OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Monday 5 December 2022

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Monday 5 December 2022

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE
36th 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:

James Dornan (Glasgow Cathcart) (SNP) (Committee Substitute)
Clare Gallagher (Council of Ethnic Minority Voluntary Sector Organisations Scotland)
Dr Caroline Gould (Skye and Lochalsh Access Panel)
Frank McKillop (Enable Scotland)
Andy Miller (Scottish Commission for People with Learning Disabilities)
Dr Pauline Nolan (Inclusion Scotland)
Karen Sheridan (Community Integrated Care)
Hannah Tweed (Health and Social Care Alliance Scotland)
Rhona Willder (Scottish Independent Advocacy Alliance)
Don Williamson (Shared Care Scotland)
Mhairi Wylie (Highland Third Sector Interface)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

William Quarrier Conference Centre, Glasgow

Scottish Parliament

Health, Social Care and Sport Committee

Monday 5 December 2022

[The Convener opened the meeting at 14:20]

National Care Service (Scotland) Bill: Stage 1

The Convener (Gillian Martin): Good afternoon, and welcome to the 36th meeting in 2022 of the Health, Social Care and Sport Committee. I am delighted to hold our first external formal meeting of the parliamentary session in Glasgow. We are in the Quarrier centre in Govan.

I have received apologies from David Torrance. James Dornan will substitute for him.

A few of our members—Tess White, Sandesh Gulhane and Carol Mochan—are joining us virtually, as is James Dornan. The rest of us are here in person. It is great to be here.

The first item on our agenda is further consideration of the National Care Service (Scotland) Bill. We will hear evidence from two panels of witnesses.

I welcome our first panel. Clare Gallagher is a human rights officer for the Council of Ethnic Minority Voluntary Sector Organisations Scotland; Hannah Tweed is senior policy officer for the Health and Social Care Alliance Scotland—the ALLIANCE; Don Williamson is chief executive of Shared Care Scotland; and Mhairi Wylie is chief officer for Highland Third Sector Interface and a member of the TSI Scotland Network. Joining us online, we have Karen Sheridan, who is chief operating officer for Community Integrated Care.

I will hand over to my colleague Sandesh Gulhane for the first question. It looks like he might have frozen. [*Interruption*.] We will try again. While Sandesh gets organised, I will ask the panel a question.

The bill has arisen largely from the “Independent Review of Adult Social Care in Scotland”, which is also known as the Feeley report. We have had Derek Feeley in front of us to talk about his thoughts on the bill. I ask all the witnesses for their views on whether the bill accurately reflects the review’s recommendations. Are any key recommendations from the review missing?

I will go to Mhairi Wylie first. You do not have to operate your microphone, Mhairi; that is done for you.

Mhairi Wylie (Highland Third Sector Interface): Thank you for having us.

By and large, the bill heads in the right direction, but most of the feedback that we have heard expresses concern about its practical application. At this stage, there is general support from our membership for the idea that the bill’s adult social care aspects respond to the report, but there is a strong interest in what that will look like in practical terms as the bill develops in detail.

There are some questions about where community justice and children’s services fit, given the absence of something that is equivalent to the Feeley report for those services. Does that make sense?

The Convener: It does. I will go to Hannah Tweed next.

Hannah Tweed (Health and Social Care Alliance Scotland): We have a broadly similar position in our membership. The phrase that we have been using to summarise that has been “conditional optimism”. Few would argue with the principles, but the practice and the detail of what is and is not included in the bill are open to concern and questions. I imagine that we will say more on that as the evidence session continues.

The Convener: Are you happy to develop that point? What aspects would you like to see in the bill that are not already there? What aspects cannot wait until the co-design process?

Hannah Tweed: Two things—care charging and eligibility criteria—are not there at all, and that is a major concern. Those are key things that affect people’s access to social care and their appropriate ability to live independently and well. We have heard again and again that those things really matter to people on the ground, but the bill, in its current format, does not explicitly engage with them.

In relation to care boards, it is welcome that there is mention of engagement with people with lived experience, but there is nothing in the bill to ensure that such engagement is a prerequisite in order for decisions to be quorate. We consider consultation not to be the same as engagement in decision making. There is welcome mention of human rights-based approaches in section 1, but further such detail is needed in the primary legislation, then the terms and conditions could be included in regulations following co-production. That is what we are looking for.

I could run through the full bill, but that would take longer.

The Convener: That is very helpful as a starting point.

Don Williamson (Shared Care Scotland): My comments will be very similar. We are very supportive of the bill and the development of a national care service. We agree with the intention behind the bill: we need to improve the quality and consistency of community health and social care services across Scotland in order to end the postcode lottery. We also agree that effective delivery of human rights should be at the core of the new national care service.

However, as colleagues have said, the bill is framework legislation, so it has been quite difficult to engage with our members and stakeholders to discuss the details of how the national care service will work in practice. Unpaid carers and the people whom they support are our main constituency, and it has been difficult for them to come to a clear view on how the national care service will work in practice, because they do not know how the structures will develop, how the human rights principles will be applied in practice or how they will be meaningfully engaged in the development of those systems and structures. It has been quite challenging to engage people in that level of detail when there simply is not that information in the bill.

We have heard people use the expression that they are "cautiously supportive" of the bill, but there is clearly a lot of information still to come, and they would like to have more details.

Clare Gallagher (Council of Ethnic Minority Voluntary Sector Organisations Scotland): My view is much the same as those of the other witnesses. We seem to be heading in the right direction, but we and other people are struggling to understand the practical elements. What impact will the bill have? How will it improve things in adult social care?

I like the fact that there is mention of human rights and of taking a human rights-based approach. That is welcome, but I struggle to see how that will be impactful in practice, given that key human rights principles are not included in the primary legislation. For example, there is no mention of dignity in the bill, and it is really important that that be included. That has been included in previous legislation, such as the Social Security (Scotland) Act 2018 and the Social Care (Self-directed Support) (Scotland) Act 2013. That is a core part of human rights law; it tells us why we have our human rights. If we do not show in our law how a human rights-based approach will have a meaningful impact and act as a safety net, it will be really difficult—

The Convener: We do not need to wait for a co-design process to bring that out, because it already exists.

Clare Gallagher: Yes. It should be included at the very beginning, not retrospectively. It should be at the heart of the system, which is why it should be included in the primary legislation, not the secondary legislation. The bill should mention specific human rights that will be impacted, such as the right to private and family life, and the right to a high standard of mental and physical health. Those should all be specifically referenced in the primary legislation, as has been the case in previous legislation. There is a lot to be learned from that previous legislation, because that has been recognised throughout the world as being really progressive in relation to human rights implementation. The bill could include that, in the first instance, before the co-design process starts.

The Convener: Thank you very much.

We will go to Karen Sheridan, who is online, for her initial reflections on the review and the bill, and how they do or do not work together.

14:30

Karen Sheridan (Community Integrated Care): Broadly, we welcome the national care service and the bill. There are gaps that we, like others, would like to see addressed as we go through to the co-design stage. Principally, those relate to how to ensure that everybody is involved in order to get the human voice of people who use the services, those who care for them and people such as me, as a representative of the voluntary sector.

We feel that the bill in its current format very much focuses on structure. It does not include the significant cultural change that will be required for the national care service to be effective. We are really pleased to see the references to human rights, especially in terms of prevention and the empowerment of individuals, but how will we work towards that in the co-design stage?

Some of the bits that we think lack clarity are between the charter and the principles. There is not much reference to the importance of self-directed support and the health and social care standards as they currently fit. That can all be clarified once we get into the co-design stage, of course.

The final issue for us is funding and how the national care service will be developed within the financial envelope, because the financial memorandum seems exceptionally light for the size of the task that we will have.

As I said, we broadly support the direction of the national care service, but we would like to see more of the culture-based work that will be required in line with the Feeley report.

The Convener: That is a really helpful start.

I think that I can now bring in Sandesh Gulhane. Can you hear me, Sandesh?

Sandesh Gulhane (Glasgow) (Con): I can. Thank you.

Many of the witnesses have highlighted a lack of detail. I think that we heard a little bit of that in response to the previous question, but I am afraid that I did not hear all the answers. Starting with Hannah Tweed, will the witnesses highlight any specific areas of the bill on which the Government needs to provide more detail?

Hannah Tweed: I mentioned that the ALLIANCE and our membership are in broad agreement that we would like more detail at the primary legislation level on care board representation to ensure proper participation in decision making. That threads through a number of other elements. For example, in sections 6 and 7, which are on strategic planning by the Scottish ministers and by care boards, we would like there to be a commitment to more than just public consultation—there should be co-production, and involvement in decision making should be stipulated in primary legislation. That needs to come along with wider data collection duties, which have been mentioned as welcome, but there is no obligation to do that. I will put it in these terms: you do not know what you do not know. Detailed data collection is required to evidence things such as unmet need and where the gaps are in terms of people not receiving equitable access to social care. We know some of that from pre-existing research, but that is not part of our routine data collection and intersectional analysis. We would like more of that to be made a prerequisite.

There is also quite a lot of concern about the role of the third and independent sectors in the primary legislation. Please correct me if I am wrong, but my understanding is that the current definition of strategic partners is more engaged with local authority and health and social care partnership delivery of social care. Given the significant role of the third sector and of volunteers in providing health and social care services and support to people, there seems to be a pretty significant omission of key partners, particularly in the wider planning processes. We would like to see the third and independent sectors mentioned in, say, section 8 as community planning partners and involved in that process.

We also have questions about the mention of the ethical commissioning of independent advocacy. Again, that is very welcome—it is great—but it would be really useful to see definitions in the primary legislation of what that means. The Social Security (Scotland) Act 2018 caused some headaches with regard to independent advocacy, but there is learning to be drawn from that—to go back to Mhairi Wylie's point about implementation—to enable people to say when we reach that stage, "Yes, we understand exactly what is meant by independent advocacy, and we therefore understand how to properly resource and commission it and how to ensure that it is available to people on the ground." Having that definition in primary legislation would enable regulation and guidance to be much more robust, and therefore the implementation to be much more meaningful and easier, albeit with some sweating from the legal team in the meantime.

We also have some concerns about the charter of rights and responsibilities. That is great with regard to putting human rights at the forefront, as has been noted in earlier comments, but what happens if the principles of the charter are not met? Currently, the framework bill does not make clear what gives that teeth, if I may put it bluntly, because, if you have rights—[*Inaudible*.]—deliver them and people do not have redress, that will cause problems. That would be contrary to the intentions of the bill and contrary to what it is proposed that the national care service would do. Therefore, we would like further detail on that so that it is really clear how things will be delivered in practice. That does not mean that we expect the fine detail of the terms and conditions—I can see why that is left to regulations.

We also had concerns about section 36, which is the care records section. Specifically, we had concerns about citizen access to records so that it would not be only health and social care professionals who had access to records, and control of records. Again, that would be done in line with human rights digital principles. We would like to see third sector access, where appropriate and with the permission of the individual.

Those are some of the key areas of concern.

The Convener: My colleagues will dip into quite a lot of that, and you will be asked specific questions on that.

I believe that Sandesh Gulhane has one more question.

Sandesh Gulhane: I do. I thank Hannah Tweed for that detail.

My last question is for Don Williamson. I want to touch on the issue of black, Asian and minority ethnic carers, which is obviously a topic that I find to be particularly important. We need to do more on that issue.

Only 3 per cent of unpaid carers are able to access paid breaks. Why is that? What are the main barriers to carers' accessing those breaks?

Don Williamson: The figure of 3 per cent is a Scottish Government figure. That is the percentage of carers who are accessing breaks with the help of statutory support. Obviously, that is an incredibly low figure, given that we know that access to breaks is reported by carers as fundamentally important to promoting their health and wellbeing.

The big question is why the number is so low. We need to gain a much deeper understanding of why that is. Carers report to us that there simply is not enough suitable provision available for them to access. They report that the systems that they need to navigate, even to get to the point at which they might be deemed to be eligible to receive a break from caring, are incredibly complex and bureaucratic. There are also eligibility criteria, which are generally set in such a way that people have to be at breaking point or in critical need before they are able to receive that statutory support to access a break. Many carers will tell you that they have just never had a discussion with anybody about the fact that they might be entitled to receive a break from caring—it has never been discussed with them—so they do not know that it might be a possibility. Therefore, there are many reasons for that low figure.

We will perhaps come later to the topic of the right to a break, but our main concern about the meaningful implementation of the right to a break is that that is completely contingent on there being sufficient availability of short breaks provision for carers. Carers will tell us that it is rather meaningless to have the right to a break if there is insufficient range, choice and volume of provision available to them.

The Convener: Thank you. We will move on to questions from Paul O’Kane.

Paul O’Kane (West Scotland) (Lab): Good afternoon. We have had useful opening comments on the general principles of the bill, but I want to ask about what is actually in the bill. It provides for the transfer of accountability from local authorities to the Scottish ministers. What is your view on that concept and on the risks and benefits therein? I ask Mhairi Wylie to start.

