OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Tuesday 13 December 2022

The Scottish Parliament
Pàrlamaid na h-Alba

Session 6

Tuesday 13 December 2022

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE

37th Meeting 2022, Session 6

CONVENER

*Gillian Martin (Aberdeenshire East) (SNP)

DEPUTY CONVENER

*Paul O'Kane (West Scotland) (Lab)

COMMITTEE MEMBERS

*Stephanie Callaghan (Uddingston and Bellshill) (SNP)
*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Gillian Mackay (Central Scotland) (Green)
*Carol Mochan (South Scotland) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Evelyn Tweed (Stirling) (SNP)
*Tess White (North East Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Mark Hazelwood (Scottish Partnership for Palliative Care)
Elinor Jayne (Scottish Health Action on Alcohol Problems)
Alison Leitch (Care Home Relatives Scotland)
Dr Kainde Manji (Age Scotland)
Kira McDiarmid (Change Mental Health)
Pippa Milne (Argyll and Bute Council)
Cathie Russell (Care Home Relatives Scotland)
Henry Simmons (Alzheimer Scotland)
Adam Stachura (Age Scotland)
Susan Webster (MND Scotland)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 13 December 2022

[The Convener opened the meeting at 09:00]

Decision on Taking Business in Private

The Convener (Gillian Martin): Good morning and welcome to the 37th meeting of the Health, Social Care and Sport Committee in 2022. The first item on the agenda is to decide whether to take item 5 in private. Do members agree?

Members *indicated agreement.*

National Care Service (Scotland) Bill: Stage 1

09:00

The Convener: The next item on our agenda is further consideration of the National Care Service (Scotland) Bill. We will have two evidence sessions. The first panel will focus on certain services relating to social care, including mental health and drug and alcohol services, as well as public protection; the second panel will focus on older people and on Anne's law.

I welcome Elinor Jayne, who is the director of Scottish Health Action on Alcohol Problems; Kira McDiarmid, who is senior policy and public affairs officer at Change Mental Health; and Susan Webster, who is head of policy and campaigns for MND Scotland. Thank you for coming.

I apologise—joining us online we have Mark Hazelwood, who is the chief executive of the Scottish Partnership for Palliative Care. Many apologies, Mark; I did not forget you—well, I kind of did. I am sorry; I just did not read below the line on my papers.

I have been asking most people who come to our sessions about their hopes for the national care service. What do you hope that it will address? Relating to that, there is an opportunity to review those aspects of integration that have not been working, but which you hope will work in a national care service, because that is essentially why it is being created.

I will go round everyone. Not every committee member will be able to do that—they will probably direct their questions—but I tend to do this to hear witnesses' general thoughts. Perhaps we could start with Susan Webster.

Susan Webster (MND Scotland): As you might know, motor neurone disease is a rapidly progressing terminal neurological illness. The average life expectancy after diagnosis is just 18 months. Within that time, people become increasingly disabled, so they have an urgent need for social care and that increases rapidly.

In a nutshell, what people with MND need from social care is a strong workforce with the capacity to respond to that quick increase of need in a very short time. In an extremely short period of time, people can go from needing only one carer twice a day to quickly needing two care workers four times a day to needing night time and 24-hour care. We need a strong workforce that is trained and able to meet those needs, because people with MND are currently not having those needs met.

Too many people get only one carer and their families have to step up to be the second carer, or they do not get care to the level that they need or at the times that they need it. The burden that that causes for people with the illness and their families is absolutely incredible. There are family members who are getting only two hours' sleep a night, just because the intensity of the care that is needed is overwhelming. We therefore need a really responsive care workforce to be in place, and that is what we are hoping for from the bill.

At the end of the day, if that care workforce is there, people with MND can be fast tracked to get the care that they need in place as quickly as possible. Anticipatory care planning can also happen; because we know how MND will go and that the person in question is going to get much worse, planning can take place and care can be prepared for right from the beginning to ensure that carers get the support that they need and, indeed, family carers can be enabled to take the breaks and respite that are outlined in the proposals for the service. Currently, the ability to do so just is not there; they cannot take a break if there are no care workers to step in, and they need to be enabled to take the breaks that they will be entitled to as a result of the national care service being set up.

Those are the key things that we are hoping for with regard to the service.

Elinor Jayne (Scottish Health Action on Alcohol Problems): The hopes of people living with alcohol and drug addictions and disorders will be different to those that Susan Webster has just outlined for people with MND. People who live with alcohol and drug use problems regularly feel stigmatised, with the knock-on effect that services provided locally by alcohol and drug partnerships can often be overlooked in comparison with other health and care services. For instance, the funding for services kept being cut until the last couple of years, when levels started to come back to those that had been in place six years previously, although I should add that some additional money has been put in place for the national mission on drugs.

That brings me to my other point, which is that people with alcohol problems can be overlooked, because of the huge emphasis that there has been on drugs in the past number of years, what with numbers rising in that area. As a result, the bandwidth, capacity and resources in alcohol and drug partnerships and the services that they provide are quite often skewed towards people with drug problems.

We would like all of that to be addressed in the new national care service. For instance, alcohol and drug services—or whatever replaces the partnerships—could be represented on the local care boards; there could be better consistency in service provision; and we could have a more joined-up approach between the services that are currently commissioned by ADPs and services provided by the national health service.

That is what we are hoping for from the national care service. On the other hand, we do not need the service in order for that to happen; all of that could be happening now, and we do not want to wait for the national care service to be up and running for those sorts of changes to be taken forward and for the needs of people with alcohol and drug problems to be genuinely met.

The Convener: What you have just said very much echoes what we have heard in our informal sessions with people who have family members in need of the services that you have highlighted.

Kira McDiarmid (Change Mental Health): We in Change Mental Health know that one in four people in Scotland will experience poor mental health in their lifetime; indeed, we support about 1,800 people a week, 80 per cent of whom reside in remote and rural Scotland. We know from our own research and from countless pieces of research that have been done by other organisations that there is unequal access to service provision in rural areas, and we really hope that that situation can be changed with the creation of a national care service to ensure that every single person in Scotland who experiences a mental health condition can access the support and services that they require within their own community. According to all of our research, people want to receive pre-crisis support within their community, and we hope that, with the creation of a national care service, people will not have to travel and will be able to get the services that they need where they stay.

During the pandemic, the third sector, particularly in mental health but in other areas, too, played a key role in providing support and services to people. As part of the national care service arrangements, we would like the third sector to be recognised as a key partner in service provision, through funding, tendering and having that access, so that people know where they can go.

As Elinor Jayne has said, stigma is a massive thing that people with mental health continue to experience. SeeMe's latest stigma study has shown that about 87 per cent of people with severe and enduring mental illness have experienced unfair treatment from a health service. Self Directed Support Scotland has seen, too, that those people are experiencing stigma and not receiving adequate social care. Health professionals do not necessarily have the training and are not always equipped with knowledge of the mechanisms to use to chat to people who have severe and enduring mental illness.

We really hope that a national care service could address those three key things.

The Convener: Thank you; that is helpful.

Mark Hazelwood (Scottish Partnership for Palliative Care): The national care service is a real opportunity to be part of improving people's experiences of living with serious illness, and of dying and bereavement. When I talk about palliative care, I am talking about holistic care for people who live with a serious or advanced illness, which aims to maximise their wellbeing towards the end of life, whether they have years, months, weeks or even days to go. That is always the aim. You heard from Susan Webster about some of the important improvements that can come through improving social care, and the illustration of the vital role of social care in improving people's experiences.

Palliative care is provided across our health and social care system at a huge scale. People often think of specialist services and hospices, which are very important, but the bulk of palliative care is provided in primary care by general practitioners, district nurses and social care workers in the community, in care homes and in our hospitals. The national care service has a big opportunity around palliative and end-of-life care because people who are approaching the end of life are probably the biggest single group in receipt of social care. Thirty thousand people live in care homes for older people, the majority of whom are in their last 18 months of life, and each week 60,000 people receive care at home, the majority of whom are frail, elderly people.

I want to touch on integration. Although the focus in the bill is on adult social care, that is not particularly how people experience services. We must not lose track of how social care and health services are supported and enabled to work together. One last statistic that I will give is that one in three hospital beds is being used by somebody in their last year of life. As end of life approaches, people move increasingly between settings—you have more admissions and discharges—so social care has a vital role in supporting people at home, avoiding admissions when they are unnecessary or unwanted, and speeding people's return to their preferred place of care after an admission to hospital.

Real opportunities exist but, as part of the picture, we must not lose sight of the need to integrate with the wider system.

The Convener: Before I hand over to my colleagues, I want to pick up on something that has been put to us—not just around palliative care, but I will concentrate on that. We have heard from quite a lot of people in our informal sessions that, often, the only consideration is the person who is receiving palliative care—not the wider family. The systems that are out there do not take into account other family circumstances. An elderly person, who might have their own health needs, might be looking after somebody who is receiving palliative care, but they are considered completely separately rather than as a family. Has that been your experience, Mark?

09:15

Mark Hazelwood: I would differentiate. Support for families and carers is absolutely a part of palliative care, so those needs are not disregarded. They are often not all met, just as some of the palliative care needs of the person receiving the care are not met. An example might be the fact that a carer who provides 24/7 care has respite care needs but the eligibility criteria for giving that person a break are becoming more and more rigorous and inconsistent across Scotland.

Support for families and carers is absolutely part of palliative care and part of the agenda that we need to progress to improve people's experiences.

The Convener: Thank you, that is helpful.

We move on to questions from Paul O'Kane.

Paul O'Kane (West Scotland) (Lab): Good morning, panel. The first section in our briefing paper for the meeting is titled "General hopes and fears". That is a broad theme, but I am keen to understand the concerns that people might have about how the bill has been structured and came to be.

Over our evidence sessions, we have heard significant concern about the bill being a piece of framework legislation and the detail being co-designed after the bill has been passed. I will quote Tanith Muller, chair of the Neurological Alliance of Scotland, who said:

> "Scotland is being offered a new structure for care—but without blueprints, a schedule or a budget. We can't tell if it will even stand up, much less that it will meet the care needs of people in Scotland. Ministers need to go back to the drawing board and show us all the plans that they have developed with people before they ask MSPs to legislate."

I know that MND Scotland is a member of the Neurological Alliance, so I ask Susan Webster whether she shares some of those concerns, and to say what could have been done differently.

Susan Webster: In the call for views, we were asked a number of questions, one of which was about whether we thought that the bill would meet its objectives. We said in our response that it was impossible to say, because the detail is not there. That is our fear about the bill. A national care service has much potential but, without seeing the detail, it is impossible to say whether it will improve people's lives, which is fundamentally what MND Scotland is about.

Our fear is that there will be structural change but the social care that people receive might not change at all although it has to. We are supporting families that are absolutely at breaking point and carers who are completely distraught and in despair. They just cannot cope with the lack of care that they receive, the lack of training that social care workers have to enable them to support them properly and the lack of support for family carers. We cannot tell from the bill whether things will improve. There is a worry that the structures will change but the service that people receive might not be that different, which it has to be.

We are also concerned that so many services have been included in the bill, or have the potential to be included in the national care service, that that might water down the capacity to improve social care for people with MND. As you say, we just cannot tell. To touch on what Elinor Jayne said, given the short life expectancy of people with an illness such as MND, we need improvement now. That is important. Five years is a long way away. We hope that the bill will deliver but we need the changes to start now and we need to have confidence in them now.

Paul O'Kane: Susan, you have pre-empted my next question, which is on the consensus that came out of the Feeley review. Given the nature of a condition such as MND, would you have preferred to see more action being taken more quickly on some of the issues that were raised in the review, particularly on the workforce, non-residential care charges and support for people and their families?

Susan Webster: The issue of workforce is fundamental because, as I highlighted earlier, we want people with MND to be fast tracked, and we want there to be anticipatory care plans. However, that cannot happen unless there is a strong, at-capacity, trained and valued workforce. The sooner we can see that, the better. All the things that we hope for from the national care service can be delivered only if that workforce is there, and if the workforce is a lot more effective than it is at the moment.

Paul O'Kane: My next question, which is for Elinor Jayne, is on a broadly similar theme. Obviously, the scope of what is proposed has extended beyond what was in the Feeley report, and we have heard suggestions that elements of social work could go into the national care service. How would SHAAP feel about that, given the strong links between social work and support for those with problematic alcohol and drug use?

Elinor Jayne: The way that ADPs operate now is quite unique and potentially overshadowed by other structures and areas of the health and care set-up in Scotland. The ADPs are overseen by health and social care partnerships—they function as the sponsoring bodies—and funding comes from the Scottish Government, via the NHS. They get core funding that way, and they get other bits of extra funding from sources to do with, for example, the national mission on drugs.

At this point in time, the set-up is not necessarily working, but that is not to say that the national care service is necessarily the answer. We would not like it if, with the setting up of the national care service, ADPs and the services that they commission continued to be in this sort of grey area, because they will continue to be overlooked. On the other hand, there is a risk that, if everyone's resources and attention are focused on the national care service—even though we do not know what it will end up looking like—ADPs will continue to be overlooked. It is hard to say what the right answer is.

