argued that, if you start in one area, you will end up with a legislative slippery slope—you will end up legislating for a succession of conditions over time, possibly eventually arriving back where you started, with a summation of specific bills that add up to the comprehensive duties that are in the 1978 act. The main point in our submission is that it is not clear to us that the legislative route would lead to faster change and improvement than one would get through the on-going implementation of "Living and Dying Well". In that case, the question that arises is why legislate.

The second part to Mr Finnie's question was about concerns or deficiencies within "Living and Dying Well". Although we could talk more about that, it does not follow from any conclusion that there could be improvements in the document that it is necessary to legislate to effect those improvements.

Ross Finnie: That is helpful.

Rhoda Grant: On the point of legislating for specific areas, is there any other area in the delivery of health services that is as patchy as palliative care?

Mark Hazelwood: That is a difficult question to answer. I know that previous witnesses have cited the *British Medical Journal* poll in which doctors were surveyed about areas that had the greatest scope for improvement. Palliative care came out at the top of that poll. Everyone recognises that there is work to be done, but I think that it is difficult to do comparisons or come up with rankings.

Michael Matheson: You said that the Partnership for Palliative Care was not in favour of the bill. Just so that I am clear, was that a unanimous view in the partnership or was there a difference of opinion among your members on the issue?

Mark Hazelwood: There was a small difference of opinion. We have 52 member organisations, and our membership includes all the Scottish hospices, the territorial health boards, 18 national charities for various conditions and a range of professional associations. We have a formal consultation mechanism and I will give you a breakdown of the results that we gathered through that, as it is important that members understand the position.

We had a 28 per cent response rate to the draft of the document that you eventually received from us. Of those responses, 96 per cent supported the submission.

Ian McKee: I have a bit of a problem with the terms that are being used. I understand palliative care to be something that every doctor and nurse does throughout people's lives—it is just treating symptoms, is it not? However, the bill defines palliative care as being that which is given to

"every person diagnosed as having a life-limiting condition".

However, as has been alluded to already, there are many conditions that are life limiting but which will limit life only many years hence. Should we be giving palliative care services to people who are leading relatively normal lives but whose lives will most likely be shorter than the life of someone who does not have that condition? On the other hand, the bill defines "life-limiting condition" as being not only one that is progressive and fatal but one whose progress

"cannot be reversed by treatment".

If that means that the person cannot be made better, that is one way of looking at it. However, some progress can be reversed by treatment, even in conditions that are getting towards a terminal state—for example, the administration of certain drugs to someone with multiple sclerosis or end-stage heart disease can improve the patient's condition for a while. Do you think that there is a problem here, or am I seeing problems where none exists?

Dr Cameron: I think that that is a real problem, and that is what I was referring to when I was talking about the move from standard treatment to palliative care sometimes being imperceptible. Organ failure, as a mode of dying, is characterised by frequent or repeated admissions to hospital for exacerbations of the condition. Someone with heart failure might have been in hospital half a dozen times over the previous few years and have recovered with treatment.

My clinical background is in rural general practice. In such a circumstance, in which the doctor knows the patient and their family well, there will often come a point at which a discussion takes place that might lead to, for example, an order not to attempt cardiopulmonary resuscitation. That can be done formally or informally.

The important thing is to ensure that the systems are in place. In the health board for which I am responsible, we know that if those discussions have taken place with the patient and family, the out-of-hours service and the secondary care service will be informed. I do not know how one draws a line in all cases between standard and palliative treatment; it is a moveable feast.

Dr Bain: We may come to this when we talk about indicators, but the issue of definition is huge with regard to monitoring or collecting information. In collecting information, it is crucial to be clear about definitions. The bill needs a lot of work to ensure that those definitions are absolutely clear. Ian McKee has given one example, but there are a number of areas in which, if we are going to monitor what is happening properly, we need to find a way to define things much more clearly. That may be possible in some areas, but there is a lot of ambiguity in other areas.

The Convener: That is very helpful.

Ian McKee: My concern is that, in hard financial times, when health boards are seeking to justify every penny that is spent, there is a slight risk that they will not give palliative care services to certain people. For example, if a patient with end-stage heart failure is told that increasing their diuretics would make them feel a bit better, they would not come under the provisions in the bill, because the progress of their condition can be temporarily reversed. The board can then say, "We will not give you palliative care." Is that a risk at all with the bill?