Mhairi Wylie: We touched on that with some of our members as part of our initial response. Generally, my impression is that they believe that there would be more transparency if the services were accountable to ministers. That probably stems from frustration with the lack of transparency, or perceived lack of transparency, at local level. Generally speaking, people seem reasonably open to that pathway of accountability, but there are significant questions about what the governance will look like in general and what impact that will have at local level. What are the intended structures through which that pathway of governance and accountability will be managed? Although there is general support, from the individuals whom we have spoken to, it appears that there are more questions than answers.

Beyond the issue of growing that pathway, the general impression that we are getting is that ministers might be more willing to honour a more equitable partnership of representation from carers, users and the third sector in a way that is not a simple tick-box experience. We are often invited to attend meetings, but our ability to influence policy or decision making is very limited. The only instance that I can recall when we have ever had the direct ability to approve budgetary spend was with the reshaping care for older people programme, about eight or nine years ago. In that case, the spend could not happen until the third sector had signed it off.

By and large, there is cautious optimism, as my colleagues have said. There is a feeling that there is an opportunity for more transparency, but I could not say how much of that is derived from the bill and how much of it derives from optimism based on the concept that change can only make things better.

Paul O’Kane: From a Highland perspective, was there any sense from the people whom you consulted in your membership that things already feel further away from communities? Was there a sense that we need to bring things closer to communities? To tie that to the proposal for care boards, do people want care boards that are more local rather than just a board that is in Inverness or wherever?

Mhairi Wylie: That was a concern. Given that there is not an awful lot of information in the bill, concerns were raised about the potential geography of the care boards. As I am sure you are aware, Highland is equivalent in size to Belgium, so the concept that there is a homogeneous Highland view is often misleading. In fact, I think that people would welcome much more local care boards that are answerable to a ministerial arrangement, rather than have a care board at region level. The biggest concern was that it would move to the level of the national health service board. In Highland, that would not necessarily be a massive change, as it would just involve the inclusion of Argyll and Bute, but for some other areas in Scotland, it would be a significant change from an accountability perspective.

I think that people would be more welcoming of a more local approach. One reason why that needs to be thought through is that the bill talks about people having equity of service, but we need to talk about equity of outcome. That is because the activities and actions that need to happen to achieve an outcome might be very different depending on whether someone is in Portree or Dumfries, so we need flexibility. We need to be careful about that. However, local would be better—obviously, we would say that from a Highland perspective.

Clare Gallagher: To build on the points about the transfer of accountability, we require a bit more assurance about what that will look like. From our point of view, we had to start from scratch and develop our knowledge and understanding of care services. That might sound a bit out of touch, given what we are here for today but, with the transfer of services, we must ensure that, regardless of whether the accountable body is a care board, the way in which it is designed and the way in which it designs and delivers services must have a human rights-based approach and anti-racism at the heart of it from the very beginning. That requires, for example, training. Earlier, we talked about staff culture.

14:45

People in the organisations that we work with are saying that what is proposed will not change their view. When we have engaged with people from ethnic minority communities on other areas of social care, such as the strategy for older people, they have said that they cannot access care in the first place because the access to translators is not viable or because they do not know where they could access care. Someone said that they would rather call a third sector organisation that supports them than dial 999, because of the translation barrier. We know that the trust in local authorities is not there at the moment, nor is it there at Government level. The bill represents a good opportunity to recognise that, to address the barriers of trust and institutional racism and to make sure that that is at the heart of everything that is done with the new accountable body.

Hannah Tweed: We would echo much of that. What has come through loud and clear from our membership is the need for people who have problems in accessing services or with the delivery of service, including the workforce—I am not talking only about people who access self-directed support or social care—to have trust in the system of redress and in the system for raising concerns and complaints, and I am not sure that that is consistently the case across Scotland at the moment. In fact, quite the contrary is the case.

That is partially because we have different systems for people to access support and seek information, some of which are quite opaque and difficult to navigate. That causes problems for specific population groups—my colleague Clare Gallagher highlighted an example. Another example relates to people with learning disabilities. I suspect that Andy Miller, who is on the second panel, will say more about that. There are problems with how accessible and inclusive the communication around accountability processes is for individuals on the ground.

In approaching accessibility and inclusivity from an efficiency point of view, if all the communication comes to a centralised body, at least it will have been worked up to a suitable standard in one instance, although there will still be a desire to engage with local concerns, as Mhairi Wylie highlighted.

The other key thing is to work through what ministerial responsibility means and how we ensure that people can maintain trust in that. In the event that emergency intervention—do not ask me which section of the bill that is dealt with in; it is about two thirds of the way through the bill—is necessary, is there a duty on ministers for that to be as time limited as possible? Is there a duty on them to pay due attention to the principles that are outlined in the charter? I believe that that would be implicit, but something being implicit in legislation is not the same as it being explicit in legislation. Making that explicit in the bill would ensure that those accountability structures would be prioritised and would be front and centre within any redesign.

Paul O’Kane: Is it the ALLIANCE’s contention, therefore, that something that is in the control of ministers and on which they are accountable to 128 of us in Parliament would provide more accountability for people than accountability to the local authority? Am I right in thinking that that is what you were saying?

Hannah Tweed: We are aware of concerns that the complaint systems involve a bit of marking your own homework, because there is not sufficient distance or independence—in other words, the people to whom someone raises concerns might be the people who decide whether their third sector organisation gets funding or who decide whether their SDS package gets cut next time they have an assessment, and it is understandable that that comes with fear. It is better to have a more removed or independent structure in which the people involved make direct decisions on things such as that. Obviously, ministers make decisions on things that affect people’s lives, but they do so in a slightly less immediate sense than someone who can say, “You’re about to lose a third of your SDS budget”, which brings with it a greater potential for problems to arise. That might also relate to your point about problems with distrust of the current system, as much as anything else. That point is relevant with regard to my colleague on my right, Mhairi Wylie.

Paul O’Kane: We are probably talking about people who would be seen as gatekeepers in the process—those in social work departments, among others, who function as commissioners. Does logic suggest that it would be better for that role to sit with a national body than for it to sit locally?

Hannah Tweed: I do not want to criticise individual social workers, the vast majority of whom are working flat out to try to get the best outcomes for folk. However, there is value in having an independent body that ensures accountability.

Mhairi Wylie: I agree that it would be better to have a bit of distance between the organisation that is ultimately commissioning services—regardless of whether it is in the public sector, the private sector or the third sector—and the individuals who are delivering the services, including those in the third sector. Therefore, we must think carefully and cleverly when we talk about representation in those decision-making bodies of users, carers and people from the third sector.

I am not criticising any individual social workers and I agree with the comments that were made but, realistically, when you are passionate about an area of work that you are undertaking, how able are you to take a step back, look at the strategic picture and make an objective decision about the best use of the resources? Often, in the commissioning frameworks, we come across specific views and perspectives that are not necessarily justified and have been expressed by people in third sector services who are very much involved in the area in an almost competitive way, as they provide services through a different avenue to others. You cannot imagine that, in any framework, such decisions about what will be commissioned elsewhere in the private and third sectors will be made without bias.

Don Williamson: One of the reasons why people are looking for some kind of radical change is that the current system is not working and there is not the accountability that people might expect.

We have good national legislation that should be driving forward improvements—a good example of that is the Social Care (Self-directed Support) (Scotland) Act 2013—but it is not being consistently implemented locally, which causes frustration among carers and supported people. We have national legislation that was developed by the Government and the Parliament and is meant to be implemented by local authorities, integration joint boards and health and social care partnerships, but there appears to be no accountability around that, and carers are frustrated because they do not seem to have any means of redress when their rights or what they might expect to flow from that legislation do not materialise.

People are saying that, if the current system is not working, we need to change it, and that if we need radical change in order to create accountability and ensure that they can exercise their rights, they would like that to happen. That approach is born out of a feeling that things are not working for them at the moment, and that there is not that accountability.

The Convener: James Dornan has questions about Anne’s law.

James Dornan (Glasgow Cathcart) (SNP): I have a question for Hannah Tweed about the concerns of carers about care home visits. Do you believe that the bill addresses those concerns? If not, how could the relevant section of the bill be amended to address them?

Hannah Tweed: My first statement would be that Anne’s law is welcome. There is probably broad agreement across our membership that prioritising people’s rights to family life and to live well is welcome, as residential care homes are homes, where people should be able to have everything that they would expect to have in their home.

We think that the relevant section could be more explicit in referencing existing human rights treaties to reinforce that, and the one that springs to mind is article 26 of the United Nations Convention on the Rights of Persons with Disabilities, which is on habilitation and rehabilitation.

On addressing carers’ concerns, I would be inclined to defer to my colleague Don Williamson, given our specialisms. However, extensive co-production would be really valuable—essential—in seeing the implementation-in-practice element being properly worked up. It is also worth considering how learning from the Covid-19 pandemic is being drawn on to inform the practicalities of that. We need to ensure that the issue is a key priority in follow-through commissioning processes and that systems are in place to enable proper visiting and proper rights to family and community engagement.

The Convener: I will bring in Don Williamson, seeing as he was mentioned.

Hannah Tweed: Tig—you’re hit, Don.

Don Williamson: Family carers complement the care that care home staff provide, which includes essential social and emotional support. We know that carers being denied access to their loved ones as a result of the pandemic caused enormous distress and anxiety. We are fully supportive of that new right.

The Convener: Does James Dornan want to come back in?

James Dornan: [*Inaudible*.]

The Convener: Can we have James's mic live? James, you will have to say that again, as your mic was not unmuted.

James Dornan: My apologies.

The Convener: It is not your fault.

James Dornan: Given your previous comments, Hannah, would you agree that this is a good opportunity to show the benefits of co-design and co-production, after the framework bill has been agreed to?

Hannah Tweed: I am unlikely to have an objection to co-production, so I can definitely see value in that.

The other area on which that aspect might be expanded—I perhaps should have mentioned this in a previous answer—is the calls from Chest Heart & Stroke Scotland and other colleagues, which we support, to include the right to rehabilitation in section 40 or other sections. That aligns closely with ensuring independent living as set out in article 26 of the UNCRPD. There is a need to further flesh out that section, particularly in relation to providing definitions on primary healthcare and social care and on the transitions between the two.

I will build on Don Williamson's comments about unpaid carers. Through various research projects that we have done, we have heard of the real value in health boards and care homes enabling personal assistants to provide support. I am referring to people who have been long-term supporters of individuals who have an SDS package or SDS arrangements providing support in hospital and residential care, particularly in cases of, say, six weeks rehabilitation from hospital to home via residential care. There is real value in having people who understand others' communication needs, their preferences and what they want. Where that can be accommodated, that has great outcomes for people. That is absolutely in line with existing legislation, and it would be really important to prioritise that through existing planning.

However, that does not happen consistently. We hear a lot of instances in which, as with family carers, personal assistants and care workers are not given that access, even when it is the desire of the individual accessing services. Ensuring that the right to rehabilitation and all the related terms and conditions therein are included would be most welcome.

The Convener: James, do you have anything further to ask?

James Dornan: No, I will leave it at that. I might come back in later.

The Convener: I want to follow that up. That comes back to your points about the charter having teeth, Hannah. You have mentioned other human rights legislation as the backdrop for quite a lot of those unmet rights.

Again, I am making a comment rather than asking a question, but I ask for your reflections on that. There is already legislation out there, and people have not felt that their rights have been met. I presume that the charter and the bill need to have something in them that allows people an avenue to question when their rights have not been met.

15:00

Hannah Tweed: Yes. [*Laughter.*]

The Convener: I know—sometimes, I have to remember that I am meant to be asking questions. Mhairi Wylie wants to say something.

Mhairi Wylie: All our members whom we spoke to about that were very welcoming of the right to access care homes, but there is a practical side of that when we start to consider remote rural and even island areas. We have individuals who, quite frankly, cannot get to their family using public transport because, first and foremost, public transport simply does not go there—and it certainly does not go there and back again on the same day. When we talk about access and the right to family life, we have to understand the interdependencies involved, which are about far more than simply a question of opening a door and welcoming people in. It is about allowing people to get from point A to point B in the first place, and making that reasonable and affordable.

That is one of the biggest aspects, particularly when we consider remote rural areas. The practical elements of people getting to their loved ones can be incredibly significant barriers not just in relation to trying to continue family life when somebody is in a care setting but in relation to rehabilitation. Continuity of care and carers is a significant issue as well.

Emma Harper (South Scotland) (SNP): Good afternoon, everybody. Don Williamson talked about unpaid carers and how we support them. In respect of rights for breaks for carers, through sections 38(2) to 38(10), the bill suggests modifying the Carers (Scotland) Act 2016. Eligibility criteria and the language that is used have been talked about. There are suggestions on changing that language to make it easier for unpaid carers to obtain or access breaks.

Some of the language is interesting. It is all very legal language. The bill suggests substituting the words "eligible needs" with

"relevant needs that meet the local eligibility criteria".

We now have to think about going back to considering what the eligibility criteria are and how we can get breaks for unpaid carers. Breaks are not the be-all and end-all, because some care is so complicated that one or two registered nurses might need to be trained to deliver care that a parent is already delivering.