We do not want ADPs and, fundamentally, the service users to continue to experience stigma. We want that to be addressed, and we think that the national care service offers an opportunity for that stigma to be removed, by including the ADPs in a sort of mainstream set-up. That could be one benefit, but there are a lot of risks inherent in the proposal, because we have no idea what the national care service will look like in reality.

Paul O'Kane: Given your mention of resources, are you concerned about the resourcing of the national care service, given the Finance and Public Administration Committee's concerns about the total cost as well as the concerns that have been expressed about the Scottish Government's budget, which we will hear about later in the week?

Elinor Jayne: We would certainly like clarity about what the costs are going to be, and we would like to know what that will translate into in terms of the provision of alcohol and drug services. It is important that we have transparency around the issue. Audit Scotland has reported that the financing of ADPs is totally untransparent; nothing is published at a national level that sets out where financing goes in relation to ADPs and what results are being delivered. At the same time, we know that the number of people with alcohol problems accessing those services has gone down fairly dramatically in recent years. If the attention of commissioners and those with a strategic view is focused on the national care service, we can expect that situation only to continue, which will let down more and more people.

The Convener: We move on to questions on mental health support.

Emma Harper (South Scotland) (SNP): What Elinor Jayne was just saying about stigma is interesting.

I have a question for Kira McDiarmid about mental health and how the bill might support a wider mental health approach. The Feeley report recommended that appropriate care be provided for people with complex issues around their care, such as those involving mental health and alcohol. Do you think the bill is sufficiently clear about how mental health services and support can be provided in the overall framework, and do you have any suggestions about what might need to be added?

Kira McDiarmid: Currently, we do not know what mental health services are to be included; we lack a definition of community mental health services for people. If people do not know what those services are, how will they know whether they are meant to go to the national care service or the NHS?

We are a bit concerned about popping people from the NHS into the national care service and about people’s transition from in-patient mental health care to treatment in the community. Currently, people have to stay in in-patient care, with a higher level of security than is required, because the resources are not available for them to go into the community. We need to try to sort that out through the bill. If we do not have the mental health resources in the community for a national care service, the system will not work.

We know that people with severe and enduring mental illness are much more likely to have physical health problems, too, and that they already face a lot of barriers to accessing those services. If people with mental health issues are covered by a national care service, how will they access NHS services? That is already an additional barrier, and there will need to be clear pathways and a joined-up approach between the national care service and the NHS.

We need to look into what community health is and the services that people want to be included in a national care service. In one of the original consultations, the possibility of having mental health officers under a national care service was considered. However, that would be a bit concerning. As they are the people who provide a medical opinion on whether somebody should be detained, they have to be a bit more impartial and should therefore not necessarily sit under a national care service.

Community link workers in a national care service will be really important not just to mental health but in addressing complex needs. Community link workers in GP practices not only link people to mental health services but work with people with additional needs and direct them to, for example, money advice, debt advice or alcohol services. We need to ensure that community link workers play a very important role in the national care service.

Emma Harper: I am also interested in the support for people with additional needs, such as those with learning difficulties. The bill talks about

> “ensuring that individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet their individual needs”.

I circled the word “otherwise” and wrote “mental health and dementia”, because the bill might need to clarify what “otherwise” means. I am interested to hear your feedback on that. The language in this framework bill should allow us to move forward with a co-design process. Does some of the language in the bill need to be tweaked to widen out what words such as “otherwise” mean?

09:30

Kira McDiarmid: Definitely. The language around mental health was a key issue that came up in the Scottish mental health law review report that has just been published. People who have severe and enduring mental illness need to be supported, and the review is looking at the idea of a supporting decision maker and someone who can help. The language in the bill definitely needs to be looked at, and a lot needs to be clarified. For example, it says that independent advocacy provision “may” happen. No—it must happen. People with complex mental health needs must have the assurance that something is actually going to happen for them.

Emma Harper: On the subject of integrated services, you have highlighted gaps such as, for example, the lack of onward care, which leads to people being held in secure facilities instead of moving on. Do you envisage the national care service bill addressing the issues that you have highlighted in order to ensure a seamless approach? In our evidence-taking sessions, we have heard about the importance of the third and independent sectors in supporting people who have mental health needs but who do not necessarily need an acute stay in a mental health hospital. Do you think that the national care service bill should be able to support a seamless transition?

Kira McDiarmid: Definitely. One of our key hopes would be for the third sector to have the funding and the service provision to be able to help people, so that they are not stuck in in-patient services for no reason when they should be able to access support within the community. As I have said, our research shows that people want to be helped before they reach a crisis, and they want to be helped in their community. There is increasing demand for things such as social prescribing and a desire to access that support.

When people think of community support, they tend not to think of severe and enduring mental illness; they automatically think that community support is not for those who require complex care. However, there are ways of helping people with severe and enduring mental illness within the community. For example, I would highlight the Stafford centre, which we run, on Broughton Street. We must ensure that we all have the resources; otherwise, there is no point in having a national care service.

Emma Harper: Thank you. I might come back to that issue later.

The Convener: I think Evelyn Tweed wants to come in.

Evelyn Tweed (Stirling) (SNP): Kira McDiarmid said that stigma is still a huge problem when people with mental health issues try to access services, and gave a stark statistic. Do you think that the national care service bill gives an opportunity to look at stigma and really to get into that?

Kira McDiarmid: Definitely. There is a section in the bill about training. Health and social care staff need the training to have the skills to speak for and care for people who have severe and enduring mental illness, because we know that they face stigma in all areas of life. People are being a lot more open about mental health since the pandemic and more people are definitely talking about it. However, people with severe and enduring mental illnesses such as bipolar disorder, post-traumatic stress disorder or psychosis still experience really stark stigma. If committee members have not read the See Me report, they should read it and they will be shocked by some of the statistics.

We recommend that all health and social care staff involved in a national care service should undergo some form of stigma training. That would particularly be about mental health issues, but would also include alcohol or drug problems. It is not only mental health staff who should have that training; it should be for everyone, because we never know which point of contact someone will access first. People can go to a number of services, not only in the public sector but in the third sector too. It is important, therefore, that everybody receives that training and that they learn and get an understanding of what actually happens to people with severe and enduring mental illness, what they have to go through, the signs of illness and why they are acting as they are.

According to a report that the Health and Social Care Alliance Scotland did a couple of years ago, people said that they felt stigma when they applied for self-directed support for their illness; indeed, one person was quoted as saying that, because they had a mental illness, they were treated as if they were stupid, and they had to tell people, “I have a mental illness, but that does not make me any different from you.” As a result, it is really important that such training takes place, and it needs to be human rights-based, too. In fact, that very point was picked up in the Scottish Mental Health Law Review, which made a number of key recommendations in that respect.

The Convener: Thank you. We move on to Sandesh Gulhane, who has some questions on the issue of homelessness and drug and alcohol support.

Sandesh Gulhane (Glasgow) (Con): My questions are mainly for Elinor Jayne. First, what impact might the national care service proposals have on the work of alcohol and drug partnerships? Moreover, is there sufficient clarity in the bill, given that, as we know, drug and alcohol services are not included in it?

Elinor Jayne: No, we do not have sufficient clarity. As I have said, many of the problems faced by our alcohol and drug partnerships will not be—indeed, do not have to be—addressed through the creation of a national care service. They could be addressed now. For instance, on the point that Kira McDiarmid has just made about stigma, we know that such issues are addressed not through structural changes but through relationships, resources and people having the time to build therapeutic relationships with those to whom they are providing care and support. All of those things come about not because of a new structure but because of the resource, the time and the commitment that are given, and we could be looking at that sort of approach right now instead of waiting for the national care service to come along and, potentially, have some impact on these matters. We do not need the service to do these things.

The service could also put at risk the time, resource and so on that we need to properly address the needs of people with alcohol use problems. I should say that, although I am here to talk about those sorts of problems, our evidence was put together jointly with other organisations that have an interest in drugs, and we are all singing from the same hymn sheet on this. It is not a matter of waiting for the national care service to come along and meet people’s needs; we could do that now with our current set-up, if the resources were in place.

Sandesh Gulhane: Can you explain why you think the service could put things “at risk”?

Elinor Jayne: As I have said, the strategic view has been absorbed into what the national care service itself will mean. At this point in time, what we have is framework legislation, and much effort and resource will be required to flesh out what it will mean in practice. Every population in Scotland will potentially have to be involved in shaping that, and although that might be good from a co-production perspective, it could serve as a distraction from the urgency of the current situation and what we could be working on and putting in place now to meet the needs of people on the ground.

We know of examples of great practice. Indeed, I highlighted to the health committee in a previous session the work being done by the Aberdeen integrated alcohol service, which brings together health, care and the third sector. It puts the person with the alcohol problem at the very centre; they are assigned an appropriate key worker, who can build a really strong relationship with them; and then all the services that are needed to support that person, whether it be housing, social security or justice, can be brought in to provide them with genuine support. That sort of thing could happen with the structures that we have now, and we do not need the national care service in order to do it.

Sandesh Gulhane: Okay. From what you are saying, time and resource are the two key asks, which I suppose most people would want. However, when it comes to time and resource, what would be the best way to put them in place for people with, in the case of your organisation, alcohol dependency? My follow-up question is based on what you just said about Aberdeen being a good example. How do we see good examples relating to alcohol being rolled out across the country?

Elinor Jayne: On the question of what is needed now with regard to resource and time, it is impossible to say because there has not been a needs assessment of alcohol use disorder and alcohol problems in Scotland for a good 10 or 15 years. Therefore, we simply do not know the scale of the problem. When the most recent needs assessment was carried out, it was estimated that about one in four people who were in need of some support from an alcohol service were receiving that service.

In the past two years, we have seen the number of people who are dying from alcohol increase, yet, over the past six to 10 years, the number of people with alcohol problems who are accessing treatment and support has gone down. Therefore, we know that need is potentially static, if not going up, but the number of people who are accessing support has gone down.

We require a proper needs assessment in order to work out what services we need to put in place. That would involve a stepped approach—we are talking about all the different types of service, from those involving quite low-intensity input right through to high-intensity rehabilitation, and all of the steps in between, some of which are more generic and some of which are much more specialist. That is what needs to be put in place.

The Convener: Emma, you have a quick follow-up question on something that Elinor Jayne has just said.

Emma Harper: Elinor, you said that some work can be done now, such as tackling stigma, rather than waiting for a bill. I have a meeting with Angela Constance next week to talk about education for all healthcare personnel, not just folk who work in alcohol and drugs, to tackle stigma. As Kira McDiarmid said, it is not only folk who work in mental health who need mental health training. Therefore, the work on tackling stigma will be moving forward now, but the bill has a section about training. Would that provision therefore be welcome, as it would embed that training in the bill, so that whoever takes the training forward would be responsible for ensuring that everybody gets the education that is required?

Elinor Jayne: Yes, that would provide a good opportunity. It is really important because that work has been talked about for a number of years. In the alcohol framework for Scotland, it is clear that there should be a “no wrong door” approach, so that wherever somebody with an alcohol problem pops up in our health and care system, they should be signposted to, or supported to easily get, the treatment and support that they need. In reality, that is not necessarily happening. We know that stigma is one of the barriers, so training, better education and awareness around alcohol problems across the whole of the health and care workforce would be very welcome. We are talking about receptionists through to consultants—absolutely everybody who is involved in care and support.

The Convener: Elinor, you have pointed to a number of things that should be happening on the ground—there are already regulations and policy in those areas—but there is an implementation gap and a geographical differentiation around the country, such that good practice is not being shared. Is there an opportunity for a national care service to close that implementation gap and have consistency across the country?

Elinor Jayne: There is definitely an opportunity for the national care service to do that, but we would have both the national care service and the local boards, which would be in charge of commissioning the services. Therefore, it is about how that would work in reality and the relationship between those local areas and any national standards or whatever is taken forward. There will be alcohol treatment guidance, which is long awaited, from the United Kingdom Government, which we then hope to filter through to services in Scotland.

09:45

For instance, if that alcohol treatment guidance was used as a benchmark for the provision of services for people with alcohol problems in Scotland, if it was monitored, and if standards were put in place to ensure that it was delivered—in a similar way to the medication-assisted treatment standards for drugs—there could be quite a big difference within the structures of the national care service.

Gillian Mackay (Central Scotland) (Green): What opportunities are there for the bill to improve support and treatment for people who experience problematic drug or alcohol use, and what changes to it would the panel members like there to be, to ensure that those are realised?

Elinor Jayne: We need the detail to be in the bill. Right now, the detail is just not there to enable us to have any meaningful discussion of what services would look like under the national care service.

As I have said, we do not necessarily need the national care service in order to make the improvements that are needed now. The fundamental question for the committee is whether you are prepared to take at face value what the bill proposes, and whether you will have the opportunity to scrutinise anything that emerges in secondary legislation that comes from co-design, and to see what that is likely to mean in practice.

The problem with the bill is that it is difficult for me to be able to say what it is likely to mean in practice, and for you to scrutinise it.

Gillian Mackay: Further to Emma Harper's question about reducing stigma, are there opportunities in the bill, beyond training, to reduce the stigma that surrounds problematic drug or alcohol use, in social care services?