Dr Bain: Speaking as a doctor, I would certainly hope not. I would assume that doctors would treat patients on the basis of their needs. However, there may be a risk that people might categorise things in different ways, which would make it difficult to know whether you were succeeding in what you were trying to achieve.

Ian McKee: One health board could categorise something in one way and another could do it in a different way.

Dr Cameron: I was just going to say exactly that. The risk is not that patients would not get the correct care, but that statistical analysis and comparisons would become very difficult.

The Convener: Would there be difficulties for the patient and family with regard to their expectations in relation to those definitions? You are looking at the issue from a professional point of view, which I understand, but there are also difficulties for the individual who is receiving treatment, because, as you say, that situation can change.

Dr Cameron: I think so. The key point is that once someone is labelled as a palliative care patient, there are all sorts of connotations, meanings and emotional baggage that go along with that. Different patients and families cope in different ways. If there was a tick-box exercise that said, "You are now a palliative care patient," it would cause problems for everyone.

Dr Simpson: Are any of the witnesses prepared to comment on the 1978 act? It includes mothers and children as a specific group, which is the only group that is currently singled out. Has that had a significant effect? As that is in the act, has it produced a statutory focus on mothers and children that would otherwise not have occurred?

Dr Bain: Not in my experience.

Dr Cameron: Similarly, certainly at health board and individual clinician level, we focus on the quality of service and the needs of the individual rather than constantly referring back to a piece of legislation.

Dr Simpson: I also wanted to ask about indicators.

The Convener: Please do—nobody has asked about those yet, although we have touched on them.

Dr Simpson: Although the bill contains a fairly comprehensive set of indicators, I am not convinced that many of them are feasible or practical. In the cases where they might be feasible or practical, it might be better to include them in the Certification of Death (Scotland) Bill rather than in a separate bill on palliative care. Do the witnesses have any comments on the indicators?

Dr Bain: I will say a word about that, as National Services Scotland contains the Information Services Division. We identify in our submission that there is very little that we could get from current national data collection to inform the indicators that are specified in the bill. The nearest we get is that we can look at the place of death for people who die in Scotland, and at what their diagnosis was previously. The recognised good practice in the collection of such information for monitoring and secondary uses is to get it out of systems that are used for direct patient care, so we would look for somewhere where the relevant information was already being collected. The source of such information is most likely to be back in general practice.

10:45

Dr Simpson: We could put the information into, for example, the quality and outcomes framework, directed enhanced services and so on.

Dr Bain: It would certainly be possible to do that. I again speak without detailed knowledge of general practice systems, because we do not collect that much information from those, but I can speak about the principles of information collection. First—I have already touched on this—we have to be absolutely clear about our definitions before we try to collect any information. Secondly, if we are not already collecting the information, there are resource implications when we collect new data, so we have to consider what those are. They are not only financial; they can be to do with time and can therefore take away from the care of patients, although the provision of care is what we want to do.

The third issue is information governance. Although we currently have the electronic palliative care summary tool, it is very much focused on one purpose: care for palliative care patients out of hours. There are no permissions to use the summary in other ways and it is not set up in a way that would allow us to do that, so a number of steps would have to be taken. I think that you are right that there is the potential to do something with indicators, but work would have to be done to see how the information would be collected and what would be the most sensible way to do it.

Dr Cameron: It is often easy to collect information that is collectible and to measure it, but it is often not the most sensible proxy measurement for what you want, which is a measure of care. I am concerned about what would happen if we did not have an easy way and an easily defined way of collecting information, because the last thing that I would want as a medical director—I am sure that it is the last thing that patients need—is our staff spending time collecting data for a purpose that is less than clear when they should be looking after the patient. I am very keen that we do not get into that situation.

Mark Hazelwood: I agree with the two previous answers. There are two basic challenges with the indicators. The first is around definitions and the second is around the systems and processes for gathering the information, which is best done on the back of systems that support the everyday clinical management of patients.

In palliative care, we are talking about people with a wide range of diagnoses who receive care in a wide range of settings from a wide range of professionals at a range of stages in their disease.

The systems that are in place are varied, may pertain to different parts of that complicated picture and are not integrated. We are not well placed to start to try to pick up information for the range of indicators suggested in the bill.

The Convener: Thank you. I have no further questions, so I thank the witnesses for their helpful evidence. As previously agreed, we now move into private.

10:48

Meeting continued in private until 12:55.

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