What are your thoughts about the language in the bill to support breaks for carers? Is that language adequate? We need to support and help the work that unpaid carers do down the line. That really needs to be valued. How can we get them the best support through respite breaks and in the language of the bill?

I will go to Don Williamson first, as he picked up that issue when Sandesh Gulhane asked a question.

Don Williamson: As you said, the bill proposes amendments to the Carers (Scotland) Act 2016 to provide rights for assessed carers—that includes adult and young carers—to have sufficient breaks from caring. We can talk about the term “sufficient” and how it is interpreted.

As far as we understand it, the bill also clarifies that eligibility criteria are removed from decisions in determining whether that right can be applied. Eligibility criteria would be taken out of the determination of whether a carer has a right to a break. We see that as a positive development. However, in order for that right to be effective and meaningful, it has to be clearly defined. That is the most important thing—it has to be understandable and measurable. We are concerned about how the term “sufficient” breaks from caring might be interpreted.

For the right to be deliverable, there needs to be sufficient supply of short-break services and support locally to meet the needs of all carers who have the right, and we have concerns about that, too.

On the point about the interpretation of the term “sufficient”, the lack of a clear definition in the bill is a real concern for us. Having a clear definition of “sufficient” would strengthen the position of the right holders—unpaid carers—and it would give them a level of accountability and provide for scrutiny. Most importantly, it would avoid the potential situation of carers finding themselves in some kind of dispute with local authorities or care boards, which will eventually take on responsibility for this, about whether they are getting sufficient breaks from caring.

The term “sufficient” can be looked at in a number of ways. Does it mean sufficient breaks to stop a carer reaching breaking point and going over the edge, or does it mean sufficient to enable them to have good health and wellbeing and live the best life that they can? It could be interpreted in either of those ways or in some way in between, so it is important that the term is properly defined.

In the absence of a clear definition, there is always the possibility of there being a proxy form of eligibility criteria, which is what we are trying to avoid. The Government has said that it wants to remove eligibility criteria from this area.

Emma Harper: What is sufficient for one person might not be sufficient for another, so it is all very person centred, to use that phrase. I suppose that a break might be a break with the person whom you are caring for. Does that language need to be in the bill? How do we define that? Can that be worked on? The bill is about sufficiency and language that is not about eligibility. Once we have the overarching framework, we can clarify what “sufficient” is and build on that through an approach that takes the carer’s view on board. Would that be part of the co-production?

Don Williamson: Yes. Your point about co-production is key to this. In statutory guidance for the 2016 act, we have a good definition of what a short break is, but we are still seeing that being applied inconsistently. We encounter situations where carers feel that their outcomes for a break would best be met by having a break with the cared-for person, but that has been denied to them because it has been felt that that is not a break from the caring responsibility. It is, however, a break from the person’s routine and it provides an important way to get away from the daily routines of being a carer, but with the person whom they care for. That should be entirely acceptable.

The concern is not just the language in the bill, but that the bill proposes to amend the 2016 act to ensure that carers get the support that they need to

> “take sufficient breaks from providing care for the cared-for person”.

We are a wee bit concerned that that might exclude the possibility of people choosing to have a break together or having a break in any way that they feel is appropriate for their outcomes.

Emma Harper: So that bit of language might be too prescriptive.

Don Williamson: That would be our reading of it.

Emma Harper: The issue of breaks concerns young carers who are caring for people, and older people who are caring for their spouses. It is a huge issue in social care.

Don Williamson: It is huge, but the existing legislation on self-directed support should give people flexibility and control over how their outcomes should be met. The right to breaks should reinforce personalisation and choice, because carers and the people whom they support are in a far better position to know what are the best means by which they can have their outcomes met.

Emma Harper: Given that carers and their breaks take up three pages of the bill, we really need to think about that, and I am happy to hear any suggestions for improvements.

Hannah Tweed: The provision in section 38(2) that Don Williamson referred to is also underlined in my copy of the bill, with the suggestion that people should be enabled to take breaks with family, if that is deemed appropriate. That is really important.

There also needs to be something about the need for proactive commissioning of services in places where provision is not sufficient. I would also highlight the language used in standard 12 of the standards for good self-directed support, which relates to flexibility of finance, because it really draws out what we have outlined with regard to person-centred choices. As long as something meets a person's outcomes, that person should be able to spend the relevant money appropriately—in line, obviously, with existing legislation; I am not suggesting otherwise.

If the best thing is for the family to go away on a short break, that is grand. That sort of thing should not have to be put on a prescribed list, with only certain providers being used, and it should not be tied to anything else. I know that Shared Care Scotland does amazing work on short breaks, but—this is no criticism of that provision—it should not be the only route. We need to allow that flexibility in the legislation while also enshrining the right of every carer to breaks and ensuring that it is not linked to, say, carers allowance so that we end up with that 3 per cent figure. We need to make it really clear that this is a universal right.

Don Williamson: As well as the need to ensure clear interpretation of the provisions and that there is no ambiguous language around sufficiency, I would just point out—carers have told us this repeatedly, most recently at last month's carers parliament—that the right to a break is rather meaningless if there is no provision available to give them that break. A lot of that is about replacement care, which can allow carers to have a break apart, because someone is able to come in as a substitute, or can ensure that care goes with the person being cared for, so that people can have a break together with that extra care in place.

As well as the right to breaks, the Feeley review recommended the development of a range of options for respite care and short breaks, but the bill does not seem to address that or provide any kind of investment strategy for improving the availability of provision and ensuring that it is the right provision for carers. This is a really underresearched area, and there is real concern about it in the sector. After all, much of the provision is delivered by the third and independent sectors, but they are really struggling at the moment, because of all the economic pressures that we know about such as the cost of living and inflation, workforce issues and so on.

If the right to a break is to be effective and meaningful, a lot of work will need to be done to understand the current status of our short breaks infrastructure and the investment that needs to be made to bring things up to a level to ensure that that right can be achieved.

The Convener: Emma, I am conscious that Karen Sheridan wants to get in, but it might have something to do with the previous questions on Anne's law. Karen, is that the case, or do you have anything to add to what has been said on these particular questions?

Karen Sheridan: I have a brief comment about Anne's law. I welcome its inclusion in the bill but, speaking as a provider of independent and supported living settings, I think that we would welcome it if the provisions were extended to recognise visiting rights for those who do not live in residential settings. We saw during the pandemic the same restrictions being applied and an inconsistent approach being taken to individuals living in their own homes or in shared tenancies with others. As it is vital to their health and wellbeing that those people have the same access, we would welcome the extension of the provision beyond residential care home settings.

The Convener: Thank you, Karen. I apologise for not bringing you in at the time—I did not realise that you had asked to come in.

Emma, do you have a final question? We will then need to move on.

15:15

Emma Harper: One of our questions in our briefing paper is directly about minority ethnic carers. We need to make sure that the questions are representative of that issue as well. What additional needs and potential barriers should be considered in relation to carers from minority ethnic communities with respect to access to breaks?

Clare Gallagher: When it comes to needs and barriers, one of the biggest things that we have come across while doing engagement work around unpaid carers is that the term is not recognisable. People do not see themselves as unpaid carers. That is not limited to ethnic minority communities, but it is definitely more prevalent there. People see it as their job to look after a loved one or a close family friend. We have learned that, when we do consultation events, we have to break the term down and say what it means. We will say, "Are you a person who provides care for a child with additional support needs or a family member?" That is the first step in addressing that barrier.

I agree with Don Williamson's comments on being explicit about what the right to a break means, but when we are talking about the implementation of that, we need to take a step back and realise that ethnic minority communities do not access social care as much as other communities do, because there are huge barriers to do with trust and language.

In care homes, is the food culturally appropriate? Do staff speak the right language? Some people say, "You can get translators in", but care homes do not get a translator in at 3 o'clock in the morning when someone has had a fall. Three-way translation calls are really difficult, and if the person is elderly, it becomes even more difficult to track what is going on.

We found it profound that, when we were doing one of our engagement sessions around the older people strategy, a lady who cared for her dad said that she knew that she would eventually require other support because of medical needs, but she had no idea where she would go to get that.

We have to take a step back and realise that, for groups in society to get equitable outcomes, they need different support. One of the big things is to recognise that ethnic minority communities do not access social care support in exactly the same way as others, due to issues around trust, language and institutional racism in the system. Workforce diversity is really important as well. All of that needs to be considered so that we can break down the barriers and allow people to access their right to a break.

The Convener: We must move on to the next theme that we want to discuss, which is data and information sharing. Stephanie Callaghan has questions on that.

Stephanie Callaghan (Uddingston and Bellshill) (SNP): Keeping in mind what Clare Gallagher has said, we are now going to talk about an integrated and accessible electronic social care and health record. The fact that that is a bit of a mouthful might in itself be something that we need to think about. I am also very aware of the complexities around access to such a record and its location and ownership.

My first question is for Karen Sheridan. What are the main benefits of having an electronic social care and health record? I am also interested in how we would make it accessible for people with learning disabilities or literacy issues and people whose first language is not English. Clare Gallagher might want to comment on that as well.

Karen Sheridan: An integrated health and care record is one of the things that we would really welcome. In the past, we have experienced real gaps in people's life stories. How do we know how to support somebody really well? It is really difficult to do that without knowing their background or their life story.

We have also seen circumstances in which there has been deliberate withholding of information that would enable you to support somebody well. Some of that relates to stereotypes and potential stigma, such as the possibility that someone might not want to support somebody with a complex life or behavioural difficulties. However, to support somebody well, you absolutely need to know all that information. We recognise that secondary legislation will be required to enable the sharing of information across the different sectors and different parties that would need it. We need a cultural shift for people to adopt that.

The system that we have now requires an immense amount of work, time and resource. There is often a lot of duplication of effort. There might be multiple records for an individual and we need to try to distil those to ensure that the right information gets to the right people. There are real inconsistencies in how that is done across different local authorities and social work departments, so we welcome the integration of a health and social care record because, ultimately, it will enable people to be supported better because we will have full access to their information. That will allow us to build care support plans that reflect their individual needs, wishes, aspirations and outcomes and let us think about how we can support somebody to have a really good life and be an active citizen within their local community.

Accessibility will require quite a lot of work, especially for individuals who might have a learning disability. How will we present the information for them? How will their families get access to the data? That is really important. Families have told us that they would like more involvement, so how do they engage with the key support of their loved one? We will have to do a lot of work in the secondary legislation stages to ensure that the care record is accessible to individuals and to be able to present it via different communication methods with which individuals can engage.

Overall, we really welcome the integrated care record. It will not be easy to disseminate it and get broad agreement across the sector about what it should look like. We would welcome much more conversation in the co-design phase about how we ensure that we have not only the right information for individuals but that it can be shared across the multiple platforms that will be required.

Clare Gallagher: I agree with Karen Sheridan. One of the biggest things that comes to mind when you talk about integrated electronic networks is digital exclusion, which cuts across many communities in Scotland. Empowerment is important to overcome that. We need to empower people to know that they can access the record.

That is not just about telling people that they can access it via a certain link or whatever but thinking about how they can access it. I know from some of the organisations with which we work that elderly ethnic minority people specifically will simply not be able to access an electronic device. They might not have access to the equipment or have internet access and the service might not be in a designated language that they use. Those are everyday barriers that such people face, so part of what we need to do is to think about how we make the system better and address the barriers.

Sometimes, we get stuck into identifying barriers and do not think about the next step after that. That might involve identifying a nominated person. It might not be a relative; it might be the person's GP, their social worker or somebody who provides them with care through a third sector organisation. It would be someone that they trust, as trust is key to this.

We also need to empower the families that provide care—I am thinking of unpaid carers—not just tell them what information is in the record. We will need to go into communities and say, "If you want to learn about this, here is the information that is about you, this is how you access it, this is what we mean and this is the kind of information that is in it." That really is required.

I presume that this would fall under secondary legislation, but we have to empower people to ask whether it is okay that they share information across boards, such as between an NHS board and a care board. There is certain information that you obviously have to share because of safeguarding and risk assessments, but people might not want some things to be shared. I am thinking of young people who, in the past, have had care and support and who, when they transition to adult services, might not want information to be shared on an incident that they had when they were 12. That is because, when they try to get adult care, people might view that and think, "Oh, that's a bit too much trouble," and will not want to provide care for that person. Therefore, we have to ask people what information we can share. There are boundaries that we have to respect to keep them safe and to keep staff safe, but we should really be asking people about that, and that should not just involve saying, "Please tick this box if you're okay with sharing information." We should tell people what that really means.

Stephanie Callaghan: That leads me on to my next question, which is for Hannah Tweed. Should social care users have ownership of and access to a single integrated electronic care record? If they should, how could that work effectively on the ground in practical terms?

Hannah Tweed: If I may amend that suggestion, I would say that it is not just about the electronic record; it is about care records. To echo the comments about digital access, I say that any system that we design cannot exclude 20 per cent, or whatever proportion, of the population based on digital literacy, but—

Stephanie Callaghan: I think that the whole point of having an integrated and accessible record is that all the information is in the one place, but I appreciate that point.

Hannah Tweed: I just wanted to make explicit that point about access. I agree that we do not want a massive filing cabinet filled with paper.