Elinor Jayne: Yes. When the Scottish Government consulted originally on the national care service, one of the reasons why we came down in favour of including alcohol and drug services in an emerging national care service was the stigma that is experienced daily by people who have alcohol and drug problems, whether in their day-to-day lives or in accessing services. By keeping alcohol and drug services separate from the national care service, we risk further stigmatising that group of people because, in effect, they would be the only group that would be kept separate. With regard to the principle of trying to undo some of the stigma that people experience, it is important that people with alcohol and drug problems are included in the national care service.

That is one way of addressing stigma. However, it is not the only way. Training is important, but much work to address stigma needs to be done within our communities at a grass-roots, local level.

The Convener: I call Tess White, who has questions on palliative care and long-term conditions.

Tess White (North East Scotland) (Con): I have just one key question, which is for Mark Hazelwood. The SPPC has said that the bill's principles do not take into account people who still need care but who have no hope or expectation of a cure. If the issue is not addressed, what consequences will that, in your opinion, have for those patients?

Mark Hazelwood: You are right. In our response, we have highlighted instances, particularly in the section on the principles of the national care service, in which the bill's language does not encompass the circumstances of people who are approaching the end of life, and we have set out detailed examples and suggestions for rewordings.

This is not just a question of wordsmithing or semantics; the bill is a high-level, enabling framework, which means that there will be a lot of detail to work through, further down the line. The thinking will be done through the detail of the secondary legislation, and it is important that the situation and circumstances of people approaching the end of life are very clearly signalled as a major concern of the service. I have already provided statistics that show that the needs of people who are approaching the end of life are a huge part of what the national care service is supposed to deliver.

Language matters—and I will give you two examples of what can happen when the issue gets overlooked. Alongside the National Care Service (Scotland) Bill, the Government has published four detailed evidence papers on the demographics of the Scottish population and people who use social care services as well as survey work on the experience of people who use social care services. Nowhere in those four detailed evidence papers are there any references to palliative and end-of-life care and the needs of people in those circumstances.

Having worked in the field for 13 years, I know that this is a phase of life that is overlooked and omitted in policy, partly for psychological reasons and partly because the field is not a specific specialty. After all, all sorts of different medical conditions can take people to that stage of life. It is very important, therefore, that the bill's principles are worded to make it clear that palliative and end-of-life care is part of the central mission of the national care service.

The current cancer strategy is another example of a policy omission. I know that it is being reviewed and renewed, but despite the fact that 50 per cent of people who are diagnosed with cancer will not survive beyond five years, it still makes no reference to palliative and end-of-life care. We must stop that sort of omission happening in future by clearly signalling palliative and end-of-life care in the principles of the bill. We believe that such care should be explicitly woven through the bill as well as through the secondary legislation, when we come to consider the charter and the arrangements for strategic commissioning at national and local level.

Tess White: You have said that palliative and end-of-life care is a big omission, and you have argued that people approaching the end of life are, by far, the biggest single group of people who receive social care. It would be helpful if you could comment further on that.

Mark Hazelwood: There are around 33,000 people in care homes for older people in Scotland—which means more beds than there are in the NHS. The majority of those people are in the last 18 months of life, and probably more than 70 per cent of them have dementia. All of those people have palliative and end-of-life care needs. Around 60,000 people each week are provided with care-at-home support, and the majority are frail, elderly people, with palliative and end-of-life care central to their needs.

Aside from the personal impact on individuals and families, which we have heard about, we also have to think about the resource implications. A large proportion of the health and social care budget is used to support people, but that is not really being done in a planned way. As we have heard, the responses that people receive tend to be fragmented and reactive, and we need to provide support for a population health approach to palliative and end-of-life care. We hope that the bill can do that. With such an approach, we would consider the needs across the population alongside the resources that are in the system—both the health and social care systems—and establish a locus of responsibility and accountability at local level, while planning and integrating services. Crucially, we would also understand the outcomes and experiences for people in receipt of those services.

In 2015, the committee conducted an inquiry into palliative and end-of-life care, and the aim of one of the reports that it commissioned was to reach an understanding of how good that care was in Scotland and what data and measurement were available. I still cannot answer that question, because we have not made sufficient progress. For example, the health and care experience survey, which informs many of the integration indicators, excludes people towards the end of life—and for well-meaning reasons. Obviously, it is a sensitive area, but there are ways in which we can systematically gather the experiences of people coming towards the end of life. Indeed, we should be doing that sort of thing, because we are spending a lot of money and we need to know what is being delivered by the system.

Stephanie Callaghan (Uddingston and Bellshill) (SNP): My question is for Mark Hazelwood, too. Palliative care brings so much comfort and reassurance to families—in fact, it is priceless—but how well are things working in relation to keeping people at home as much as possible? You talked earlier about one in three hospital beds being used by someone in their last year of life and increased admissions and discharges. How can we improve that situation, and how could the national care service help in that respect? I am wondering about the ability to quickly step up and step down care at a local level. What are the important factors that should be considered?

Mark Hazelwood: It is important to say that it is often the right thing for someone to be admitted to hospital towards end of life. After all, hospital care is an important part of palliative and end-of-life care for people; we should not be aiming just to avoid admissions, because many of them will be entirely the right approach for the individual person.

Susan Webster started off by talking about the responsiveness of social care services. Sometimes people are admitted to hospital, because we do not have the right resource in the community, or because we have the right resource but it cannot be mobilised quickly enough. That is an area where we need to do better. At the moment, workforce issues mean that it is sometimes not possible to provide the level of support that someone might need to stay at home when that is what they want.

I have just had a bit of a rant about the lack of measurement of experiences. I cannot tell you how well the system is working and how much it is not, and that is a big problem; I should be able to give you some good data on people's experiences and some idea of the level of admissions that do not need to take place and which can be avoided, but I do not have those figures. Given the financial and workforce pressures on the system, things are clearly not going in the right direction.

The Convener: Do you want to bring in Susan Webster, too, Stephanie?

Stephanie Callaghan: Yes, and then I have a quick follow-up question.

Susan Webster: I will just add that we have examples of people with MND who, obviously, have limited life expectancy but who are stuck in hospital for no other reason than they cannot get enough care at home. They are well enough to leave but they are prevented from doing so, because the local care provider cannot provide them with care workers. That is hugely problematic and it has a massive impact not just on that person but on their families, who want to spend those last precious months at home with that person.

Similarly, because of the lack of care-at-home provision, some people find that they have no alternative but to go into a care home, when they would much rather be at home with their families and have that kind of care at home that is potentially more intensive than is considered the norm or than most companies are set up to provide. Having that intensive care at home available could make a huge difference, because those people want to spend their final months at home with their loved ones instead of being in a care home. Some people choose to be in a care home, but for those who do not want to be in a care home or stuck in hospital, a strong care-at-home workforce will be essential.

Stephanie Callaghan: I could not agree more, and I think that most people will feel exactly the same.

My next question is for both Susan Webster and Mark Hazelwood. Is there anything specific that you would like to see in the bill to support what you have been talking about?

Susan Webster: Like Elinor Jayne, I would like to see more detail. The bill contains no detail in any shape or form. I understand that it is a framework bill and that the Government has said that it wants co-design and co-production, but I do not think that having more detail in the bill would prevent that. Both things can happen.

Stephanie Callaghan: Will you give us a couple of examples of the type of detail that you would like to see?

10:00

Susan Webster: There could be a lot more detail—it is just a case of where to start. For example, as Mark Hazelwood has said, there needs to be more recognition of terminal illness, the needs of people with such illness and the fact that they need increased and really responsive levels of care. They are a group of people with definite needs, and that has not been recognised at all. The needs of people with terminal illness are really important.

We would also like to see more detail about the workforce so that we know that we will have a workforce that is paid and trained appropriately and which is supported and valued. This is an ambitious piece of legislation, and a really ambitious strategy will be needed to get the workforce that will be essential to it.

I could go on forever, but that is maybe enough to start with.

Mark Hazelwood: If this is to be a framework bill and not morph into something else, we would certainly like to see changes to the bill's principles so that they clearly encompass the end-of-life phase along with other phases of life, and we have suggested wording for how that could be done. We would also certainly like to see reference to palliative and end-of-life care and the need for a population health approach at local level in the strategic planning and commissioning.

As for what ought to be in the bill or the sort of detail that we need to see, one issue that we have not really touched on is the powers that it gives care boards to have oversight of and responsibility for community health services. There are only a couple of references to it in the bill, but it is an absolutely huge proposal. I understand that co-production is about putting the flesh on the bones, but it would be helpful to know what sort of skeleton we have. Is it that of a giraffe or an elephant? How many legs does it have?

This is all about where community health services are going to sit, which is a pretty fundamental question for our health and social care services. At the moment, the statutory responsibility for commissioning palliative and end-of-life care lies with the integration joint boards, which not only cover community health services but have responsibility for swathes of unscheduled hospital care activity. I have already mentioned a couple of times now the number of people in hospital who are receiving end-of-life care.

It would be helpful to get some sort of steer about where those community health services will sit in the new world of the national care service. Obviously, I am particularly concerned about where palliative and end-of-life care will sit and whether there will be a broad move of responsibilities from the IJB across to the care board. I do not know whether the Government envisages something else, so it would be helpful to get a steer about the thinking on that.

Within whatever the structural solutions will be, we will be looking for things that support integrated working. As the committee knows, people do not really care whether they are accessing a social care service or a health service; they simply want the right service. We therefore want a framework in which that can be delivered and commissioning that recognises that palliative and end-of-life care involves the NHS, third sector organisations such as MND Scotland—which Susan Webster is representing—Marie Curie and Macmillan Cancer Support and all the voluntary hospices that provide huge amounts of specialist palliative care. There is also the independent sector, which is the main provider of care homes and care-at-home services.

The point is that we need commissioning processes that support and enable integrated and collaborative working. I note that there are references to ethical commissioning in the bill, but we need to ensure that there is financial sustainability for organisations such as voluntary hospices.

The Convener: We will continue the discussion on co-design with Evelyn Tweed, who has questions on self-directed support in that regard.

Evelyn Tweed: Some of the answers that have been provided so far have been quite useful in relation to the next set of questions.

How can we make sure that everyone, including those with, for example, communication difficulties or reduced agency, has a say in the co-design process? How do we ensure that everyone has the opportunity to shape the bill? I put that to Mark Hazelwood, but if anyone else would like to come in, that would be great.

Mark Hazelwood: There are particular practical and ethical issues around involving people who are approaching end of life, but we really must avoid paternalism, because people are often keen to tell their stories and to share their experiences. There are ways in which we can support that, which would require time and resource.

There is another aspect that we should not overlook. We already know quite a bit through some excellent qualitative research, a lot of which has been done at the University of Edinburgh. It has done a series of qualitative interviews with people approaching the end of life and with their carers. Those are often triangulated with care professionals, too.

We should be feeding into the co-design process what we already know from having previously asked people with experiences. I do not think that we should always go back and start with a fresh sheet of paper when we have already been told what the answers are. The issue is very often that we have not listened to those answers or that we have not done enough to deliver what people want.

We need to do a mixture of things: we need to draw on the existing research and evidence; we need to sensitively and supportively ask people; and we must also involve bereaved carers of people, who have been on the journey with their loved ones and who are often keen to share their stories about both the good and bad things. That can certainly be done.

Elinor Jayne: With regard to people who use alcohol and drug services, it is essential that we do not overlook the wider communities and families that are around them, as it is really important to people’s recovery that everyone involved in their lives gets the support that they need. It is also essential that everybody, whether they have a primary role or they are one degree removed, is involved in co-production.

We have a new—I cannot remember the exact title—national collaborative that is focused on co-producing and co-designing services and involves people who use services and healthcare professionals and others who are involved in that service provision looking at issues collaboratively. That body, which has been set up under Professor Alan Miller, should be able to contribute towards co-design. However, as I said, it is really important to include everybody in that, including families.

Susan Webster: It is interesting that you highlighted people who have speech problems. That includes many people with MND who lose their speech as part of their illness, as well as the dexterity in their fingers, which can mean that they are unable to type, for example. Therefore, it is really important that people with such illnesses are enabled as much as possible to contribute through the various methods that are available, such as lived experience panels.

With regard to the lived experience panels, one concern that we have is that, with, for example, MND, the intensity of the illness—by “intensity”, I mean not just the intensity of the disability that is experienced by someone, but the intensity of caring for that person, which, as Mark Hazelwood has said, is a 24/7 role—makes things incredibly draining for carers, and we need to enable people who have these huge caring responsibilities to make their contributions, too. We must ensure that they are not getting left out, simply because they do not have the capacity to contribute, and we must be creative and person centred in that respect.

Work should be done with charities like ours, which already have that contact and the feedback that Mark has highlighted. We have lots of input and quotes from people that could be very helpful, and as has been mentioned, bereaved carers should be involved, too. We just need to be aware that we are talking about people who are extremely disabled and people who have very intense care demands on their lives and that any interaction with them must be really flexible, open and inclusive.

Kira McDiarmid: People with severe and enduring mental illness can have—there is no other way of putting this—good days and bad days, and from my own experience of conducting focus groups with users of different services, I know that you can go in at a certain point and find that people are having a great day and are eager and wanting to participate but that, when the time comes, something might have happened and they might not be in the headspace where they are able to contribute. It is therefore important that there is flexibility so that, if someone who has agreed to participate on a particular day cannot do so, they can come back and make a contribution.