I think that citizen control, rather than just access, should be in primary legislation. We have heard that from across our membership, so I am speaking more broadly. Specifically, that means the right to state who has graduated access, as Clare Gallagher outlined. Maybe your physio needs information on your day-to-day personal care needs, but they probably do not need to know that you had postnatal depression 20 years ago or that kind of detail.

In practice, that means ensuring that provision is made in secondary legislation for the training of individuals to access and control data about themselves and ensuring the empowerment and training of all sorts of people who provide social care, including unpaid carers as well as people in the third sector, independent providers and local authority and health and social care partnership providers.

My understanding of the legislation is that, at the moment, there is no explicit engagement with who in the third sector has the right to access information. It will be really important to tailor that right to ensure that it applies to as broad a range of people as the citizen in question is happy to have access. That also needs to explicitly include guardianship situations.

Mhairi Wylie: I support everything that has been said, but we need to inject a degree of pragmatism into the discussion. The individuals who are probably most likely to be disadvantaged by the open sharing of information and the disclosures that they are likely to have made—

particularly those relating to complex backgrounds and multiple adverse childhood experiences—are the sort of individuals who we see in services that we run, and they are least likely to exercise any of the rights that we have discussed. Frankly, training will not do anything at all in that respect.

We therefore need to ensure that safeguards are in place so that we do not disenfranchise those who are the most vulnerable to what is potentially being put in place. That will require more than independent advocacy; it will require real consideration about helping individuals who have potentially become institutionalised as a result of being in care as a young person and an adult and who possibly have gone through prison multiple times—frankly, they have just had intensive public sector involvement in their lives. For such people, it has become a social norm to share everything about themselves. A wee bit of thought needs to be given to how we protect those who are most vulnerable in the circumstances. For those who have capacity and agency to undertake that, they absolutely should do it, but not everybody is on the same footing, and that needs to be recognised somewhere.

Gillian Mackay (Central Scotland) (Green): What challenges currently face social care users and carers when making complaints, and how could those challenges be addressed by the bill? Are there any ways in which you would like the complaints handling provisions of the bill to be altered and/or strengthened and, if so, for what reasons? I see that Mhairi Wylie is nodding, so I ask her to answer first.

15:30

Mhairi Wylie: One of the things that comes back reasonably regularly from forum discussions with service providers and people who support individuals who make complaints is that, more often than not, it is about differentiating the system, the structures and the institution from the individual in front of them. People often feel very protective of the individuals who directly support them, but it is still not okay for a carer to turn up to put somebody to bed well before 6 or 7 o'clock at night, for example. People are frustrated that, if they complain, it will seem as though they are criticising an individual, so we have to try to differentiate between the two.

Another element relates to where complaints are handled and processed. I have no doubt that many of us will have experience of raising concerns about things that have happened within the system. In my experience, the knee-jerk reaction to that is defensiveness; people have not been open or willing to explore. I could give multiple examples of that, but I will not give them in a public committee meeting.

We need a more independent pathway, and we need more independence in investigating what has happened. That should be a primary tier, not a secondary tier, in the complaints process. We need to encourage individuals to tell us when something is not working right. The word "complaint" is part of the barrier, but we should encourage people to raise issues and say, "I don't like this. Could we change it? That is not a complaint against Sandra, who comes in to help me. I like her, but I don't like what is happening around that." Does that make sense?

Gillian Mackay: Yes.

Hannah Tweed: I second, and will build on, what Mhairi Wylie has said. We should explicitly prioritise improvement processes. That links to the point about language. We should have a system that enables staff to put forward proposals and raise concerns, because such a system is not consistently in place at the moment, and that compounds the issues. That would be part of a co-production approach, because it would enable as many people as possible to provide constructive input throughout the life of a system.

Another important element that I want to flag up is that, in many cases, under the current complaints system, if someone passes away, that is it—the job is done and the complaint does not go any further. That is a real problem, because it means that there is not the capacity to follow up on concerns that have been raised in relation to palliative and end-of-life care. For example, somebody might have passed away while a complaints process was lumbering along, and the person's family might not have the same right to follow through with the complaint. To be blunt, that means that learning is lost. Any system needs to be flexible enough to accommodate that, while respecting the general data protection regulation and everything else.

Clare Gallagher: I agree with Mhairi Wylie and Hannah Tweed. I will build on what has been said. Often, if people complain more than once, or even if they say, "I don't like this", as Mhairi Wylie said, they get tarnished and are thought of as a complainer, and their standard of service then changes, usually to their detriment. That is a real fear, especially among people who receive self-directed support. They are afraid to say, "I don't like this", in case more money is pulled away from them.

People do not want to complain about the individual who provides the care; it is the system that they have a problem with. There needs to be a change in language. People want to complain about the system but, if the system does not allow them to complain, there is nowhere else for them to go, so they become disenfranchised.

It is also really difficult to make a complaint. People do not know where to go. They get told to phone one number, but then they are switched to another number. The system is not accessible.

We need to consider that, when someone makes a complaint, information gets shared. If someone phones up to make a complaint, a note might get lodged for somebody to follow up on. We need to consider people’s microaggressions and unconscious biases, as well as institutional racism, because those little notes and comments can affect how the next person reacts. As well as having processes in place, what is in place to ensure that those on the front line who receive complaints are aware of such issues for people?

The Convener: That is helpful.

Don Williamson: It goes back to the importance of independent advocacy. The bill states that ministers “may” bring forward regulations to ensure that people who use national care services have access to independent advocacy, but on that sort of issue, it is particularly important that people can access that advocacy.

Gillian Mackay: I will follow that up. How do we ensure that the complaints process is transparent and accessible for everyone? Clare Gallagher summed things up very well. Due to the number of different providers and where, when and through whom you can complain to those different providers, there is a complete spider’s web of issues, especially for service users whose first language is not English or who have other access issues. How can we ensure that any national-level process takes account of geographic variability and who the providers are, as well as access issues, to ensure that the complaints system is fit for purpose? How can we ensure that information about how to access and navigate through the process is well advertised, so that someone who does not want to take up independent advocacy or who does not have someone to advocate for them can still navigate it in their own way and in their own time?

Clare Gallagher: In order to be transparent for someone who is not, in the first instance, going down the independent advocacy route, the information about how to access the complaints process needs to be available in easy-read text and in different languages. However, there is also something to be said for breaking down those barriers. Some people feel, “I should be grateful enough that I get anything”, so they do not want to complain about things, and that can be especially the case for elderly people. Within ethnic minority communities, there is also an institutionalised feeling that comes from having been told for generations that they are a burden on the state. We saw that in some of the work that we did with Social Security Scotland about accessing benefits. It is the same for social care.

We need to change the mindset so that people understand that they have the right to receive care but also the right to ensure that they like that care. Perhaps it needs to be framed in that way rather than as a complaint, because a complaint is usually negative. It is not usually personal to the person concerned, although sometimes it is personal and someone might want to complain about the person who delivered the care to them. However, we need to break down that barrier so that people understand that they have a right to complain.

It might be a case of going into communities and reminding people that that process is available as we provide that support. There are people who are better placed than me to say that, because the people who provide the care and the people who receive the care should be at the heart of that process.

Mhairi Wylie: I was smiling because Clare Gallagher mentioned Social Security Scotland. The committee could learn a lot on how to get the balance right and have a footprint in local communities from the way in which Social Security Scotland is rolling out its engagement process locally. We have asked Social Security Scotland to come back in a couple of years’ time—I am sure that we will have some complaints by then—but right now, everything that it is doing is really encouraging and we are getting incredible feedback from different areas. Therefore, if the committee is looking at how to take that forward, I encourage you to look no further than Social Security Scotland.

The Convener: That is really good feedback for us to hear.

Hannah Tweed: I will make the connected point that, although we have talked a lot about what is not working, learning is also going on in parts of the country about complaints being dealt with well. One of my colleagues did a bit of work assessing what complaints information is available publicly on local authorities’ websites. Some of them provide very clear information, such as, “This is who will contact you; this is the timeline,” and so on. Even on a very basic level, it is helpful to know what your expectations should be. The website might provide information on whether services can be provided through British Sign Language. Glasgow City Council provides community language information. It is not absolutely everything, but it is a step in the right direction. It is difficult to overstate the importance of that communications work.

I would twin that with the need to have proactive working with local community groups that have built up trust and that can address the concerns that Clare Gallagher has raised. Putting the basics out there is really powerful. I know that some colleagues in social work have that as part of the standard information pack that they give out on every assessment visit to individuals in the community. It includes information about the local independent advocacy organisation and about how to raise concerns—I think that that is the language that is used in the one that I am thinking about.

That is an example of good practice. Not everything is awful. There are plenty of problems, but you can draw on and use the good practice as you move forward.

Paul O'Kane: I suppose that when the Scottish Public Services Ombudsman was before the committee she would have raised concerns about duplication of processes, if we had gone for a new national complaints procedure. The Scottish Social Services Council and the Care Inspectorate would probably say similar things.

Would the intention be that there would be a requirement to resource a new national complaints service—in essence, to spend money at national level on people to handle complaints, do an investigation and then feed back to whoever was providing the care? Is that the vision that has come through the consultation?

I know that Community Integrated Care said that there was concern that taking the complaints process out of the local context is perhaps not helpful. If there is time, perhaps Karen Sheridan might want to comment on that.

The Convener: I will go to the witnesses who are in the room before we go to Karen.

Mhairi Wylie: [*Inaudible*.]—support service. I have not kept up to date with that, but it was an independent process through which someone could raise a concern, although not necessarily a complaint. I suppose that there are two or three things in that. From the feedback that our members have given on the bill, my impression is that they would prefer an independent process that links straight to the Government, because that is the avenue through which they see an ability to hold it to account, to some extent. However, on a practical level, there is something in ensuring that there is a local aspect to such a process and that, rather than setting up a new service, there is an opportunity to commission on a local basis, with the concept of independence at the first stage, which is not necessarily about creating a new bureaucratic process. Looking at examples around the patient advice and support service—PASS—might be an option.

The Convener: Paul O'Kane, will you re-emphasise what your point was? You wanted to ask Karen Sheridan a question but she might not have caught it all.

Paul O'Kane: Sure. We were talking about the complaints system, and I had noticed that Community Integrated Care said in its submission that responding to a complaint as close as possible to where the issue has occurred, at the local level, is important—I am paraphrasing, obviously. Does Karen Sheridan have a comment on the importance of locality in the complaints procedure?

Karen Sheridan: When we spoke about the complaints process with some of the people who use our services and their families and carers, there was a strong feeling that there should still be a localised element to it, especially when things can be done very quickly by engaging with the provider, the local authority and the Care Inspectorate. In the conversations that people have when they make a complaint, they want to ensure that they are being heard and they want it to be an easy process. There was a feeling that that happens better when they can speak to somebody local who perhaps knows them and their family and who knows the community in which they live.

There still needs to be a process for when somebody wants to challenge a decision or when somebody feels that they have not been heard. For more serious complaints that cannot be resolved, there is a need for a more nationalised structure. However, on the need for a local response—which the people we have worked with would certainly like—another thing that is key is ensuring that people have help and support to make a complaint. Don Williamson has already touched on advocacy. Another key issue is how people access advocacy to help them to make complaints and how to ensure that support for individuals is available in different accessible formats. The people we spoke to made a clear request still to be able to raise their concerns locally in order to get a speedy response.

15:45

The Convener: We have 10 minutes left for our final theme. I know that we have talked a lot about co-design throughout the session, but Paul O'Kane and Evelyn Tweed have specific questions on the matter.

Paul O'Kane: Thank you, convener, and thanks to the panel for indulging me again.

Co-design is to be at the heart of the process, and, as we understand it, there will be an element of co-design in, if you like, the secondary stages of the bill. Do you feel that that was the right way to go about this, or would you rather have seen more co-design at the front end, before we reached the legislative stage?

Clare Gallagher: There is a lot to be learned from the co-design processes and experiences that we have had so far on the bill. We can take that learning away and improve on it, because there was a lot of unhappiness with and a lot of exclusions from the process. Co-design should always happen at the start of the process; otherwise, you have to fit people's needs and wants into your own framework, and that sort of thing should never be retrospective.

I always say that co-design is like dotting the i's and crossing the t's. With something like the national care service, you need a diverse workforce that includes those who provide support, those who take a more strategic approach, those who will be involved in the proposed care boards and so on. They should not be pulled from the same talent pool. As we know, the social services workforce is not diverse, and that really needs to be taken into consideration.

That said, although co-design is important—I would never say that it was not—you then face having to make something out of a process that you have spent lots of time and money on. Therefore, co-design should happen first and foremost in the initial stages of the process.

Don Williamson: I agree. I also think that co-design should be on the face of the bill, because there appears to be quite a disconnect between the language in the policy memorandum and the language in the bill, which talks about consultation rather than co-design. Indeed, in some cases, it refers to consultation after a draft strategy has already been produced, which does not strike me as proper co-design. I would prefer to see what it will mean in practice set out clearly in the primary legislation.

The Convener: Did you want to comment, Hannah?

Hannah Tweed: I reiterate my point about threading it through the legislation and ensuring that people are included not just in a consultation process but in the decision making. I know that I have made the point already, but I am flagging it up again.

The Convener: It bears repeating. Paul, do you have any more questions before I hand over to Evelyn Tweed?

Paul O'Kane: No, convener, I will let Evelyn come in.

The Convener: That was not a hint. [*Laughter*.]

Evelyn Tweed (Stirling) (SNP): I am keen that we move forward with a co-design process in which everyone feels included and feels that they have a say, but we have caught the general drift that you do not really know what that process looks like just now. Given that, how can we ensure that we include and are listening to rural and remote areas? Mhairi Wylie talked earlier about the challenges with such a huge area; what does good co-design look like for you?

Mhairi Wylie: It should start with putting things on an even footing. Whether we are talking about the development of the legislation or about the governance processes that come after, we need to give serious thought to the question of where the capacity for the co-design will come from. That might mean involving individuals who have some form of barrier to participation. In remote and rural areas, that might be about transport but it might also be about their being an unpaid carer, their having a part-time job and so on.

The question, therefore, is: how do we remove those barriers from social care providers? If you are already incredibly short staffed, how can you possibly travel to, say, Inverness to do that work? The third sector is already running at zero capacity to do anything, and, if we are talking about participating on an even footing, the fact is that we are already at a significant disadvantage compared with individuals who might be coming from a committee with clerks, who have other background support and so on.

Truthfully, we need to see investment in the capacity of all of the audiences that we want to see participating in co-design. We need to ensure that we are clear about people's sense that they are achieving something. I have participated in a number of exercises and—particularly in relation to things such as policy development, pieces of legislation, changing elements of practice or system change—it can be difficult to see evidence that you have achieved something. If you cannot see that evidence, your interest in participating lessens, because you cannot see the pathways to the difference that you might be making. When all the other pressures of your work life and home life press in on you, it becomes difficult to justify the time, energy, travel and costs that are involved in participating. The costs of co-design are often hidden—the cost of going somewhere, the cost of giving up a piece of work or the cost of getting someone to do the work that you should be doing.

As I said, we need to think about resourcing people's capacity. I do not think that moving everything to a digital platform is the solution to that.

Hannah Tweed: There is a lot to be learned from groups such as the people-led policy panel in terms of its longevity and the empowering of people to engage, as well as the proper financing and resourcing.

Feedback loops are also important. I know from talking to colleagues in the civil service that a huge amount of good work is going on at the moment, but there is not necessarily transparency around what has happened, who has been involved and why certain individuals have been chosen. That also speaks to the issue of public trust.

I am not asking for anonymity to be breached, because there are general data protection regulation and ethical issues involved in that, but the idea of public transparency is important, and a "You said and we did" approach must be part of any process.

Clare Gallagher: I want to expand on what Mhairi Wylie and Hannah Tweed have said. If you are creating a co-design service that people can get involved with, you need to use a human rights-based approach and the participation, accountability, non-discrimination, empowerment and legality—PANEL—principles, which are endorsed by the United Nations and the Scottish Human Rights Commission. That framework should take you through a process that will ensure that you are inclusive and that you are breaking down barriers as much as you can.

Using a human rights-based approach is important because it captures intersectionality, which can often be left out in co-design—people choose one person because they have a disability and another person because they are from an ethnic minority background, but what about the person from an ethnic minority background who has a disability and whose experiences will be entirely different from those of the other people I mentioned? A human rights-based approach avoids that becoming an issue because it focuses on the human being and not on the protected characteristic.

A human rights-based approach also delivers empowerment, which Mhairi Wylie talked about, as people are updated on what is happening at every stage of the process—they are told what information has been collected, that it has been shared with the committee, that certain actions will be taken, that certain recommendations have been made and what the implementation will look like. If that does not happen, people feel that they have not achieved anything and they might become apathetic and never participate again because, for instance, they might feel that they disclosed some difficult things about their care experience but were not even told what happened to that information or what it was used for.

That comes back to valuing people and their time. We talk about valuing lived experience, but we do not really value it, because, often, we do not value people's time. We might cover someone's transport costs, but what if they have to take a day off work or pay for another family member to get a bus over to their house to look after the person they care for? If we really value lived experience, we should pay for access to it, just as we would pay for access to the experience of someone else whom you might want to come to speak to you.

The Convener: That is a great note to end on. We could speak to you for longer but we have run out of time and we need to bring in our second panel. Thank you all for your time; it has been extremely helpful.

We will suspend the meeting to allow the panels to change over.

15:54

Meeting suspended.

16:07

On resuming—

The Convener: We come to our second evidence session on the National Care Service (Scotland) Bill. I am delighted to welcome our witnesses. In person, we have Frank McKillop, who is head of policy and research for Enable Scotland, and Andy Miller, who is strategic lead for participation and practice lead for the Scottish Commission for People with Learning Disabilities. Online, we have Dr Caroline Gould, who is a trustee and access auditor for the Skye and Lochalsh access panel; Dr Pauline Nolan, who is head of leadership and civic participation for Inclusion Scotland; and Rhona Willder, who is development manager for the Scottish Independent Advocacy Alliance.

I will put the first question to the witnesses—I guess that I do that every time and I did it with the first panel. How do you feel that the bill could be strengthened? I will go round everyone. Not every committee colleague will have the luxury of going round everyone, because we do not have time, but I will take convener's privilege in that regard to start things off. I will go to Frank McKillop first.

Frank McKillop (Enable Scotland): I thank the committee for inviting us to participate.

We feel that a reference to self-directed support is missing. It might be an accident rather than on purpose, but we were quite surprised not to see that written into the bill. There are references to person-centred support. We often find that those are used as interchangeable terms, and wrongly so.

We would like self-directedness to be at the heart of the bill. That is particularly important if we are going to achieve human rights for people who access care services, which is rightly and nobly a high priority for the national care service.

Therefore, we would like the right to self-directed support to be written into the bill.

The second priority that we would like to see written in is the community-first principle for social care: that the priority at all times is to enable people to have support within the community where they want to live and that someone will have institutional or congregate living arrangements only because they have chosen to live with other people or in a particular building-based service. The learning from the pandemic has led us towards the view that there should always be a community-first principle. A number of local authorities are increasingly thinking about delivering as much care as possible within community settings. Enable supports that principle and would like it to be in the bill.

The other priority that would be an important addition to the bill is the principle that care will be free at the point of use. In the wider national care service project, the Scottish Government says that it wants to achieve that, but it is not written into the bill.

Whenever we have events at Enable with our members—people who have learning disabilities, people who access care services and their family members and carers—they always ask, “Will care and support be free?”. We can give a beautiful slide presentation about the National Care Service (Scotland) Bill, but the first question is always that one. At the moment, we cannot say that they definitely will be free. We hope that the direction of travel is towards that, but that is the understanding.

Obviously, the phrase “national care service” echoes “national health service”, which I think is deliberate. It is important to remember that when people who are not like me—those who are not involved in all the policy and in the weeds of what is in the bill—hear “national care service”, their immediate assumption is that it means that care and support are free when they need it, just like NHS care is. We have to ensure that the legislation gets us to the place where we can meet those expectations.

Andy Miller (Scottish Commission for People with Learning Disabilities): Thank you for inviting us to the committee. We are pleased to be here. I hope that it will not be a boring afternoon for you in which I just repeat everything that Frank said, but we echo a lot of the points that he made.

The lack of a reference to self-directed support is a big miss. We did not really understand why it was missed out, because it is such an important part of social care. It is the mechanism by which social care should work well, and Derek Feeley spent a lot of time considering how it could be put right. Therefore, it was a bit mystifying for it to be missed out.

I will make a general point about what would make the bill better. There is a lack of detail. The Feeley report gave people so much optimism and hope about a transformation in social care. What is missing from the bill is any detail about how the new structure, about which there is a fair amount of detail, would bring about all the great outcomes that Feeley mentioned.

It was not just outcomes that Feeley talked about; he talked about some specific things that Frank McKillop mentioned: support being free at the point of use and the breaking down of the binary system that eligibility criteria create. People are assessed as being eligible or not and, if they are assessed as not being eligible, in essence they get nothing. Feeley’s vision was for some kind of spectrum of support, in which whatever someone’s needs are for support, they are eligible for that level of support. There is nothing in the bill that shows how that can be brought about.

Fundamentally, the principles in the bill are fantastic. We totally support them, but the bill does not have detail about how they will be brought about. Our big fear is that the focus of the bill is the structure of the new service and, in the way that it has been presented, there is a dislocation between those terrific aspirational principles and the structure that has been laid out. We have been left feeling that if that structure is put into place, it will not deliver the outcomes that Feeley talked about and that are aspired to in the principles.

I am not sure whether this is covered in your question, convener, but the financial memorandum is also disappointing and reinforces the fear that the bill will deliver a structure but none of the vision that Feeley hoped for.

The Convener: That might be because a lot of the detail that you are looking for will come after the co-design process. Do you recognise that that is the vehicle? Because it was successful with the Social Security (Scotland) Act 2018, the co-design will inform the secondary legislation. Do you feel that there must be more detail ahead of that co-design?

16:15

Andy Miller: We really hope that that will be the case. It is clear that it is being promised that the detail will come in secondary legislation, which is fine.

We are not sure whether more finance will come with the secondary legislation. However, many big-ticket items that would be fundamental to the success of the new social care service were specifically excluded from the financial memorandum.

The Convener: That is helpful. We will, of course, have the minister in front of us just before we break for Christmas, so we will be able to put all those questions to him.

I want to go to those who are joining us online. Can Caroline Gould come in?

Dr Caroline Gould (Skye and Lochalsh Access Panel): Thank you. I would have liked to have been at the meeting in person, but no one seemed to consider asking about my needs as a disabled person who uses a large powered wheelchair, who needs to employ carers, and who has an unpaid carer and is also an unpaid carer, or about the time that is required to enable what needs to be put in place to be put in place to support me to get there, to be there, and to stay overnight. Initially, that disappoints me completely, given what we are here to talk about today.

Although I like some of the principles in the bill, I am concerned about what we are referring to when we say "human rights". Are we referring to the possible future human rights (Scotland) bill or are we talking about current human rights? Where does the United Nations Convention on the Rights of Persons with Disabilities come into that?

I feel that, in the processes in which I have been involved through the social covenant steering group and the people-led policy panel, for example, there has been almost a constant fight for disabled people, the disabled people whom I represent and their unpaid and paid carers to be heard in any real way.

When we talk about going to stage 2, I wonder what will happen beforehand. What happened first was that the consultation was formed without the input of disabled people. The consultation results proved that that was a mistake. As disabled people, we are now almost being asked to run before we can walk to keep up, because the process has started and it is simply going to run over us if we cannot keep up. However, I am not seeing a huge amount being done to allow us to keep up or to be on a level playing field with others.

I seriously question whether you really want our views. I am sorry to have to say this, but although I have been pleased with the people-led policy panel and the social covenant steering group is improving, there are a lot of things that people do not necessarily realise. In a remote rural area such as Skye and Lochalsh, when a person pays a carer so much for an hour, they might get them for 11 minutes at most before they have to drive another 45 miles to somebody else. All those long distances mean that it is not easy for them to come back, as nobody pays for their fuel.

I think that the person-centred approach is completely wrong. I am told that being person centred should mean being centred on the needs of the person who needs care, but in my area and that of other people in Skye and Lochalsh, we find that being person centred means a load of social workers and integrated team members in a room talking about us. That is often overheard, and a person will be told in the local supermarket car park what was said about them, as their confidentiality has been breached. However, people are not told at any point what has been discussed about them as the centred person—the person for whom the decisions are being made. That has to change drastically.

I would certainly like to see much more in the bill in relation to SDS and more reference to it. I am also very concerned about access to notes, particularly in a remote rural area. In particular, that is because 60 per cent of disabled people are unable to access or use digital technology.

Why should they be forced to use a method that clearly does not work for them? We have seen that throughout the pandemic. Disabled people tell us that they feel even worse than second-class citizens, which is what they would have called themselves before the pandemic. Disabled people, people with long-term illnesses and their unpaid carers need to be included, because, as I discovered recently when I went into hospital to visit my husband, it is all too easy for staff to say, "Oh, great! You're his wife. That's the unpaid carer—we can send him home now." I cannot get my own care needs fulfilled, let alone fulfil my husband's. My husband resigned as my unpaid carer six years ago and that is still being ignored by the NHS.

That is what it is like to be in a remote rural area. You do not know how many calls I get from people who tell me that their neighbour came to hospital to visit them and, because the hospital did not want them to be blocking a bed, the neighbour was asked whether they could do such and such for them. When the neighbour said, "Yeah—I could do that once in a while," they suddenly became the person's unpaid carer. There is none of the formality that should be there. There is no independent advocacy for people when they need it. There are not enough people doing it—there are not enough carers—and the distances involved do not seem to be understood at all by people in cities, who are mainly the decision makers.