I know that there is a lot more to come and that this is just the beginning of the process, but I note that the co-design work that has been done so far on the national care service has very much taken place online. I hope that that will change as things move forward; however, as research shows, a lot of people with severe and enduring mental illness are digitally excluded, too, and require support in that respect. Perhaps that work can be taken forward with them in person, if that is what they prefer, or—and this brings us back to the Scottish Mental Health Law Review—they could be allowed to bring someone along with them as a supporter who has been trained not to interfere with their response, I suppose, but to help them to get their opinions across.

As I have said, we support a lot of people in remote and rural Scotland, and it is really important that we are not just focusing on the central belt or on main areas, such as Inverness, that we might think of as rural but properly going into remote and rural areas of Scotland and ensuring that everyone and their experiences are being represented in the co-design process.

The Convener: Do you have anything else to ask, Evelyn, before we move on?

Evelyn Tweed: I have one more question, convener. It is for Mark Hazelwood, first of all, but if anyone else wants to come in, they should do so.

What can we learn from the implementation of self-directed support, and what do you want the bill to do differently?

Mark Hazelwood: To be honest, I do not know a huge amount about that area, but that might be partly because people approaching the end of life will often need social care only for quite a short period. I have heard that some of the current processes for setting up and managing self-directed support are quite burdensome to people with regard to the administrative stuff that needs to be done, and things can be quite slow. Often, people do not find that an attractive proposition, particularly when their time is short. To be honest, though, I would hand that question on to others who probably have more experience in that area.

Susan Webster: We have found self-directed support to work quite well for people with MND, because it gives them person centredness and the ability to develop their own care in the way that they would like. Sometimes, people with MND can be put off by others telling them, “You don’t really want to bother with this, because it’ll be too much work for you”, but when it is done well, it can be quite effective. For example, we know of someone who has employed a family member to do night-time care so that the full-time carer can get some sleep, and that approach has worked really well for that family.

We have another example of a family in the north of Scotland, which has been able to use enhanced payments through SDS to get a care worker with the training that is needed to provide support at the necessary skill level for MND. It is obviously more difficult to recruit people for SDS in the north of Scotland, but the person was then able to pay that little extra through the system, and it is working incredibly well for her—she has the support that she needs when she needs it to help her and her family. The system can work really well, but people need to be enabled and supported to use it properly, so that they are not put off unnecessarily.

10:15

Kira McDiarmid: We know from the ALLIANCE’s “My Support, My Choice” research papers that uptake of self-directed support for people with poor mental health is, surprisingly, quite low. From the research, we see that people who do receive it are finding that it is really improving their experience of social care. I have spoken to service users from some of our services who are on self-directed support, and they like the fact that it allows them to get out of the house. We also support carers of people with severe and enduring mental illness, and they have said that self-directed support has really helped them, too, because they see the change in the person and how the support has improved their life.

However, people with poor mental health experience many barriers to accessing self-directed support. When they are going through their options, they are not told the four options that they can have—they are told, “Have this one.” They are not able to make an informed choice about the support that they are receiving, the budgets and so on. We really need to ensure that people with poor mental health have equal access and can make an informed choice to get self-directed support.

No data indicates the specific option that people with poor mental health choose, so it would be great if something in the bill could enable us to monitor and gather data on those options. Through that, we could also get data on different demographics and protected characteristics to see the type of support that different people receive.

The Convener: Thank you. That seems like a good note on which to move to our final theme: evaluation, monitoring and sequencing.

Stephanie Callaghan: I will go to Mark Hazelwood first, because he has mentioned a couple of times having the data to be able to make decisions. I realise that we have a wide range of experiences here—different types of people with different challenges—and we have always spoken about lived experience being central to the national care service. Across the board, for different people in different situations, what should we consider measuring and how do we measure that? What are the things that really matter, which we should focus on?

Mark Hazelwood: We have quite a lot of data about activity; there has been real progress with regard to linking data so that we can see where people are at different parts of their journey towards the end of life. The big gap is in understanding people's experience of care and considering how far those experiences ended up from people's own wishes and preferences. That is what matters. We have a huge and complex system, but we do not have a way of asking people, "How was it for you?" We ask what matters to them, but we do not ask how it was for them, particularly in that phase of life, which is universal—we will all go there—and that is a huge gap.

There are complexities in populating that gap, but there are things that we can do. In Northern Ireland, England and Wales, they have been doing a national audit on care at the end of life, which is a model that could be adapted and used in Scotland. There has been a pilot for a national survey of bereaved carers. They act as a proxy for the person whose life has ended and report back on what that person experienced and how it matched their preferences.

We recently produced a report that looked at a number of things around how to improve palliative and end-of-life care, and there is a whole chapter in there about how to measure, understand and learn from people's experiences. I would be very happy to write to the committee and send you the report to cover the detail on the opportunities and the challenges that were involved. It is definitely doable, though; it just needs will and a bit of resource at national and local levels.

Elinor Jayne: When it comes to alcohol and drug treatments, it is important to take a step back, because the role of alcohol and drug partnerships is not purely the commissioning of services; they also have a public health role about the prevention of alcohol and drug harms. That is notoriously hard to measure, and it is taken forward in very different ways in different local areas. It is important that, whatever is measured or evaluated as part of a national care service, it is not purely about services but is also about trying to prevent some of those problems and harms from occurring in the first place. A method of measuring those would be great.

One of our challenges is that we do not know the number of people in Scotland who have an alcohol or drug problem; specifically on alcohol, it would be helpful to have a starting point to assess the level of, for instance, alcohol use disorder across Scotland. Then we could start looking in the longer term at measuring that to see how much impact services and the public health element are having on reducing that kind of harm.

At this point, we have an alcohol treatment target that measures how many people are seen within a certain timeframe after being referred to an alcohol service. That is a very crude measure and is interpreted differently in every local area; it could mean that it is assumed that that person is starting on their treatment journey, but it could be that they have been triaged and assessed as needing treatment but have been put on another list to access that treatment. That treatment target is currently not particularly helpful, but the Scottish Government is going to set up a group to review that and put in place a more meaningful target for alcohol treatment. That should be helpful and it will sit alongside the alcohol treatment guidance that we expect in the course of the next few months.

Stephanie Callaghan: I will wind back a bit. How do we ensure that people who are receiving support are kept central to the evaluations that we are talking about? Would the national performance framework be helpful, and would it be part of that in your view?

Elinor Jayne: DAISy, which is the drug and alcohol information system, is a newish system that has been set up in Public Health Scotland, which means that data is collected on everybody who enters an alcohol or drug service. Establishing whether that system is a good way to evaluate outcomes would be helpful. Rather than reinventing the wheel to make sure that that system works, it would be helpful to assess outcomes for people who enter services. Making sure that that works in practice and that data is entered into it by all our partners in Scotland would also be helpful, because I am not sure whether that is happening now.

The Convener: There is time for a final question from Sandesh Gulhane, and then we must break.

Sandesh Gulhane: My question is to Susan Webster but is open to anyone else would like to answer. We have heard a lot about the co-design process. What evaluation, safeguards and transparency should we have in primary legislation before we start the co-design process to review what the Scottish Government produces?

Susan Webster: Are you looking for what should be included in the bill?

Sandesh Gulhane: Yes.

Susan Webster: It is what I touched on earlier. As I highlighted, we would like the bill to include mention of how the Government will secure the workforce that is needed. What is the strategy and plan for that? When I am talking about this, I am really talking about social care, because that is what people with MND use and they are not experiencing what they should. In the primary legislation, we would like to see mention of terminal illness as a group, fast tracking and anticipatory care planning.

You mentioned primary legislation and co-design. I was not quite sure about the connection between those two in your question.

Sandesh Gulhane: The primary legislation is the framework bill and the co-design is where the implementation will happen and where we will see what the plans are. What needs to be in the framework bill to enable us to evaluate effectively what we get after the co-design process? The bill will be passed—or not passed—before the co-design process.

Susan Webster: The key things that need to be considered for evaluation include whether people are receiving the care packages that they were assessed as needing. Is that care being delivered for them? One of the key issues for us is the regularity of care workers. Just the other day, I spoke to somebody whose mum has had 19 different care workers in two months. The times of visits are also an issue. People are being tucked in at 6 and 7 o'clock at night. Some care workers are also not able to use the equipment that a person has been given.

Those are huge things. They make a huge difference to the experience of people with MND. They need to be assessed, and the only way in which they can be assessed effectively is if people with lived experience—be that people with the illness or bereaved carers—have the opportunity to co-design at the beginning and to be a key part of the evaluation at the end. All those points are critical to assessing whether the national care service has the desired impact on people's day-to-day lives.

We want as much of that as possible to be in the bill. As I said, we want to see fast tracking, planning and a workforce that is trained, supported, valued and paid appropriately so that people want to work in the sector and do not leave it in hordes to go and work in a supermarket that has just popped up in a local community. We want people to want to work in the sector when they leave school.

As much of that detail as possible needs to be in the bill. That does not prevent co-design and co-production. We saw that with the Social Security (Scotland) Act 2018. We worked closely with Marie Curie to ensure that a fair definition of fast tracking was included in the act. It, too, was initially supposed to be a framework act. There has been loads of co-design and effective co-production since then. We have been working for years with the chief medical officer's office and the Scottish Government to co-produce guidance and various implementation practices.

There is potential for a lot more detail to be in the bill. We would like the key points that I mentioned to be in it, and that does not preclude co-design thereafter.

The Convener: We have run out of time. I thank the four witnesses for their time. If there is anything that they want to follow up on, perhaps because there was not an opportunity to discuss it—90 minutes goes past incredibly fast—they can write to us and we will include their responses in our report.

We will stop for 10 minutes before our next panel of witnesses.

10:29

Meeting suspended.

10:42

On resuming—

The Convener: Welcome back. We now move to our second evidence session on the National Care Service (Scotland) Bill. I am delighted that everyone is here in person—it is a treat not to have to look at both the screen and the faces of people in the room. I welcome Alison Leitch and Cathie Russell, from care home relatives Scotland; Dr Kainde Manji, head of dementia for Age Scotland's "About Dementia" project; Henry Simmons, who is the chief executive of Alzheimer Scotland; and Adam Stachura, who is head of policy and communications for Age Scotland.

It has become my tradition in our scrutiny sessions to ask witnesses for their views on the bill as it stands and about their hopes for how the national care service might address the unmet need that people have experienced. I will go round everyone. As always, I note that although I have a round-robin question for everyone, other members will not have that luxury or we would quickly run out of time. Members will direct their questions to specific witnesses.

I turn first to Alison Leitch.

Alison Leitch (Care Home Relatives Scotland): I have been involved in my mum's care for more than 10 years, since she was diagnosed with dementia at the age of 60. I have been through the whole process of care at home, care packages, day centres and a move into a care home. My purpose in being here today is to talk about the importance of Anne's law in relation to the National Care Service (Scotland) Bill.

I and the other core members of Care Home Relatives Scotland lived with the horrors of the pandemic and being separated from our loved ones. It is not only older people who are in care homes; people from a range of ages are in care homes. We started out as five daughters and a mother ranging in age from Hollie who is 37 to Alice who is 98. We must bear in mind that people from a range of ages and with a number of conditions live in care homes. What we lived through during the past two and a half years should never be allowed to happen again.

10:45

Cathie Russell (Care Home Relatives Scotland): As well as being involved in the care home relatives group, I am on the social covenant steering group. Like everyone else in Scotland who is interested in social care, I was delighted when I saw the Feeley report, which I thought was a great report and great read.

In a way, the bill does not live up to that report. It is all about structure, and it is hard to get across in the bill the emotion that was behind Feeley. I fear that things are missing from the bill, such as dealing with the terrible situation that is faced by an awful lot of self-funders—there are 10,000 of them—in care homes. They might get a personal care allowance, but that covers them for only about two days a month in a care home, so they are having to sell their homes to pay for the rest of their care.

There is an awful lot wrong with the system and part of the reason for setting up the social covenant steering group was the recognition by Feeley that we needed a nationwide drive and nationwide support to improve care. However, the bill is all about white-collar jobs, planning and commissioning—all of those things—and the structure seems very similar to the structure that we have at the moment, only with a minister in charge and a national care service board.

We want to see something that will really improve self-directed support, do an awful lot more to attract people into the industry and do an awful lot more for people on the front line of care, so that they can enjoy being empathic, helpful care workers.

Henry Simmons (Alzheimer Scotland): The Government made dementia a priority in 2007, and since 2010 there have been three national dementia strategies, which each made probably 35 or 40 recommendations and commitments. The policies have been fantastic—they have been co-produced, really well thought through and heralded as world leading—but their implementation has been incredibly difficult. In his report, Derek Feeley identified the problem as being about transferring a national strategy, national agreements and national commitments into local delivery.

For 12 years, we have been trying really hard to work with Government and local partners to get some of the basics of the strategies put in place, but they still are not there today. We do not have prevention, diagnosis, post-diagnosis support, integrated care or advanced care models and pathways. They have all been agreed to and tested, but we do not have anywhere that implements them all. There is a real breakdown between national aspirations and local delivery—we might come back to that later.