I would like there to be a lot more understanding of such issues. Having your rights under the Human Rights Act 1998 fulfilled means not having a social worker or someone such as a doctor constantly coming into your house. You want to be able to go and see them and have a meeting with them, as you would normally. Instead, you are told, "No, we can't do that, because there isn't somewhere where your wheelchair can get in or where you can go to the toilet." That includes our brand-new Broadford hospital, which opened only in March this year. More and more, people are being forced back into their homes in a way that they do not want to be and are having their privacy invaded. Remote rural living has to come a lot more to the fore here, and understanding of it must be shown because, so far, that is not happening.

The Convener: Thank you. My colleagues will want to come in on a lot of the detail of what you have said. We will come back to many of the issues that you have brought up.

Dr Pauline Nolan (Inclusion Scotland): Thank you for inviting Inclusion Scotland and for inviting me to speak on behalf of Inclusion Scotland and the people-led policy panel that we support, which is a group of disabled people—supported people—and unpaid carers who need social care support, who are co-designing and co-producing social care support. We will come back to that.

I will elaborate on some of what my colleagues have said about the things that we think are probably missing from the bill. Article 19 of the UN Convention on the Rights of Persons with Disabilities explains how support should be given to disabled people. It explains that that support should be in the community, away from institutions, and that independent living means having choice, control, dignity and respect; it does not mean looking after yourself or fending for yourself, which it could be misconstrued as meaning. It means having the supports that you need to have that right upheld.

The right to independent living is a really important enabling right that is connected to a number of other rights in the convention, such as the right to travel and transport, the right to employment, the right to involvement in the community, the right to participate and to uphold your civic rights, and rights to family life and so on. Therefore, the right to independent living is extremely important.

As colleagues have said, self-directed support is not mentioned in the bill. That is a massive omission. However, the independent living rights are laid out in the Social Care (Self-directed Support) (Scotland) Act 2013. We consider that to be really important.

Another thing that is missing is any mention of charges, as colleagues have said. I know that work is going on in the background to remove charges, but I do not think that that is as far on as it could or should be, which is a little concerning. I agree that social care support should be free at the point of delivery.

Something else that is missing is housing, which has always come up when we have consulted over the years. We consulted on social care support when the Public Bodies (Joint Working) (Scotland) Act 2014 came in and found that people wanted to connect it to housing, because a lot of support is received in housing. I realise that that is a complex area, but it could be looked at in the future.

Carrying out equality and human rights impact assessments is missing. The financial memorandum does not mention how different types of advocacy will be funded. We want to give a big shout-out to centres for inclusive living and other disabled people's organisations that provide the initial support for people to access social care support independently, and provide peer support and advice from other disabled people who have been in the system. That could be in the financial memorandum. It should be an on-going investment.

My colleague Hannah Tweed from the ALLIANCE mentioned the issue with the care boards. The bill talks about co-designing what the care boards will look like, but it does not talk about how that co-design will be an on-going feature of the care boards. The fact that participation is not included in what the bill says about governance is a real omission. It should really be in the bill as part of a human rights-based approach, because the first letter in the PANEL principles stands for "participation".

Amendments could be made to that—

The Convener: Okay. There will be ample opportunity throughout the session for you to make quite a lot of your points.

I will go to Rhona Willder and then I will hand over to my colleague Gillian Mackay.

Rhona Willder (Scottish Independent Advocacy Alliance): Thank you for inviting me to represent independent advocacy and our membership. We are particularly pleased to see independent advocacy mentioned in the bill, although, as one of my colleagues on the first panel mentioned, section 13 says:

> "The Scottish Ministers may by regulations make provision about ... independent advocacy".

We feel that that does not have any teeth, and that framework legislation in this form means that it is unclear how independent advocacy will work in practice.

We have three particular concerns around that. First, there is not currently a definition of "independent advocacy" in the bill; secondly, the right of access to independent advocacy is not in the bill; and, thirdly, there is no duty to provide independent advocacy. We are concerned that all of that will fall to secondary legislation, which would narrow scrutiny.

We know from other legislation that how independent advocacy sits in primary legislation is key to how it is accessed by people in practice. For example, the Mental Health (Care and Treatment) (Scotland) Act 2003 includes the right of access to independent advocacy, meaning that people who find themselves subject to the 2003 act can access independent advocacy better than they can when they are subject to other pieces of legislation in which there is neither the right of access to independent advocacy nor the duty to provide it. Having the right to independent advocacy clearly stated in primary legislation is incredibly important to how independent advocacy operates in practice.

We have several other concerns, but, from an initial look at the bill, that is what we are most concerned about.

The Convener: Thank you all for setting out your stalls—that is why I always go round the whole panel. Colleagues, I remind you that you do not have that luxury; it would be hugely helpful if you could direct your questions to individual witnesses.

Gillian Mackay: My first question is for Rhona Willder. Should a single organisation such as Citizens Advice Scotland be appointed to provide or co-ordinate the provision of advocacy, or do you see that happening in a different way under the bill?

Rhona Willder: Advice and independent advocacy are different services, which are mutually supportive but separate. Under the SIAA definition, which is agreed by our members across Scotland, people who access independent advocacy should not be put under pressure to receive any undue advice from their independent advocates.

Independent advocates are there to help people to access information and understand their rights and to gather their views. They then help those whom they work with, which could include people in the national care service, to understand those views and opinions and what the person wants to happen. They are never there to provide advice.

16:30

We hope that independent advocacy will be provided at the local level, although it could be procured nationally. With a national procurement model, the conflict of interests that often arises locally when services are procured through health and social care partnerships would not be so apparent. However, we would like independent advocacy to continue to be provided locally. We feel that it is very important for it to be rooted in communities. Our members tell us frequently that the independent advocacy that they provide is strongest when it is embedded in their local communities.

Gillian Mackay: That is great.

Dr Nolan, what are the key considerations for you in the development of a model complaints system for the proposed national care service? For the service users that you support, what do you see as the biggest barriers in a nationally structured model of complaints handling?

Dr Nolan: Many disabled people and supported people feel unheard when it comes to complaints. There was a lot of talk about this in your first session this afternoon. It is very difficult when the people that you take complaints to are the same people who will be making decisions about your social care support in the future. We absolutely have to get away from that model and move to an independent complaints system.

I echo what Rhona Willder said about advocacy. There should be a mixed economy of advocacy with national training and localised delivery, but there should be a national complaints system that is completely independent of the national care service and the providers of social care support. That is really important. It needs to be developed and co-designed from the ground up. It should not use other complaints systems as a basis.

Our people-led policy panel members said that we need a co-designed approach because social care support is so unique. One of them said that they phoned up to complain about a service and they were told, “Why are you complaining? Can’t you say something positive?” That is why it needs to be separate; feedback is separate from complaints and that is an important distinction.

Will you repeat your question, please? I was looking through my notes, because I have lots of notes here.

Gillian Mackay: I think that you have covered most of it. I asked what the key considerations are for you in the development of a model complaints system. What pitfalls must we look out for, particularly when we are considering service users?

Dr Nolan: The other thing is to consider the right to redress and what happens after a complaint is made. It is important to make sure that the complaints system is completely accessible for all disabled people and that it includes information in accessible formats about what will happen throughout the complaint because, let us face it, anybody who comes to complain about their social care support or a decision that has been made will already be extremely stressed out. The system needs to be completely accessible and use different formats and languages such as easy read and British Sign Language. It also needs to set out clearly what will happen straight away and what will happen afterwards. When there are service failures, there need to be definitive commitments about what the redress will be—that should be in the bill.

Gillian Mackay: Thank you.

James Dornan: I have a question for Rhona Willder about access to the independent advocacy service. Should that be a right for everyone who uses the NCS, or should it be restricted to certain groups such as those with a disability?

Rhona Willder: That is slightly dependent on how independent advocacy provision sits across the country. We would like independent advocacy to be accessible to everyone who uses the national care service, although specialist provision should remain for people in protected groups.

One of the recommendations in the most recent independent review of the mental health legislation is to have opt-out independent advocacy provision. To align with that, it would be useful for the bill to include an opt-out independent advocacy provision for anyone who uses the national care service. However, currently, there is a lot of specialist knowledge and independent advocacy provision for groups such as people with learning disabilities and disabled people because of the way in which independent advocacy has grown in Scotland—for example, there is a lot of specialist knowledge and an understanding of working with advocacy partners who have learning disabilities. That should not be lost if there is opt-out advocacy provision for everybody who uses the national care service.

James Dornan: I bow to the experts on this, but I suppose that part of the danger is that, if everybody has access to independent advocacy, those who need it the most might lose out. Is that a fear?

Rhona Willder: If independent advocacy was resourced sufficiently and there was a good procurement model that worked across Scotland, that would not be a concern. Because of the way in which independent advocacy is procured, there are groups that should be provided with such services that are not provided with them currently. For example, there are gaps for children and young people who should have independent advocacy under the mental health legislation but who do not receive it. That is an example of where an independent advocacy service should be provided but currently is not. Such gaps could be rectified by having a good procurement model and sufficient resources.

James Dornan: That is an opportunity for the co-production process to come into play.

Rhona Willder: Absolutely.

The Convener: We will move on to self-directed support and transitions, which a lot of people have already mentioned in their opening remarks. Emma Harper will lead on that.

Emma Harper: Good afternoon, everybody, including the folk online. I have been interested in the issue of self-directed support since the previous session of Parliament. We have heard evidence that it is not being delivered well in some places but that it is absolutely fantastic in other places. Self-directed support seems to offer people choice about the kind of care that they want.

Should there be more on self-directed support in the bill and, if so, what should the bill say? On pages 20 and 21, the bill refers to modifying the self-directed support legislation. What are your thoughts on self-directed support, and should there be more on that in the bill?

The Convener: Would you like anyone in particular to go first, Emma?

Emma Harper: Not really—whoever is the self-directed support expert.

The Convener: I will go to Dr Gould first.

Dr Gould: I am not an expert on SDS, but I am in receipt of it and I deal with a lot of people who also receive it.

The main problem for us in a remote rural area is finding enough carers. They are not being recruited, they are not paid well enough, they are not being retained, and some are given short-term six-month or one-year contracts. If a carer moves to the area, their spouse or partner must also find a job, they have to find a home to live in and they might have to find childcare. All those things prevent there being enough carers to enable the provision of SDS.

There are no agencies that people can go to, because many of them have closed over the past 10 years or so. People must do all the hard work, because the NHS does not tell them where they can get carers locally, unless they use care-at-home services, which are already oversubscribed and therefore not readily available.

We have people in our area who had independent care reviews way back in early 2018 who were told that their care needs had never been assessed properly and that that needed to be done now by someone with an understanding of their condition and how it affects them. We are almost at the end of 2022, yet that still has not happened. The whole system is failing in many ways.

The Convener: Frank McKillop, as you were the first to mention self-directed support, we will come back to you.

Frank McKillop: As I said, self-directed support must be at the heart of the care model that is developed and delivered through a national care system to a consistent standard across Scotland.

As we see it, the sign above the door says the right thing, but when people go through the door, they do not get what they expect. That has been the experience of a lot of people. The SDS legislation that is in place is excellent; it is fantastic. However, that is not being realised.

The first challenge is with option 1 of SDS, in which people get a direct payment and, in effect, employ personal assistants. A lot of people find that off-putting, frankly, because they must become small businesses, employ staff and go through all the related processes and back-office things that must be done in that regard.

We are aware that a lot of people who would like to have that level of choice and control around their support are put off from choosing that option. Enable's PA model gives people the flexibility and control that option 1 provides but via option 2, with Enable taking on all the responsibilities as the employer and everything else that goes with that, including human resource law, finance and payroll.

Our recruitment team advertises for personal assistants, but the individual tells us what they are looking for, they interview the candidates who are put forward and they choose their staff. We have developed our PA model so that people who might not have had the confidence to progress option 1 without the support of a large organisation with resources can experience that option.

Our model is one of a number of models. As a charity, we developed that solution to reflect what our members and people across Scotland were telling us they were looking for.

We must find solutions like that. From our perspective, the Social Care (Self-directed Support) (Scotland) Act 2013 is great. The sign above the door that I referred to is the 2013 act. Perhaps the national care service legislation can fill out the foundations to make that a reality for everyone who wants to access SDS, with that becoming the core model for social care in Scotland.

Dr Nolan: Derek Feeley's independent review of adult social care illustrated clearly the implementation gap. We have pockets of good practice across the country, and the Convention of Scottish Local Authorities has said that we should not use a sledgehammer to crack a nut. However, although we have a great policy, the issue is delivery, which is why we refer to there being a postcode lottery.

It is not just between local authorities or partnerships—say, in remote and rural areas—that a person's choices and control with regard to self-directed support can be limited; it can happen within a local authority area itself. There are areas where you can access good support, get the right information and so on, and there are others where you will not get even that information.

16:45

Public Health Scotland estimates that four out of five people are involved in choosing and controlling their support via various options, but I note that, in a report from 2020 by the ALLIANCE and Self Directed Support Scotland, 50 per cent of respondents said that they did not have access to all the self-directed support options—the four options had not been explained to them properly, they were not given proper guidance and so on. We are talking about the very first hurdle in accessing social care support. If you do not have that information, you do not have choice or control, and that is the right that is written into the 2013 act.

Emma Harper: I heard this morning from two young people in receipt of self-directed support, but that was not the language that they used to describe it. In fact, they did not know that that was what they were receiving. Is it important for people to understand what is being delivered as long as the necessary care is delivered? Does the language matter?

This might not be a matter for the primary legislation, but I note that, when we were in Dumfries, a care home owner told us that people in care homes did not get self-directed support, even though they were in their own home. Given that other folk get it in their homes, why do care home residents not get such support, too? That might be a question for down the line, but is it relevant to what should be in the primary legislation in order to pin down what such support is all about?

The Convener: I remind the witnesses that, if anyone wants to come in on a specific question as they hear it being asked, those who are online should put an R in the chat box and those here in front of us should indicate as much—as Andy Miller has helpfully done.

Andy Miller: There have been a lot of reports over the years on how well or otherwise SDS has been doing, and a number of difficulties have been identified, with inconsistency clearly being part of the picture. Option 2 has not been mentioned an awful lot—Frank McKillop referred to it when he talked about the Enable model—but when SDS does not work well, it is often because of low uptake of option 2. The option gives people a lot of control, but it does not place as much responsibility on them as option 1—which involves a direct payment—would. Part of the answer, therefore, is to facilitate uptake of option 2.

Partnerships often do not offer option 2, simply because it is too difficult or because of a lack of resources. When I say that it is too difficult, I do not mean that it is too difficult for people to get their heads around; I just mean that the easiest course is either option 1, in which you simply hand over the budget and responsibility to individuals or their families, or option 3, which is, in essence, the status quo. A big part of the answer would be to restructure or rework option 2. I support Enable's excellent model, which makes option 2 easier for everyone to get their head around.

Option 3—the status quo—does not mean that there would be a bad service, although that is often taken to be the meaning. Option 3 is the majority option across most parts of Scotland.

If people are saying that they would like the health and social care partnership to deliver the support that they need, that could be a positive option, so the new national care service needs to consider the basics around how to deliver a good service. One of the key things that people have said would make a huge difference is for a no-wrong-door approach to be taken. Many folk have talked about how difficult it is to navigate the system or even to get into the system in the first place, whether that happens in a transition period or later in life, as an adult. If there was a no-wrong-door approach, it would not matter who lifted the phone or who was on reception when someone first made an approach, because whoever it was would take it on themselves to do the heavy lifting and the navigating for that person and to ensure that they were seen by the right person, were assessed appropriately and received all the support that they were entitled to. That would be a major improvement. I do not know whether that requires secondary legislation, but it is one of the biggest improvements that we could make.

Dr Gould: In remote rural areas, there is a tendency for people to know other people's business, and quite a few people want to know everybody's business. A lot of disabled people tell us that they believe that SDS option 1 is their best option. When we ask them why, the majority of them tell us that it is because they could then keep from the NHS or anyone else the name of their carer, which would mean that, when they were in hospital or fell ill and needed changes in their care assessment, their carer would not be contacted. People tell us that, when they are in hospital, staff constantly demand to know the name of their carer so that they can contact them and sort out their return home, but that is not a person-centred approach by any means. That is one reason why many people favour option 1, which involves employing a carer directly, even though that takes extra time and is difficult to arrange.

That is also why I am concerned about the issue of who sees people's records. Recently, someone came to us and said, "I was raped in my early 20s and have been unable to have children, although I tried very hard. It is all in my medical records, but I don't want someone bringing that up during a social care assessment. I don't even want them knowing about it. I don't want them knowing about my post-traumatic stress disorder and so on." Of course, in a small community, once a piece of information gets out to one person, it can get out to everyone else, which can result in people being treated differently. That is something that urban dwellers—I was one for many decades—might not appreciate. There is a huge difference between going to a supermarket checkout in an urban area and being anonymous to the checkout operator and the experience in a remote rural area, where everybody knows who you are and knows the bits of your history that have been made public. I cannot stress enough how important SDS is for people, for that reason alone—they want to keep their business to themselves.

Paul O'Kane: I am interested in the transition from childhood to adulthood, and the associated services. There is a member's bill on that issue and there are Government bills going through Parliament that relate to a lot of issues that are to do with what we are talking about. Might it be better to capture some of the elements of those bills in this legislation? Is there an opportunity to do that? Frank McKillop and Andy Miller have been close to some of the work on those bills, so I would like them to respond to that first of all.

Andy Miller: I will make a general point. As well as the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill, there are a number of other relevant pieces of legislation, and it is important that they are aligned, that they support each other and that they do not duplicate what the others are doing. There are several points where that could happen. For example, the bill that we are discussing today contains a proposal to have a social care commissioner, but there are other proposals to have a learning disability, autism and neurodiversity commissioner or perhaps a disability commissioner. I am just not sure how much alignment there is among the various teams that are working on all that difficult and complex legislation. I am not minimising the task, but that point is important.

I have forgotten the specific question that you asked.

Paul O'Kane: It is important to pull some of those threads together. Is there an opportunity in the National Care Service (Scotland) Bill to do that? Obviously, it is a Government bill, and we would not want to lose sight of some of those elements that are broadly supported by the learning disability sector and others.

Andy Miller: The human rights bill, which should incorporate the UNCRPD, which Dr Gould mentioned, would lay out the framework for the human rights approach that is legislated for in the National Care Service (Scotland) Bill, with the detail being provided in that bill.

With regard to transitions, what is laid out in the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill belongs in that bill. I do not think that there is anything that should be transported over to the National Care Service (Scotland) Bill. However, we need to keep an eye on the other bill. Obviously, with regard to function, there is a lot of potential overlap, and the oversight that is mentioned in the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill with regard to the national strategy could be really helpful. The national transitions strategy and the national care strategy need to align, too.

Frank McKillop: An important element of the transitions crossover is whether the intention in the longer term will be to include children's services in the national care service. If that comes to pass—I know that that will be separately consulted on with the children's services sector—it might make sense to have transitions as part of the National Care Service (Scotland) Bill to reflect that.

However, while there is uncertainty about whether children's services will be part of the NCS, I agree with Andy Miller that the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill as it stands—we hope that it will enjoy support across the Parliament; we have supported it since it was originally proposed in the previous session in Parliament—is probably the right place for that currently.

That crossover is important to ensure that we enshrine those rights as young people transition to adult social care services, leave school and, potentially, home and look to use their right to have a home of their own and a right to independent living. It is important that we capture that in the National Care Service (Scotland) Bill, so it is certainly worth looking at the issue, but the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill, as a separate piece of legislation, still has a great deal of value.

Dr Nolan: Inclusion Scotland and Camphill Scotland led on promoting the idea of a national care service and getting an MSP to sponsor it. We are completely supportive of the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill, which we wrote the policy memorandum for.

Why do we support that bill? Over the years, we have been told so many times that, for young people in particular who are going through transitions—from being aged 16 to 18 and then into adulthood—the support, including social work input and everything like that, drops off and ends. In fact—this example relates to England—that happened today to a family member of mine who is autistic and has turned 18. My sister phoned me in tears because the social worker had called her today to tell her that all the support has been dropped because he is 18 and has some money in the bank. Therefore, there is no support for him to have a personal assistant or to travel independently—that is all gone.

That has been a constant story over the years. The Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill will bring in the right to have a transitions plan and on-going discussions with the right people throughout the transition.

17:00

PLPP members agreed that including children's social work in the NCS would help with those transitions. It was proposed that it would be part of the NCS so that the services could all be delivered under one roof. There is absolutely no continuity at the moment. If children's services are to be brought into the national care service, that should be done alongside work on the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill.

Paul O'Kane: That follows on from Frank McKillop's point about social work. There is a debate—we have heard evidence on both sides of the argument—about whether social work and children's services should be in or out of the scope of the NCS. Is it important that the social work profession stays together, whatever the end point is, because of what has been said about transitions?

Frank McKillop: There is value in that. The priority for Enable is that the recommendations that the Feeley review made about adult social care should be realised. It is important to ensure that social work is kept together and that there is recognition of the value that social work delivers in terms of children's services and adult social care. It is also important to ensure that people have access to options for the self-directed support that they need.

There is value in that, but our priority is very much to ensure that the Feeley recommendations on adult social care are fulfilled.

The Convener: Emma Harper wants to pick up on the issue of care records.

Emma Harper: Dr Gould mentioned how everyone knows everyone's business in rural areas. I represent the South Scotland region, which is very rural. She is right to say that folk in rural areas know what people are up to—sometimes, they even seem to know before those people know themselves. Other members will probably be very aware of how news about rural healthcare gets round the town or village.

Digital care records are a way of sharing information. Some stories can be repeated while other stories remain buried, if that is a person's choice. My question is for Dr Gould. What fears do you have about care records? What do you hope to see that would be deliverable and would help to improve care?

Dr Gould: I would like to see a variety of options for how records are held and accessed, with a full log of what has been accessed and by whom. It would be easier for some people if a certain portion of what they want people to know could be made available and accessible, so that they do not have to constantly repeat themselves to staff.

It is difficult. There can also be something like the childhood game Chinese whispers, when the more that information gets passed on to someone else, the more that it changes, grows legs and becomes something that is far from the truth. The people who hold that information should show far more respect for the use that it is put to. I have come across people who have used information to their own advantage to win a professional argument rather than showing any real care for the person about whom the information was about.

The matter must be further looked into. We are intending to become digitally reliant and put all our eggs in one basket, which might not work in remote rural areas, given issues with the supply of electricity. I have been to hospitals where I have been told, "Oh! The computer system has gone down. Oh! We can't access your records. Oh! We don't know what you've had before now." If you are attending hospital for something important, that is not the point at which you want to find that no one is able to access your records.

Emma Harper: Therefore, a digital care record that is accessible, secure and safe is absolutely what we need to think about in the bill. You are right about choice, traceability and the ability to know who has accessed records. I come from a nursing background and, from that point of view, when we are operating on somebody, we want to know what has happened in the past, including about previous surgeries, and it is really handy to have a record to check for safety reasons.

The third sector does not have access to records. Would you support that access? When we consider who is looking after the person—someone might have self-directed support, for example—is it necessary that the right people have access to the record?

Andy Miller: That is an important question. The key thing that people with learning disabilities have told us is that they need to have control over that access, rather than their saying in advance that, in principle, certain people should have access or certain people should not have access or that they must specify the amount of access that those folks should have. The complex system that Dr Gould described must be co-designed so that it is owned by the people who will benefit from it or be harmed by it. That might sound like a fudge, but it is not. As designing the system is technically complex, it would be easy to leave it to the technocrats, but it is so important that there is a co-design process.

I want to remind everyone of the difficulties with regard to data sharing and the getting it right for every child policy. It is really important that we do not make that mistake again, so the system must be co-designed.

We must also think about the scope of the process, because it links with support planning. To what extent does the support planning link with the data records, and how will all that be afforded? Some health and social care partnerships have two IT systems—one for health and one for social care—and an effective data-sharing system should, ideally, use one system or at least two compatible systems. That is not the case, so we would be talking about a massive investment, which I do not think has been included in the financial memorandum.

The Convener: Emma, do you want to pick up on what Andy Miller said before I bring in Dr Nolan and Dr Gould?

Emma Harper: The Food Train and other services that are equivalent to meals on wheels deliver to folks' homes, and their staff might pick up on increased memory loss, for example, which might trigger an assessment or more care. Should such services be involved as part of the co-design process? Should they feed into the records even though they may not necessarily have access to them? Again, that is about on-going assessment. Should we think about that as part of the co-design process?

Andy Miller: That is a great example and a great idea, but I do not think that I should be the one who has the say-so on that. The extent to which the rest of the third sector, which has a great deal of the day-to-day contact with people, has input and access to records must be a decision for the people who use social care.

I remember someone who lived in Skye saying that the lunch clubs that she helped to run were a brilliant early warning system. If somebody did not turn up to the weekly lunch club for a couple of weeks in a row, that would be a red flag and it would be time to look into it.

Dr Nolan: I reiterate what my colleague has just said. It is really important that it is down to personal preference and that it is all co-designed. It would be a really good idea to make sure that that is co-designed. The only thing that I want to add is about control over the information that is gathered. You could look to the Scottish Government's recent consultation on the health and social care data strategy. The PLPP had lots of input on that strategy and it had lots to say.

Although not having to repeat your story over and over again can be liberating, it is really important that, if confidential information is recorded wrongly, you have an opportunity to feed that back and that the information is changed in accordance with your feedback, rather than it being shared with other people and service providers such that the wrong information keeps coming back to you. That is all that I wanted to add. I agree with everything else that has been said.

Dr Gould: I reiterate what Pauline Nolan has just said. When something is found to have been recorded incorrectly, there can be major difficulties in getting the information corrected. That happens quite frequently. Somebody may have a condition that changes over time, but the changes may not be recorded correctly or they may not be updated everywhere. That can cause major issues, such as people not getting a single meal while they are in hospital as an in-patient because people do not understand their care needs in terms of food intake and so on.