For those reasons, it is quite appealing for us when someone talks about a national care service. However, looking at the detail in the bill, I would agree with some of what has been said already, in that there are issues and difficulties that need to be bottomed out.

For a number of years, we have been significantly concerned about and campaigning about the challenge of the inequality that people who progress to advanced dementia experience in our care system. When someone with dementia enters a care home, their needs will progress, because dementia is a progressive brain disease, and invariably those needs will become healthcare needs.

You may have seen someone with a terminal condition in the end-of-life stages, and that is what someone living with dementia will end up experiencing in a care home. They have nothing but healthcare needs that need to be met at that point: they cannot walk, feed themselves or go to the toilet—they need help with everything. In a sense, you cannot call that social care, but we still charge people about £1,000 to £1,200 per week for it.

We would like a definition of advanced dementia and the opportunity for people to have an assessment, so that their needs are paid for and covered by the NHS. In our opinion, that is a duty on the NHS. With the integration around the bill, we have to get the interface right between what is healthcare, what is social care and what is free at the point of delivery, and we need to say how that has been assessed. We have big aspirations for the bill on that basis.

The Convener: That is very helpful. We will go to Dr Manji.

Dr Kainde Manji (Age Scotland): We absolutely welcome the principles of the bill and the vision that has been stated. The commitment to co-design is welcome and long overdue. However, I am concerned—we, as an organisation, are concerned—about the lack of detail in the bill. I recognise that there is a balance to be had with co-production, but it is sometimes useful to have more than a very broad framework to give people a key so they can express what they want to express and what needs to happen and change.

There is a sense of urgency about this piece of work. It is now two years since Derek Feeley took his evidence, but we are not very much further forward in seeing the changes that we want to see implemented.

It is absolutely fantastic to have the charter of rights ingrained in the bill, but a lot of the teeth will come from secondary legislation. There is a need to future proof the legislation. The aspirations in the policy memorandum are what we want in a national care service, but how do we ensure that that is what we get, if it is not in the primary legislation?

There are significant gaps in implementation that have not been addressed and, with a bill that is very structure and process driven, we miss opportunities. That has happened time and again, including with the introduction of both self-directed support and integration: there has not been enough investment in time, skills and resource to bring about a genuine culture change among the people who implement the legislation, so it does not work.

It is about future proofing against a change of Administration and to the way that things work, to ensure that the visions and aspirations are protected and locked in at this stage, as well as to protect against the things that we do not want to happen again.

Adam Stachura (Age Scotland): The hopes for not just the bill but the national care service are about how we can deliver the necessary reform of social care that is required for 2022 and beyond. It was quite clear before the Covid pandemic that social care was in a difficult place in terms of investment. Money buys things—it buys the people who are there to deliver social care. It was clear before the pandemic that we were experiencing extraordinary waits for assessments and for the delivery of packages of social care.

As an organisation, Age Scotland has been calling for much more investment in and reform of the system. The hope is not only that a national care service delivers that and brings together a lot of the excellent care that is provided across the country, but that it makes provision far more consistent.

At different committee meetings that I have been at, we have talked a lot about the idea of a postcode lottery for care, and it has been mentioned in evidence sessions before your committee that I have watched. I slightly dislike the phrase “postcode lottery”, but the point remains that, depending on where someone lives in Scotland, even if their needs are very similar to those of someone who lives in another area, they might not be able to access what they need at the time when they need it. There are reports of care packages being downgraded and of more asks of family members to take over more and more care. That goes back to the point that, when people are assessed for needing a certain level of care, their package should reflect that assessment and not what is possible from a system that is teetering on the brink, as it often is. That is not just about care homes; it is very much about care in the community and how to strengthen it.

The hopes for the national care service are that the necessary reforms will take place, that there will be far more investment and that it will deliver what we all need today and what we will need in the future. It is not just about tinkering around the edges. We want a system that will be consistent for decades to come and that we can build on. Free personal nursing care for the elderly is 20-plus years old in Scotland; it was revolutionary at the time and it was a big opportunity to go much further with social care than anything else that was available in the UK. It put social care on a much better footing, closer to parity with the health service, although, as we saw in the pandemic, social care often plays second fiddle.

Finally, we need far more political accountability for delivery. During the pandemic, there were times when social care was almost crumbling, with packages being stopped overnight, and not a single soul in the Government was able to do anything about it.

The Convener: We needed emergency powers to be able to do that.

Adam Stachura: Even then, when it came to having the powers, it was almost impossible to change anything. There is a health secretary who is accountable for long waiting times in the NHS—as we are seeing just now—but they can only do so much because a lot of it is operational. However, at the same time, the health secretary is also the social care secretary. Having that accountability means that members of the public who use social care or have family members who use it have someone whom they can hold accountable for a service that might be lacking.

The Convener: Thank you. That is a very helpful start to our conversations this morning. I call Gillian Mackay.

Gillian Mackay: Thanks, convener. I will come to Adam Stachura, in particular. Age Scotland's "About Dementia" project submission highlighted a lack of trust between service users and carers and professionals working in social care, because they have been consulted on change for many years, with little result. How can that trust be rebuilt, and will the reforms that are proposed by the bill contribute positively to that building of trust?

Adam Stachura: Dr Manji might be able to come in afterwards. On the last part of your question, there is a lot in the bill, although it is pretty vague—that has been the general reflection of everybody who has seen it. It is a framework bill; that is its nature. The bill could do a lot to help, which goes back to my point about accountability and structures that are not hidden. Let us look at IJBs, for example. How many members of the public know what they are, who comprises them, the decisions that they make, how they are formed and whether there is input from people who use and understand health or social care? Thre is a disconnect there in terms of political, governmental and parliamentary accountability. People need to know that when they go to their MSP, there are levers that they can use.

On your question about trust, we are, for example, looking at how care home residents have been unable to have visitors for years. It is not just months; it is years—we are almost at three years now, and care home doors are still closed.

Another issue is the length of time that it takes to get a package in the first place. In 2018 or 2019, we looked at waiting times, and 40 per cent of people, I think, who needed a social care package were waiting longer to receive it than was set out in the national guidelines. For every day or week that a person goes without the package, their needs will progress; they will become more needy in terms of what they require. The longer they go without, the harder it will be to recover or sustain good quality of life, which is the aspiration of all this.

Those are issues that we hope the bill can fix, but it is a framework bill. In our view, the bill says lot of good top-level things, and the secondary legislation will hopefully fix all of those issues, but the proof of the pudding will be in the eating. The bill could do a lot, but at the moment it is hard to tell what it will actually do.

The Convener: Dr Manji—do you want to come in?

Dr Manji: Yes, please.

On the lack of trust, co-design will be absolutely critical to the process. Within that, it is necessary to allow people to express their dissatisfaction. It is necessary to be open to that and to allow it to be a strong part of the process. People are very unhappy; they have been let down consistently. As Adam Stachura said, the issue has gone on for significantly longer than the pandemic. It has been a systemic issue in the social care sector—the system has not delivered for people's hopes and aspirations and has not even been able to deliver on very basic needs. Therefore, having the space to allow people to absorb and process that anger and resentment openly is a healthy approach.

After that, the proof of the pudding will be in the eating. It is about that culture change and enabling a genuinely preventative approach to social care—an upstream approach—that takes people at the earliest possible point and ensures that support is there right from the beginning.

11:00

Consistently, it is incredibly difficult for people who live with dementia to get access to social care support, and often, by the time that they do, they are looking at long-term care in a residential setting. The evidence leads us to strongly believe that, if they receive such support earlier, that period in long-term care can be held off—that people are able to live well with dementia for longer and to contribute to their communities.

Investment in community-based support and activities is a critical part of that. People need to receive the care where they are, from people they already know. The model of meeting centres that is developing across Scotland—in which very small, hyperlocalised forms of informal local support are provided to carers and to people who are living with dementia exactly where they are and on the basis of their wants and aspirations, with a co-design approach to the way in which they are run and organised—can be a very positive way of achieving that.

Again, that type of approach and model, in which there is co-design at every level—even in the commissioning and the design of services—

will help to rebuild trust. However, that will take a long time.

Sandesh Gulhane: I turn to Adam Stachura. From speaking to Age Scotland’s Scottish ethnic minority older people forum, it is clear to me that we have not heard enough from people from black, Asian and minority ethnic communities. I would like to know what their hopes and fears are. For example, we spoke about tea. Tea is important to someone who is Indian because we drink chai, not tea. That might seem like a little thing, but it really does matter. Give me a little of the flavour of what you were hearing.

Adam Stachura: It was good to speak to you about that at our offices, not that long ago.

With colleagues, I spoke to members of the Scottish ethnic minority older people forum ahead of the Feeley report, I think, or maybe a year or so ago, to ask about people’s understanding of social care in its broadest sense. There was a wide disparity in people’s knowledge of what it was—even of what the phrase “social care” meant. That was one of the more eye-opening moments of the past few months.

Separate to what is covered by the bill, in speaking with people about the Scottish Government’s plan for a new health and social care strategy for older people, when we talked about “social care”, we got a bit of a blank look to begin with. “What do you mean by that? Is it a care home?” Yes, it might be a care home, but it could involve other things such as a home help or other care in the community. It encompasses many more things.

An interesting thing that came out from members of the forum was their view that social care is free in every sense—that it is a bit like the health service and that people do not have to pay anything or sell their homes. When we said, “Actually, you might have to,” people were taken aback. Their homes meant far more to them and their families than just bricks and mortar or capital that could be used for social care; they were safe havens for family members when they had settled in communities. They could be safe there from racism, and they had integrated communities of children and grandchildren who relied on those homes. When it came to paying for social care, that was interesting to hear and was put across in a way that I had not heard before.

On the more cultural elements of social care, the issue partly goes back to the availability of social care—or, sometimes, the lack of it—and it links partly to Dr Manji’s point about trust. Often, a person doesn’t have options: they have a social care package—or a carer, at times, who is often very rushed—that is barely able to provide a 15-minute visit to them in their own home. The idea of providing a visit of just 15 minutes is fairly inhumane if the person requires care, never mind all the things that they want to do, and it is barely time enough even for them to express those things if they regularly have a different carer, who may not remember what they need and want.

Care is not just about having things done to people; it is about supporting people to live their lives. You make a very good point about people drinking chai—care providers need to be able to support that, through cultural training in the service, and they need to know that what one person wants might look a lot different from what somebody else wants.

Going back a couple of years, to the pandemic and the support that was available for people who were shielding, we remember that the food parcels that were provided were often far from culturally appropriate or suitable for certain diets, but the recipients really did not have any choice. For example, some of the items that were delivered were not suitable for vegetarians, but they had no other choice.

That goes back to the idea of social care providers understanding what is right for a person and their need to express how they live their life. That should be, at the least, a big aspiration for a national care service if not for right now. People should not have to wait for that. We have not heard anywhere near enough on those subjects from people from ethnic minorities—and it is about not just those who are older people today, but those who will be in the future. The issues include, for instance, how people would like their parents’ future care to look if they are unable to undertake it. You made a good point about that.

We do not hear enough about social care because, for many people, it is quite abstract. The number of people who receive it might look like a lot, but it is also a percentage of our whole population, so it is not a huge amount. Someone’s first experience of social care can be in a crisis, and, up till that point, they will have had no training to enable them to understand what it is about. Often, they are just grateful to get what they get; they cannot really shape that care.

Paul O’Kane: Good morning to the panel. I will pick up on what Adam Stachura said about the cabinet secretary’s accountability for social care. Would you contend that local councillors are not currently accountable in that way and that people would have a better chance of holding the whole system to account via the 129 members of the Scottish Parliament than they would through our hundreds of councillors? I have to be honest and say that it can be challenging for MSPs to hold health boards to account. In my 10 years as a councillor, I often found it easier to hold social care providers to account. Could you expand on that?

Adam Stachura: I suppose that it goes back to the Covid pandemic, when there was not much accountability for social care. Good examples of that were cases in which people who did not have capacity were discharged from hospitals to care homes. Some health boards or health and social care partnerships—I cannot remember which ones—basically skirted the courts. Their decisions were found to have been unlawful but no one was held accountable for them.

You made a good point that, as a councillor, you found it easier to go through health boards. However, I am also talking about accountability to the public. They need to understand the role that councillors have in that process—whether it is through IJBs or health and social care partnerships; where the funding comes from; how things are commissioned; and that, although when something critical goes wrong, we have a Cabinet Secretary for Health and Social Care and a Government department that is responsible for social care, the reality of what they can do is limited. You made a good point that councillors might achieve much better accountability and that public or national accountability for individual cases or local authority areas can look very different.

Going back to the point about parity, it is important to say that, to some extent, although social care and healthcare are different areas, they are very much linked. Much of the focus is on both being provided in the community as opposed to primary care settings and on people not going to care homes if they do not have to. What we are getting at here is that, when we have seen a crisis, there has not been the ability to act. Also, although people might try to understand social care, many of them do not care enough about it. Members such as Paul O’Kane, who have been councillors, will understand that very well, but many people simply do not. It will be difficult for someone to be able to hold the Government to account on that if understanding it is not part of their normal responsibilities.

Paul O’Kane: My question is this: if, for example, Mr and Mrs Smith decide to make a representation to an elected member, where does that responsibility sit most effectively and appropriately? I take your point, but I wonder about that more local focus.

Convener, if I may, I would like to move on to the points that Age Scotland made in its submission about aspects of the Feeley report that the bill does not cover. Adam, you alluded to the financial memorandum not correlating with what is in the bill. Are you concerned that things are being missed because they are not in the bill? I am referring to things such as free personal nursing care rates, the removal of non-residential care charging and the terms and conditions of social care staff. Should they have been in the bill in the first place?

Adam Stachura: That is a good question. The issue is partly about how we understand how the bill will work and get through the Parliament and whether there will be commitments to use secondary legislation to address those matters. Our concern is that there are headline and flagship policies in social care that are not mentioned but that are really important. The same applies to all the political commitments. Where does removing non-residential care charges sit in the process?

You are absolutely right. Our submission stands. We need those kinds of commitments to be built in. However, one aspect that can trip us all up is the aspiration for what the primary legislation can do against the secondary legislation, what will be co-designed and what will happen in the process, which we do not have much sight of. That relates to Dr Manji’s point about the need for more framework with regard to what is being co-designed, so that there is something more to work around.

There are some things with regard to money that could be better indicated in the framework part of the bill.

The Convener: Do you want to move on to your next topic, Paul?

Paul O’Kane: I wonder whether I can briefly pivot to Cathie Russell on that question. She mentioned the Feeley review. Are there things that could be done now, outwith the bill, that would make a difference?

Cathie Russell: A lot could be done on care home charging. For a kick-off, it would be good if people who are self-funding did not have to subsidise underfunding through the care home contract, because that definitely happens and care homes are telling people that their bills are going up because they are not getting enough through the care home contract to cover the costs. That is financial exploitation by the state of some of the most vulnerable people in the country, and it is appalling.

What was the other bit of your question?

Paul O’Kane: It was just about whether things could be done now in terms of the Feeley agenda.

Cathie Russell: What worries me, to some extent, is that we hear figures such as the £500 million cost of the new structure—Audit Scotland thinks that it could be more than £1 billion—but we will not get one extra hour of care for that. None of that will be spent on the front line.

We would like an awful lot more to be done to fund better self-directed support, because that has never really been delivered. When my mum was assessed and we were told that we needed to find a care home for her, I was not told that there was such a thing as self-directed support. I did not know anything about it until I got involved in this. It has not been rolled out to any great extent.

There is also the workforce. A few weeks ago, you had a doctor from down south along to the committee who said that a dog walker gets £15 an hour and a care worker gets a tenner. We will never improve care with conditions like that. We have to see it as a profession. When my mum was in a care home, I saw some of the most wonderful workers—people who have great insight and make people feel really good about themselves. Much can be done on the workforce. I know that things are happening with that. It has not been totally neglected. There are things happening on workforce planning, but we need to see the money. It all comes back to resources. We need to know that there is a way to improve the funding for social care, or nothing will improve.

Having been through major local government reorganisations, I fear what will happen. You will not make an omelette without breaking eggs, but, with that degree of reorganisation, I know that you will lose an awful lot of experience. An awful lot of people will hope that this is their chance to bail out. You will lose a lot of experience out of the management side. It can be very destructive.

I know from the people who were involved in the Feeley review that there is huge support for an NCS. In particular, people in the disability rights movement are very much in favour of it.

11:15

There is a feeling that the Government is making money available but that that does not seem to deliver on the front line and that we do not always know why, because the whole thing is so confused. I totally get what is driving this, but I have huge fears about how will it work in practice.

The Convener: Paul O’Kane, can I bring Emma Harper in before I come back to you?

Paul O’Kane: Of course.

The Convener: Emma, you have a quick question based on something that Cathie Russell said.

Emma Harper: Thank you. I want to pick up on what Cathie said about self-directed support not really working. I am aware of some local authority areas where that works really well. Even in one particular local authority area, where it is the perception of my office staff that it is not working well, some folk do get really good self-directed support. During the summer recess, the minister, Kevin Stewart, visited Dumfries to hear directly from folk about the good and bad sides of self-directed support.

I am interested to know whether you think that the national care service will help to raise awareness of what self-directed support is and what it can achieve. There are some folk who get good packages. I think you are right that some folk have never heard of it while other folk really know how to access self-directed support.

Cathie Russell: I know exactly what you mean. I was at the gym this week and happened to get chatting to someone on the way out. She told me about her sister’s package from Capability Scotland, which I think was in Renfrew. Her face lit up about the wonderful care that her sister was getting. She has learning disabilities and would not be able to manage all that by herself. It is managed for her, but through deep conversations about how her week will be shaped and what her family and carers will be doing.

We have all seen the example of Marion McArdle and Laura in the Feeley report. Laura went from having about 40 different carers a week to having a very small team of carers who really understood her needs, which kept her much healthier.

Self-directed support can be great, but it is very expensive. I was interested to hear Mark Hazelwood talk earlier about people who are reaching the end of life. Self-directed support is fantastic for a younger person with disabilities, but for people who are approaching the very end of life, who might previously have been looked after in a geriatric hospital, care homes can often provide a really excellent service. I have some anxieties about the extent to which that service area is being privatised. The overprivatisation of elder care has not been great and is a warning for the rest of social care. We need a mixed economy; we cannot put all of our eggs in that basket.

Emma Harper: I have just one more question.

The Convener: Be very quick, because we must move on.

Emma Harper: One of the care home providers whom we spoke to in Dumfries, Jim Gatherum, thought that self-directed support should be available in care homes. Has anyone taken part in any discussion about that?

Cathie Russell: No, because the first question someone is asked at a social care assessment nowadays is whether they own their house. If they own their house, they are on their own and are told, “Go and get yourself organised.” I think that when someone from Scottish Care came to the committee, they said that self-directed support should be available in care homes, but at the moment, I would settle for people in care homes being able to get funding at all, let alone self-directed support.

Emma Harper: Thank you.

The Convener: Paul O'Kane is going to talk about co-design and care boards.

Paul O'Kane: Thank you. I will pick up on co-design. To what extent have people felt involved in co-design thus far? Should there have been more co-design before we got to the draft bill? What should co-design look like in the future? Perhaps Alison Leitch could comment from a family perspective before we come to the other side of the table.

Alison Leitch: The six of us sit on, I think, 12 different committees, with Cathie Russell taking the lead on the National Care Service (Scotland) Bill. We have all been able to feed into her representations on the bill.

It is quite hard to think ahead of the bill. Personally, I welcome the bill, because something needs to be done about social care in general. However, it is quite hard to see what can be done, given how broken it is just now.

Cathie mentioned the workforce. When the pandemic hit and people working in pubs and restaurants lost their jobs, it was suggested to them that they could become carers. People like that could go in and look after my mum the day after taking on a carer's role, with very little training. We are talking about the most vulnerable people in society.

Time and again, our members have spoken about social care provision being a postcode lottery and about there being no accountability. We had public health, providers, managers, the Care Inspectorate, social work and staff making decisions about our loved ones—everyone could do that but us.

All of the legislation that was in place was completely ignored. I spoke to Henry Simmons earlier. I worked for Alzheimer Scotland when my mum was still at home. I was really enthused by Scotland's dementia strategy—the Government's approach was world leading. However, all that was done away with; all that was scrapped. Everything was overruled as a result of Covid.

The six of us have different experiences, because we have different conditions and we are in different age groups. I think that we feel that we have good representation on the different committees on which we sit, but the bill mainly sits with Cathie so she would be best placed to represent our views.

Paul O'Kane: Should there have been more co-design before the bill was introduced? What co-design would you like to see included in secondary legislation?

Cathie Russell: People in the social covenant steering group and Government staff who work on that area are really sincere about co-design, and there is a real determination to make that work. However, there is a tendency for co-design to be around specific products—for example, we have had discussions about what is in the complaints procedure and in the national care service charter.

I have noticed that the bill says that the charter will not confer any rights or responsibilities. That is disappointing. I think that a lot of people would have wanted the inclusion of specific rights, particularly the right to see a loved one. I know people who did not get to see their husband or wife for a year.

I worry that the focus will be narrow. The past few years have taught me that social care is all about relationships. It is not about having 40 people coming to your house every week but having a handful of people whom you can really trust. Those are the important aspects. There are brilliant examples of great social care currently. What makes a real difference are meaningful conversations about how we can make people's lives better. That is what is required. Maybe you need co-design to get to that stage, but the real co-design takes place when people are working out their own package and what is right for them, whether they are in a care home, in their own home or in a community setting.

Henry Simmons: Many organisations in civic society are expert in engaging people on co-design and they have been doing so for many years. It is welcome that there is an opportunity for that to be perceived much more strongly in the policy.

The way in which the legislation is framed means that we are discussing structure and co-design. I would much prefer to talk about our long-term care estate, for example. Who designed that? That was designed in the early 1990s, primarily through entrepreneurial investment, but it was never commissioned. It certainly was not designed by people who might use it and it certainly was not designed for the long term.

We would very much like a conversation about alternative models—models that are Covid safe, and models that would suit localities in rural areas and communities. I would like to engage in that type of co-design, but I do not see that provided for in the bill. We can do something about that of our own accord—we can engage the public in those discussions—but, frankly, if we have to work with the estate that we have all the way through and we do not become more ambitious about revolutionising it, we will have missed a huge opportunity for co-design.

The Convener: Cathie wants to come back in.

Cathie Russell: I absolutely agree with that. I was speaking to one commissioner recently, who said that a new 80-bed care home was being built in his area, but he did not need another one. If you allow the private sector to drive what style of care home you get and where it is, they will base that on where the biggest houses are to sell that might give them the biggest bang for their buck. You will not get a care service that reflects what people need, but one that will make the most money for the big corporates.

Henry Simmons: I will add that care home staff have done a tremendous job of trying to get through the pandemic in those circumstances. However, that should not deter us from debating what the future looks like. From our perspective, not only should the design process be about long-term care, we should also consider how to educate people on prevention, because 30 or 40 per cent of dementia is preventable. New treatments with disease-modifying drugs are coming down the line and we hope for a significant revolution around how we approach care, from prevention to diagnosis to integrated advanced care.

At present, everything is down the line, but we need to talk about that and engage the public in those discussions now, because people do not understand what care looks like, how much it costs and what they are facing.

Paul O'Kane: Thank you; that is very helpful.

I move on to talk about the whole concept of care boards. Do you feel that there is still too little detail around what they will do and what their composition will be, including who will have the voting rights in them? I go to Dr Manji first.

Dr Manji: We are disappointed that the membership of care boards does not appear in detail in the legislation. We really welcomed the emphasis in the Feeley report on lived experience for the membership of care boards, which is a significant opportunity.

About a year ago, we did some work talking to people who live with dementia and with carers of people who live with dementia. We interviewed somebody who was serving as a member of a care board as an unpaid carer rep, to explore what they would need to get out of that experience to make it meaningful and how to make that experience as easy as possible. It is a big ask of somebody to serve on a board such as that, and if we put that pressure on just one individual, it becomes an even bigger ask.

Our members and I would like to see more emphasis on pooled approaches, so that a number of people with lived experience can attend the board. As an absolute baseline, there needs to be voting rights and full participation, because if you are going to sit on a body, you need to have the opportunity to make key decisions and your expertise needs to be recognised. That is about parity.

We need to consider what training and support is given to people. One of the wonderful suggestions that one of our members made was that care board members need to be trained in how to support and listen to people with lived experience because, at the moment, the training is all in the other direction—the carers and people with lived experience are trained on how to serve on a care board. It can often be quite a frustrating experience when their expertise is not recognised, welcomed or acknowledged.

11:30

There is a huge role for the third sector as well. It has been consistently recommended since IJBs were first created that the third sector should have a role there. That should include not just the large third sector organisations but some of the very small grass-roots voluntary organisations that could also play a significant role in supporting people with lived experience to access care boards. That would allow them to fulfil their duties and represent the views of people with lived experience in that local area.

The Convener: We move to questions on this theme from Emma Harper, then I will go to Gillian Mackay.

Emma Harper: I have a quick question for Dr Manji, and for other witnesses if they have thought about the issue. As care boards are established, what will happen with integration joint boards and health and social care partnerships and the movement and flow of people? How would that be perceived, and how would that be implemented in practice?

Dr Manji: I am not sure that I have sufficient expertise on that issue to be able to comment. I am happy to defer to another member of the panel.

Henry Simmons: We have substantial historical evidence—Cathie Russell mentioned some of it—on mass integration projects, and we have seen IJBs attempt to come together. We find, and you will find in most circumstances, that a lot of mergers are unsuccessful because the cultures do not merge together well.

We presently have a split on whether a national care service is a good or bad thing. We probably have to take time to win people over to the fact that if we are going to go down this route, we should include staff and the people who are involved in that co-production. It will not work if we try to impose it; we have to make sure that people want to believe in it, feel valued as part of it and feel engaged with it. That is just those who come under the banner of a new service, and all of the Transfer of Undertakings (Protection of Employment) Regulations issues that will have to be dealt with there. There are significant issues and challenges, and many of us have experience of dealing with such matters.