There has to be a way of correcting information that is wrong. As someone who has had it recorded in my medical notes and occupational therapy notes multiple times that I have had several surgeries to both ankles when I have never had surgery to either ankle, I would really welcome some way of changing that information, among other things.

The Convener: Thank you very much. We will move on to discuss co-design and sequencing.

Paul O'Kane: Co-design is at the heart of the bill's approach, and the Government is keen to co-design once the framework legislation has been passed. Should there have been more co-design in advance of the bill going through the legislative process? Also, to go back to the question that we started with, what co-design processes are missing? People have advocated that such processes should be on the face of the bill.

Frank McKillop: As many respondents to the consultation have noted, the bill is a framework bill. We would like to see a lot more of the detail behind it, and there is always a feeling that some more co-design before this stage would have been a good thing. However, I also appreciate that, especially in the third sector, we always call for more co-design and there is a point where you just have to get on with things.

I think that it is more than two years since the Feeley review began. There was a lot of sector input at that point, and there was a great deal of consultation—we could perhaps call it co-design. Many people across the sector feel that a lot of work was done at that stage to build the Feeley recommendations. Where they have been pulled through into the bill, we are satisfied that a good deal of consultation with the sector has already happened.

Co-design is certainly important to us as a charity that represents many people with a learning disability. They are very keen to be involved. Indeed, many of them are involved in the various panels that are supporting the design of the national care service.

I am conscious that there were a lot of responses to the Government consultation—I think that there were 1,291 responses—so many people have views, but they are not always 100 per cent in agreement. There is always a danger that co-design will become an excuse to hold things up, and we would be concerned about that.

17:15

There is a lot of effective practice in the sector, and we should learn from that. It is important that co-design is genuinely productive, that we bring in views on and experiences of social care, and that those inform how we design the national care service off the back of the bill. It is also important to learn from what already works and is effective in the sector.

Our key point is that social care is not working in Scotland and we need to change that. Urgent action is required. Things are never perfect—there are always imperfections—and more co-design at an earlier stage would have been preferable, but we do not want things to be held up. We support on-going co-design to ensure that we definitely get this right. We need reform.

Dr Nolan: Some of the co-design has already started, but we are not sure which parts. We are not sure what has happened to the design school, which was supposed to train people in what co-design is. We are still unclear about the difference between co-design and co-production, which is what we do. We do not start co-production with a blank sheet of paper, but co-design should start in that way.

A lot of the bill was created through consultation and not co-design. I will use local care boards as an example. A lot of co-design is needed and the detail needs to be added, but the bill should not say

“the board must seek views on a draft of the plan”;

it should say that the board must co-design the draft of the plan. It should talk not about the “community”, which might include people who have no interest in social care support, but about supported people, their families, their supporters and unpaid carers. In the case of a special care board, the bill should include disabled people, including survivors of mental health issues, as well as families, supporters, unpaid carers and their organisations.

If the co-design had been done properly, it would be more specific and it would be embedded through the governance processes. There would not be just a consultation. That is really important. If we are to have co-design of the system, on-going co-design must be included as part of the monitoring and evaluation of every part of the system. It is important from the start, but it must be on-going, too.

Paul O’Kane: There is a commonality about co-design being part of the process. Andy, what is your vision for the involvement of people with disabilities, and particularly learning disabilities, in co-design? How do we ensure that they are involved?

Andy Miller: I commend the vision for and commitment to co-design, which are so refreshing. The commitment has been there from the start. I echo the concern that some people have expressed about a lot happening before the co-design kicks in. That is a little regrettable, but the commitment, which is now visible and tangible, is great.

You asked about the involvement of people with learning disabilities. There is some way to go, but there is a commitment to learning how to do that better. A small example is that meetings with stakeholders are now being done on Zoom. It was apparently impossible to do that earlier, but folk have made a commitment and have realised that Zoom is a more accessible platform than Teams for many people. That change has been made and it is great.

We have some concerns about the accessibility of the lived experience panels that have been implemented. Folk in the national care service team borrowed that model from the social security lived experience panels, pointing to their success, but people with learning disabilities struggled to get involved effectively in that process. There is a lot of learning still to be done on that. If we break it down, there can be inaccessibility at many points, including when people apply to join the panel. I helped someone to join because, although there was a number that they could phone if they wanted support, they did not have the confidence to phone it. They did not know who they would be phoning or who would answer the phone, which was enough to make it too difficult.

It is a question of always coming to back to folk and asking, “Is this working for you? How can we improve it?” A lot of it is to do with accessible information and gaining people’s trust. It is not just about easy read; it is about having a range of available formats for people. There is forward motion there, which I am very pleased about.

On the second part of your question, I echo what others have said about the need to continue the co-design ethos after the national care service is in place. For example, the three-year national care service strategies should be co-designed, but at the moment there is nothing that suggests that they will be. There needs to be an on-going commitment to co-design and implementing each thing as it comes up. I am sorry—that ended up being a bit of a waffle.

Rhona Willder: We would like the independent advocacy that we want to see in the bill to include collective advocacy, because it is important for co-design. The inclusion of a right to collective advocacy would be incredibly useful, particularly if the collective advocacy groups were able to refer systemic human rights concerns to an independent complaints body.

Having collective advocacy groups that are autonomous from the system is a really useful way of making sure that people can highlight their on-going concerns. That is important from the point of view of co-designing from the start. However, as colleagues have mentioned, it is also important that people’s views are gathered on an on-going basis, because not everything will be perfect from the start. Having independent advocacy models that support the principles of the bill would be a very useful way to do that.

Tess White (North East Scotland) (Con): My question is for Andy Miller. The SCLD has said that some areas of the bill

“are within the scope for co-design, while other areas are not.”

What areas do you feel are not subject to co-design?

Andy Miller: I am sorry; if I wrote that in our response, it was the opposite of what I meant. What I meant to say was that in the original paper and in the language of the bill, there were certain areas where a co-design methodology would be brought to bear—for example, in the development of the charter and realising rights and responsibilities. However, those are specific areas, and the point that we wanted to make—we obviously made it very badly—was that we hoped that those delineated areas would not be the only areas where co-design applied and that the bill should be co-designed more broadly.

The other point beside that was that it felt like one side had decided which areas were to be amenable to co-design and which areas were not, and it was not the side that included people with learning disabilities, so there was a slight objection to that. I am sorry if that came across wrongly.

Tess White: It may have been my interpretation, so that is really helpful; thank you.

The Convener: The final set of questions comes from Evelyn Tweed.

Evelyn Tweed: I would like to go back to the point that Dr Gould made at the beginning of the meeting about the issues that disabled people and those in remote and rural areas experience. How can we make the co-design process more inclusive, to ensure that the issues of the past are not carried forward into the running of the national care service?

Dr Gould: The issues in remote and rural areas are far bigger than those that might affect the national care service. We are talking about people being included in their communities, so their communities need to be accessible to them. A 6m-long wheelchair-accessible vehicle—which requires an additional 4m at the rear to allow the person to get in and out—takes a lot of money to fuel, yet disabled drivers often have to pay for fuel in smaller shops in their communities that are run by one person and do not have card machines. They cannot use cards there so they need cash to buy their fuel, but sometimes they have to travel for more than 50 miles to the nearest place that they can get cash. They cannot use an ATM because they are not designed to be accessible to them. Neither can they get into their post office or use the toilet in their brand-new all-singing, all-dancing hospital; those places are not accessible to them, because their needs were never taken into account in the first place.

We have a huge problem with that—in remote and rural Scotland, in particular, but in other parts of the country as well—and it does not apply only to social care situations. It will not go away until it is addressed nationally, in relation to every area where a service is provided. There is no way that a disabled person should be penalised, first, financially because they are disabled, and then again, because their community does not seem to care enough to follow the law. The onus is on the disabled individual who has been discriminated against to take a case. It is very difficult to find someone who is able to do that. If they lose on a legal technicality and then lose the roof over their head, what is the point?

We are already being penalised if we need adaptations and aids in our homes. They are not covered by the bill, but I strongly believe that they should be, because they link to our being freely able to do things ourselves as independently as possible. If someone has to save up to have certain aids or adaptations in their home, and as a result they lose their access to SDS because they have built up savings, they have to pay for that. Disabled people can never win—it is as simple as that. They never will win until other people see them as equal members of society who have a right to be treated equally, which does not happen in Scotland. Nothing will change until that happens. I am very sad to have to say that and to have to represent people who say that to me all the time.

The Convener: Can I just follow up by asking Dr Gould a question? We totally appreciate everything that you have just said—[*Interruption*.] What would be your plea on making the co-design process that the Scottish Government wants to adopt accessible so that the views of people in your position in rural areas can be heard? [*Interruption*.]

Dr Gould: I am sorry; someone is on my other phone line. May I come back to you in about a minute?

17:30

The Convener: We will write to Dr Gould for a specific answer to that important question from Evelyn Tweed about the co-design process, because it might be helpful to get that feedback. We have run out of time anyway. The committee can follow up with Dr Gould because, obviously, somebody needs her attention at the moment and I do not want to disrupt that.

I would like to put to everybody that question about the accessibility of the co-design process—when it comes to time, capacity, funding, support and making sure that various people have had the opportunity to input into it—because that is part of what we might want to feed back in our report.

Dr Nolan: Andy Miller, I think, talked about the use of Zoom. For people in remote and rural areas, that will probably be better for accessibility, and it will help people who cannot travel to things in the central belt. I am aware that it is being used.

The trouble is that, as mentioned earlier, a lot of disabled people are excluded from digital engagement. Consideration is therefore needed of in-person co-design, perhaps in some of those remote and rural areas, where there are probably going to be even more barriers. That might involve going not just to a region but to very specific localities or to somewhere that everybody can easily access: for example, going to Skye as well as to Inverness, because the Highlands is such a huge area, and, similarly, going to numerous places in the Scottish Borders, because the transport network does not necessarily connect.

Consideration is also needed of the impacts on remote and rural areas of different aspects—for example, the charter, and whether to have a national advocacy service or local advocacy services. That goes right through the co-design of those aspects of the bill.

In addition, consideration is needed of the impacts on different people, who have different impairments and different social care support needs. A lot of consideration needs to be brought into co-design, and I appreciate how hard that is going to be, because, currently, the delivery of social care support is incredibly complex.

At the start, I should have said that the bill has not addressed the eligibility criteria and how people are going to have their needs met. What will replace the eligibility criteria is going to be really important.

The Convener: That was mentioned by the previous panel as well, and by a few other people.

We have Dr Gould back. The last word is for you, Dr Gould, before we wind up.

Dr Gould: I am sorry; could somebody remind me what the question was?

The Convener: Given all your wider concerns, which we totally appreciate, we are keen to know what your message would be to the Government as it starts its co-design process after the passing of the bill, to help somebody in a remote and rural area to be involved in that co-design. What—practically—could the Government do?

Dr Gould: It should involve people in whatever way they feel that they need to be involved, by whatever method. A lot of people have been using Microsoft Teams for meetings. Disabled people find that really difficult to use. They find Zoom much easier. Personally, I have found the software for this meeting really challenging, because of my disability.

The Government should find out what people's needs are, when it plans communications. Over the past year and a half, I have shocked researchers and the various civil servants whom I have spoken to, when they have said, "This is how the pathway to social care will work; and it will take only about two weeks", and we have had to stop laughing and say, "Actually, that would take more than two years."

There needs to be complete understanding, which is why, after the first national care service forum took place in Perth, I suggested that people might like to move it to Skye next year. Then they would see what it is like: they claim that people should use mobile phones in areas where there is no mobile phone signal and they ask individuals or small charities to be involved when they do not have a whole IT department behind them. Things are just so different, and there must be some degree of understanding on the part of the decision makers and researchers of how different it is. Not everybody here has broadband—they do not even have access to broadband if they want it—but there is an assumption that the whole of Scotland can be connected easily and digitally.

We have disabled and elderly people who can use only mobile phones that have large buttons and who can only receive or write a text or receive or make a phone call. Not everybody has all-singing, all-dancing technology, as people do elsewhere. It is important that those people feel involved, because when other people do not even understand what it is like for them they do not plan for or allow for that, so it is really important that we are discussing it.

I was at a meeting recently and somebody said to me, "Oh, it's quite simple—you just go to your local library", and somebody who was in Shetland said, "Well, for me that's two ferry rides and half an hour's drive." The person who had said that they should just go to the local library could not believe the distances involved. There are huge distances involved, and it means that people get left out. I ask that you do as much as possible to feed back that these people must not be left out, because they are the ones who will end up being excluded in the whole national care service.

The Convener: Thank you. That is a good note to end on.

That brings our formal meeting to a close. At our next meeting, the committee will continue its scrutiny of the National Care Service (Scotland) Bill with two further evidence sessions, which will focus on related services, public protection, older people and Anne's law.

I thank everyone who joined us in Glasgow today—everyone who was involved in the formal meeting, Quarriers for hosting us, and everyone whom we met in the centre of Glasgow this morning. I thank everyone for their time; it has been hugely helpful. This type of outreach and going out to different places in Scotland as much as possible can only help to make it a better scrutiny process, so I thank everyone for helping us in that regard.

Meeting closed at 17:37.

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