On the social care workforce, I was a member of the Fair Work Convention and chaired a social care inquiry for two years. We produced a very detailed research report, which was published in 2019, which made several recommendations about the social care workforce prior to the pandemic. We argued for many things at that point, such as having a voice for the workforce. This is a workforce of 200,000 people, who are mainly women and who do not have a collective voice. There is no national negotiating position for them at all. The Government has tried to support them through small increases in the living wage, but there should be a stabilised set of terms of conditions and contracts that people who are in that environment will all be offered; it cannot be left to the vagaries of different organisations to try to get a competitive edge on that.

The social care workforce needs that depth of support, engagement and absolute security. You cannot imagine how insecure it is for someone who comes into a job on a small four-hour contract or zero-hours contract but ends up working 60 hours per week. All of those things were highlighted in that research. Derek Feeley spent a lot of time with us at the convention looking at that, and he made some recommendations, but it needs to be driven forward sooner rather than later, alongside the big merger issue that also requires a lot of work.

Emma Harper: I have another wee question about establishing the care boards. Part of the bill covers training and the recognition of the exemplary skills that are required in order to provide care at home or in a care home. Career pathways need to be thought about, established and progressed, because we should value the carers who feel less valued. Is the bill able to create a formalised recognition of the skills that are required to be a carer?

Henry Simmons: We have some good criteria in relation to Scottish Social Services Council registration. We need a national set of terms and conditions and a national set of agreements that become part of the ethical commissioning processes that we have talked about.

One of the biggest challenges that organisations in the caring sector face is that they are signed up to non-committal framework agreements, which means that they do not know how many hours of care they will be asked to provide. Lots of potential difficulties with staff recruitment and retention and with the management infrastructure can be traced back to that, because people do not know how many staff will be needed, so they hold back until they are asked for provision.

As part of any tender agreement, any contract and any other part of the new service, we should have set terms and conditions so that everyone knows how much supervisors will be paid, how many supervisors will be required, what their training days will be, what the support structures will be and what the expectations will be. There is a great opportunity to fix all that, because it is very broken just now.

Gillian Mackay: Cathie Russell, how do we ensure that the process of co-design is ethical and sustainable for people to participate in? We are aware that a multitude of workstreams is on the go, and I am a bit concerned about how individuals and small organisations can continue to participate in co-design throughout the national care service’s implementation.

Cathie Russell: Participating is difficult. When I encouraged people to join the lived experience panel, some went to initial meetings but then pulled out. That was because, having done the dementia strategy and having done this and that, they felt that they had been consulted to death, when all they wanted was to have better services. It can be difficult to get people involved.

In the care home community, people who work in care homes will not get involved in any co-design, because they are just trying to get their shift in or their management are busy pulling shifts. As Karen Hedge from Scottish Care said, it is hard for care homes to make people available to participate in a lot of these things.

People very much need to know exactly what they are co-designing. Take the structure of care boards as an example. We do not know yet what care boards will be. Will they provide services? Will they employ people to do the caring? Will care boards be able to send in the troops if that is needed in an emergency? Will they always just commission, and, if so, who will they commission from? There is an awful lot that we do not know about what a care board will look like. We need more information.

Alison Leitch: Before I got involved in the care home relatives group, I had never been involved in any consultation. When consultations were running on Anne’s law and care standards, we encouraged our members to get involved as much as possible. The consultation on Anne's law had 268 responses, which the policy team told us was quite a good response. We are a country of more than 5 million people—we should get a better response than 200-odd.

People who have never experienced social care have no idea about what goes on. Given the scale of the bill's proposal for a national care service, the whole nation needs to get involved and have its say. I do not have a magic answer for how to achieve that, but the discussion needs to be much bigger.

Even when I talked to some of my friends and relatives about Anne's law, I had to set out in black and white the situation and ask how they would feel if they had been cut off from their daughter or had never hugged their grandson for a year and a half. It was only after that did people suddenly see the reality.

The question is: "What would you like your care to look like if this happened to you?" Nobody wants to think about getting old or having a disability or illness that really impacts their life, but I would definitely like to see much wider engagement and for people to be encouraged to have their say. If the national care service is to be the next biggest thing to the national health service, that needs a national conversation. I wish that I had an answer for the committee.

Henry Simmons: An important point is that co-design must come in stages and steps. We must be a wee bit careful to avoid this feeling a bit like the emperor who had no clothes on. If you say to everyone that you want to co-design the system but then say that you will not do that, that is a challenge.

The Scottish dementia working group, which is a group of activists who have been diagnosed with dementia, has been involved for 21 years in detailed co-design of national dementia strategies, as Cathie Russell said. However, something has to be brought to the table to ensure that people have a sense of the options that are available and of what things might look like.

We then have to think about individuals with, for example, progressive advanced dementia, who cannot engage in consultations and do not have a voice but who are probably treated the most unfairly in our system. We have to rely a bit on civic society, charities and organisations in the third sector to enable those individuals to have a voice. Some people are able to speak for themselves, but some groups cannot engage in that process and they are probably the ones with the greatest needs that require tackling. This type of engagement and the consultations that have taken place allow some opportunity for that, but co-design will not be a panacea; it will not resolve every issue. At some point, somebody will have to say, "No, we're not going to do it that way. We want to do it this way." We will then need to see how the co-design principles can be applied throughout that process.

Carol Mochan (South Scotland) (Lab): It is disappointing that the stuff that is in the Fair Work Convention's 2019 report has not been progressed. I want to be clear about whether you are saying that we could do a lot of that stuff now—particularly in relation to pay for the social care workforce, who make a big difference—and then move on to the framework bill and so on.

Henry Simmons: Carol, I am saying that 100 per cent. The Fair Work Convention prioritised social care. Back in 2015-16, I was able to commission two years of work on that. We consulted a national group, and we commissioned two pieces of research from the University of Strathclyde. The work was first class and incorporated self-directed support. Every recommendation that was made could be implemented right now. Some work has been done in that regard, but it was obviously delayed because of the pandemic.

The most important thing that I want to say is that the social care workforce has no collective voice. Every other workforce connected to public service and to the public sector has a voice and has someone arguing for them, but no one is arguing that the social care workforce should receive a 5 or 6 per cent pay increase.

If we are to give our social care workforce the rights, the opportunities and the security that it deserves, that needs to be put in place and structured in such a way as to fill the present void. Every problem that sits in the NHS—1,800 people are waiting to be discharged, for example—is connected to the social care issue, which could be fixed by putting in place some of the convention's recommendations.

The Convener: We will move on to questions specifically about Anne's law. Evelyn Tweed will lead on that theme.

Evelyn Tweed: Cathie Russell has said that everything that we are talking about must improve people's lives for the better. Anne's law is about ensuring that those in residential care have the same rights as people at home. How can we encompass that in the bill? How can we do that well? What would that look like?

Cathie Russell: I will pass over to Alison Leitch to answer most of that.

The bill says that there should be a right to respite care for carers, for example. We would like the bill to express equally clearly that people in care homes have the right to have visitors and to go out of their care home. We have been doing a lot of work in that regard—Alison has been working with a team in the Scottish Government—so that part is being co-designed.

Alison Leitch: I will give a bit of context. In July 2020, Natasha Hamilton lodged the public petition on Anne's law in desperation at not being able to see her mum, who was in a care home. I read some of the research papers that Lady Poole—before she stepped down from the Covid inquiry—had instructed be prepared. Three of the reports are specifically on care homes, and I looked at them last night. Right from 13 March 2020, it was said that essential visits could take place for those receiving end-of-life care and for those in distress, with specific mention being made of dementia and learning disabilities.

Out of the six of us, four of us asked for essential visits. None of us got them. I did not know about essential visits until I had a conversation with Jim Pearson from Alzheimer Scotland in September 2020. All four of us were told that essential visits were only for the end of life, and we know that some people did not even get to see their loved ones in those circumstances.

11:45

If all the rules and regulations that were there to support people in care homes—such as those on adults with incapacity and on power of attorney—had been respected, we would not be sitting here talking about Anne's law. The reports mention restrictions on human rights, including the right to family life, and deprivation of liberty.

Last night, I also found out for the first time that, when restrictions were brought in, the instructions were to keep people in their rooms. They were not animals! Thankfully, we have progressed, and it is also noted in the research that the guidance became more humane when we started having conversations with Jeane Freeman, the then health secretary. It is noted that human rights were actually first mentioned in the guidance only in February 2021.

We want the national care service to ensure that such a situation is never allowed to happen again and that there is accountability for decisions. We were really pleased that, when the new care standards came in, they reduced the complaints that we heard from people being locked out. That was earlier this year, when we were still suffering from omicron, so the two new care standards have certainly helped. The introduction of Anne's law will give ministers the power to set directions, with the default position being that visits should always take place.

In September, at the start of the new parliamentary term, the First Minister stood up in the chamber and stated that she would bring in Anne's law, which would give relatives and friends the same access rights as staff. There have been some challenging conversations with the Anne's law policy team. However, when we met the team last week, we saw a revised version of the directions, which we are confident will work. The directions have been cut down from seven pages to one page. For us, it has always been about ensuring that, as the First Minister said, families and relatives have the same access rights as staff. Also, staff do not get directions to go to their workplace, so why should we?

The National Care Service (Scotland) Bill should enshrine all the things that we have discussed about accountability and about a valued workforce, because it has been a postcode lottery across the country as to what access you get and as to the staffing that you get. I mentioned earlier that we see a very broken social care service right now—there is trouble recruiting staff, who are just not valued. However, they are valued by us because they are looking after our loved ones.

I do not know whether that answered your question.

Evelyn Tweed: Does anyone else want to come in on that aspect?

Henry Simmons: I support what has been said. In addition, I note that, during the pandemic, those in public health held all the cards, and we did not necessarily have counter-evidence or the opportunity to challenge them. When we were looking at why people were making a decision, we asked for evidence of that, but it took a long time to get that evidence, which left people in very difficult positions.

If you make something a right, you must work backwards from that point, because you cannot give somebody a right then take it away as a result of those in public health making a blunt decision about things. Pandemic fears and issues will be with us for a long time—that is the world in which we will be living. I would love that not to be the case, but we must think about things on those terms.

In line with redesigning the property and the structure in the estate to make it Covid-safe, we must build in those rights so that they are unequivocal. When you have an unequivocal position, you will find a solution; when you have the opportunity for an opt-out, you will take it, particularly if there is a risk to you as an organisation or a policy maker. Therefore, the position must be really strong, clear and unequivocal going forward, now that we have vaccinations, testing and evidence, which have all come to the fore over the past few years.

The Convener: Cathie Russell wants to come in.

Cathie Russell: We always had human rights, including the right to a family life—I had power of attorney for my mother and I know that those rights were there. We are talking about adults with incapacity who had legislative rights. The problem is that, once the pandemic struck, all those rights were forgotten. We believe that, if we could have got into court, we would have won a case on the human rights issues.

Apart from one very short and difficult visit, I did not get to be with my mother for a year; I could see her through a closed window and, for a while, through an open window, but I did not get to sit beside her or be her companion, which I was, for a full year. We needed a way to challenge that situation.

The problem with the bill is that it is not clear. There might be a complaints procedure, but there is no access to justice for people whose needs are not met. If Anne's law is not met, how can someone challenge that? It is not clear to me that there is any mechanism to address that that would be affordable for ordinary people.

Tess White: I have a question for Dr Manji and Cathie Russell. Is there a lack of ambition in the implementation of Anne's law? Are you satisfied with the pace of change?

Dr Manji: The pace of change is too slow. We know that lockdowns are, in effect, still happening. Just two weeks ago, a member of the about dementia forum told us that her mother, who lives in a care home in East Ayrshire, was in lockdown again because there was an outbreak of norovirus. Norovirus has been around for a very long time and there are well-established mechanisms for treating it and for infection control. In that situation, there is absolutely no need for an entire unit in a care home to be under lockdown. It is incredibly concerning that that is still happening. It speaks to the urgency of the issue.

Tess White: That is alarming.

Dr Manji: It is very alarming.

Cathie Russell: The new health and care standards have come in, but Anne's law is very limited: it is about the right to visit during an outbreak. Without an outbreak, people should be able to come in and out of the care home as if it were their own home and there should be no limitation on visits—all that sort of thing should be quite straightforward. The issue is when there is an outbreak.

There have been a few cases where homes have been shut because of norovirus. However, we are quite happy about the current direction of the approach because that is about saying that our relatives cannot live without the support of carers and that at least one or two of their relatives need to be counted in the cohort of people who look after them. The most recent terminology is "essential contact person". That person would always be allowed to get in to see their relative.

Let us imagine that there was an outbreak of Legionella in a care home. The home could advise people, when telling them about the outbreak, that they might want to leave visiting for a few days or a week—that is, until they work out what the situation is and they get back to them. However, in that case, if a person feels a visceral need to get in to see their loved one or to advocate on their behalf, they should be able to do that, using the same infection prevention and control measures as staff would use in that situation. We are no different from the staff—we are our loved ones' main carers.

Alison Leitch: The only lockdowns that I knew were when there were cases of norovirus. It was just accepted that that was one of the things that happened—they had to get through it by taking that action because it spread like wildfire. However, now that we have been through enforced separation during the pandemic, I think that we need to use more common sense about it.

If I was to find myself in that position just now, I would use Anne's law as a basis to say, "Look, you could be shut down for three weeks—these are the care standards", instead of just accepting the situation as we did in the past, because we know the damage that lockdowns do. If my mum was not infected or she had come through it, I could say, "Let's use common sense—can I see her in the garden or take her out for a walk, or can she come in my car?" We should never go back to those enforced lockdowns. However, prior to Covid, nobody thought twice about care homes being shut for three weeks because of norovirus.

Henry Simmons: Alzheimer Scotland presented evidence on the detrimental effect of some of the measures that were taken during lockdown in the report that we produced on "COVID-19: the hidden impact". However, that aspect does not receive the same weighting, as we are looking at the world through an infection-control prism rather than through a person-centred prism.

The lasting impact of the decisions that were taken has yet to be fully felt and the trauma that people have experienced has yet to be resolved. We have an action on rights team that is still dealing with many issues and complaints, and we have a counselling service that is still dealing with the aftermath of what happened.

The most important thing is that we place the right level of weighting on the impact on the individual and on their carer, alongside the risk management issues that are associated with infection control. To date, risk management and infection control issues have always won out, but we are now in a different world and we have different measures in place. We must campaign to get person-centred practice, and consideration of the humane issues and impact, to be on the same level as that aspect. Those in public health should be held to account when making decisions about the impact of that assessment. I know that they will consider that aspect, but the consideration is nothing like as strong as it should be.

The Convener: We move to questions from Emma Harper about breaks for unpaid carers.

Emma Harper: Although the framework bill is pretty short, section 38, which covers three pages, is dedicated to rights to breaks for carers. We have had feedback from various people who have raised questions about what constitutes a break, whether it is a break for everybody and whether it is a break to get out or disengage completely. I am interested in hearing views on what the bill says about breaks for carers—in particular, unpaid carers—and whether it is sufficient to achieve what is required.

Dr Manji: Age Scotland is concerned about the lack of a definition of "care break". For our members, flexibility is key, as is the need for a person-centred approach. Carers often do not need a long break away from the person for whom they care; in fact, leaving the person for whom they care can sometimes be more stressful than it would be to stay.

Is a break about having time to sleep or finding other ways to practice self-care and self-management? Is it an opportunity to do something together and to be able to enjoy time together, with support to get out of the house, such as through installation of a lift or other equipment?

Something important and special is encapsulated in a term that one of our members came up with: "enabling the ordinary". That is about recognising everydayness and the importance of everyday interactions, such as eating a meal, getting some rest and being able to do chores around the house. We hear consistently from our members that carers are not currently achieving their entitlements under the Carers (Scotland) Act 2016; that absolutely needs to be addressed through the bill.

We have been consulting on the national dementia strategy, and we recently held two sessions with a group of carers. We asked how many of them had heard of adult carer support plans: most did not know anything about them. Of those who knew about them, none was getting an adult carer support plan or had any support in place. They are all carers of people who are living with dementia, albeit that they are in a community setting, so they might be at an earlier stage. However, it is of real concern that we have been hearing that story consistently since before the pandemic.

It is great to have the emphasis on breaks—as Emma Harper said, the bill contains three pages on the subject—but we need to pin down what that means, and we need flexibility to ensure that carers can get the best possible impact from breaks, which must be shaped according to their needs rather than the needs of the service.

12:00

Henry Simmons: There is fantastic depth of experience in short-break and creative-break schemes that demonstrates how well they can work. Towards the end of the pandemic last year, we were fortunate enough to be asked by the Government to distribute some funding that had been made available. We set up the "Time for you" fund, which offered a £300 grant to individuals living with dementia and their carers. It was overwhelmingly utilised for very creative simple things that gave people little chances to find their own space—it was very much about "Time for you". For example, people got a shed in their garden, got a fishing permit or did things that gave them a short break. The feedback was fantastic. There is a report on that, which we can share with the committee.

That fund demonstrated two things to us. First, people do not ask for much; very few people asked for the full £300. People asked for things that they felt they needed. For example, a woman asked whether she could use the funding to get a tumble drier because of the time she spent hanging her washing outside to dry. She was doing that very often for a person who has issues with continence.

Secondly, really simple but very creative solutions rest with individuals. They are much brighter than we are at finding the best way to use small amounts of money.

If we scale that up, it takes us into the construct of self-directed support. The intention behind personalisation, which led to self-directed support, was that the natural support in a person's life would be accentuated by state funds being given to the individual for them to make choices. Unfortunately, we have regimented that to a point at which it is just about four options and some services, but if we track back 20 years to when that movement was beginning, it was all about creativity, alternatives and substitution.

We have to put some money behind the provisions on breaks and allow people freedom and the choice to do what they feel will make the best break for them.

Emma Harper: The word "sufficient" is used in the bill—it mentions "sufficient breaks". We need to consider how looking after a parent, grandparent or sibling interferes with the education of a young person. I am interested to hear your thoughts on what we need to do in order to take a relationship-centred approach to determining what "sufficient" is. There has to be an agreement with the person who is providing the care about what works for them. Henry Simmons said that people dinnae want a lot; they just want what is sufficient for them. Is more guidance on or a definition of "sufficient" needed in order to make the provisions in the bill work for unpaid carers?

Henry Simmons: We need to return to the basics of social work practice. Social work practice and skills are about assessing where individuals are in their world and their lives, and finding out what their strengths and weaknesses are and what their hopes and aspirations are. We do not have a lot of front-line practitioners who can help people to make decisions. What is sufficient for me might not be sufficient for someone else, so what happens has to be person centred.

On the situation that you described, it is not right that any young person is denied the right to good-quality education and life because they have caring duties. That is entirely wrong. It is important that needs are properly assessed and understood, because what is sufficient for a young person in that situation will be entirely different from what would be sufficient for me.

We need person-centred assessment processes and practice, with the right understanding and skill sets, in order to place in a person's life a level of support that will accentuate their ability to live as well and as independently as possible.

The Convener: We have time for only one more question. Stephanie Callaghan wants to ask about evaluation and sequencing. We have just over five minutes left. I hope that you can do it in that time—she hinted.

Stephanie Callaghan: I was panicking there, convener, because I have two questions.

The Convener: Well, do what you will with your five minutes. [*Laughter.*]

Stephanie Callaghan: My first question is to Henry Simmons and Dr Manji. Are there parts of the bill that you would like to be enacted immediately and are there other provisions about which you think that more time should be taken to co-design them?

Henry Simmons: There are issues around paying for care and, as I mentioned earlier, around having an agreement in principle about what a national care service will stand for, in terms of where care being free at the point of delivery ends and paying for care starts, and what we mean by that.

I would like all the inequalities that we are highlighting being ruled out, as a matter of urgency. We have a strong legal argument that suggests that the NHS has duties that are not being fulfilled because of the guidance that we have on advanced care. We would very much welcome a very quick decision on that, with an understanding that some things might need to be set up on an interim basis but would progress until they became part of the full system.

We have to broaden out the discussion about models of care. I mentioned earlier people who live in rural and remote areas whose only option for long-term care is to travel 150 miles and to pay substantial amounts for doing so. Why have we not designed for them smaller four-person or five-person units as we have done for other groups, including people with learning disabilities and people with some mental health conditions? We spent decades closing institutions and creating alternative community-based models for those groups. It seems to me that we have not even engaged in that debate in relation to people with more advanced dementia, or older people in general.

We need public engagement on alternative models of care. We cannot accept that what we have was ever designed: it was not designed. We need to commission a redesign of models of care using high levels of creativity and engagement. That will not happen overnight, and it will need to be resourced. My view is that the Government cannot do it all on its own; this is where organisations, including third sector and small community organisations, come in. Many people can engage in new ways of thinking. I am sorry if that was a bit long.

Stephanie Callaghan: That is fantastic. I will just mention the Blantyre care hub, which is absolutely fantastic at some of the stuff that you are talking about.

Dr Manji: There are already things in legislation that we could be getting on with in the meantime—in particular, around self-directed support and support for carers.

Apart from that, independent advocacy is missing from the bill. I see it being an enabler of self-directed support and of the personalised carer support that I have already talked about.

Stephanie Callaghan: I will pick up on the point about independent advocacy; I suppose that family advocacy would go alongside that. Alison Leitch said something earlier that really struck me:

that everyone can make decisions about our loved ones, except us. That was very striking to hear.

Kainde Manji talked about success being about achieving outcomes that matter to people and their families. What provisions need to be in the bill that could be linked to monitoring and evaluation?

Dr Manji: I would like there to be a really strong role in the evaluation for people with lived experience. Co-design needs to run all the way through the process.

Outcomes-focused evaluation is absolutely needed, and a strong emphasis on qualitative research is needed within that. We have seen the benefits of qualitative research. The Scottish intercollegiate guidelines network—SIGN—is currently consulting on a guideline for dementia, and for the first time it has included qualitative data in that process, which has enriched it enormously.

We can go a lot further with that involvement, not just by using co-design for the outcomes, but by working as co-researchers. There is a lot of evidence on the benefits of involving people with lived experience as co-researchers in evaluation work.

Stephanie Callaghan: So, it is about continuing the co-design, if you like, through the process so that it keeps impacting on delivery and policy.

Dr Manji: Absolutely. There is something in there about trust as well. People might be more willing to talk to somebody who has a shared experience about whether their outcomes have been met. Trust would support and enable legitimacy in the system and ensure that evaluation genuinely captures people's lived experience, rather than just ticking boxes.

The Convener: I thank all of you for your time this morning. It will be very helpful and valuable to us as we move on to thinking about the questions that we want to put to the minister next week.

European Union (Withdrawal) Act 2018

Food Supplements and Food for Specific Groups (Miscellaneous Amendments) Regulations 2022 (SI 2022/377)

12:10

The Convener: Agenda item 3 is consideration of a notification from the Scottish ministers for consent to a statutory instrument. The purpose of the statutory instrument is to make provisions for minor technical amendments to units and forms of nutrients in various pieces of nutrition legislation in order to ensure uniform and coherent interpretation of regulations, as well as alignment with the European Union, of which Northern Ireland remains a part.

Under the protocol between the Scottish Parliament and the Scottish Government, the consent notification has been categorised as type 1, which means that the Scottish Parliament's agreement is sought before the Scottish Government gives consent to the United Kingdom Government to make secondary legislation in an area of devolved competence.

Do members have any comments on the instrument?

Emma Harper: I have no problems with minor technical amendments to the units and the forms of nutrients in various pieces of legislation. I just want to highlight the issue of pesticide residues. Any time that that kind of language is flagged, it reminds me of work that I did previously, when I was a member of the Rural Economy and Connectivity Committee, on food safety, food standards, imports, trade, trade deals and things like that.

Without going into detail about the US Food and Drug Administration's "Food Defect Levels Handbook" on approved defects, I basically just want to state that I am happy with proceeding with the instrument, because the information that we have on pesticide residues refers to widening the definition, or

> "expanding on the potential sources, to include veterinary and biocides."

On further reading of the information, I am satisfied that it is okay to proceed with the instrument.

The Convener: As members have no further comments, is the committee content that the provisions that are set out in the notification should be included in the proposed UK SI?

Members *indicated agreement.*

The Convener: Is the committee content to delegate authority to me to sign off on a letter to the Scottish Government informing it of our decision today?

Members *indicated agreement.*

Subordinate Legislation

Official Controls (Import of High Risk Food and Feed of Non-Animal Origin) Amendment (Scotland) Regulations 2022 (SSI 2022/341)

12:12

The Convener: Our next item is consideration of two negative Scottish statutory instruments.

The Delegated Powers and Law Reform Committee considered the Official Controls (Import of High Risk Food and Feed of Non-Animal Origin) Amendment (Scotland) Regulations 2022 at its meeting on 6 December 2022, and drew the instrument to the attention of the Parliament on the general reporting ground, for a failure to follow proper drafting practice, in that one of the statutory consultation requirements was not referred to in the preamble. The regulations will amend Commission Implementing Regulation (EU) 2019/1793, which imposed a temporary increase of official controls and emergency measures governing entry to the European Union of certain goods from certain third countries.

No motion to annul has been lodged. As members have no comments, I propose that the committee make no recommendation in relation to the negative instrument. Do members agree?

Members *indicated agreement.*

Processed Cereal-based Foods and Baby Foods for Infants and Young Children (Scotland) Amendment Regulations 2022 (SSI 2022/342)

The Convener: The Delegated Powers and Law Reform Committee considered the Processed Cereal-based Foods and Baby Foods for Infants and Young Children (Scotland) Amendment Regulations 2022 at its meeting on 29 November 2022 and made no recommendations in relation to the instrument. The regulations will amend the Processed Cereal-based Foods and Baby Foods for Infants and Young Children (Scotland) Regulations 2004 to add additional forms of vitamins and minerals that can be used in manufacture of processed cereal-based foods and baby foods.

No motion to annul has been lodged. As members have no comments, I propose that the committee make no recommendation in relation to the negative instrument. Do members agree with that proposal?

Members *indicated agreement.*

The Convener: At our next meeting, the committee will take evidence on the National Care Service (Scotland) Bill from the Minister for Mental Wellbeing and Social Care. That will be our last scrutiny session at stage 1 of the bill. That concludes the public part of our meeting.

12:15

Meeting continued in private until 12:28.

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