OFFICIAL REPORT
AITHISG OIFIGEIL

Health, Social Care and Sport Committee

Tuesday 14 January 2025

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 14 January 2025

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE

1st Meeting 2025, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Joe FitzPatrick (Dundee City West) (SNP)
*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Gillian Mackay (Central Scotland) (Green)
*Carol Mochan (South Scotland) (Lab)
*David Torrance (Kirkcaldy) (SNP)
Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Tressa Burke (Glasgow Disability Alliance)
Vicki Cahill (Alzheimer Scotland)
Stephanie Fraser (Cerebral Palsy Scotland)
Liam McArthur (Orkney Islands) (LD)
Lyn Pornaro (Disability Equality Scotland)
Marianne Scobie (Glasgow Centre for Inclusive Living)
Susan Webster (MND Scotland)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 14 January 2025

[The Convener opened the meeting at 09:01]

Subordinate Legislation

Food and Feed (Regulated Products) (Amendment, Revocation, Consequential and Transitional Provision) Regulations 2025 [Draft]

The Convener (Clare Haughey): Good morning, and welcome to the first meeting in 2025 of the Health, Social Care and Sport Committee. I have received apologies from Elena Whitham.

The first item on our agenda is consideration of a consent notification from the Scottish Government on a draft United Kingdom regulated products statutory instrument. The UK Government is seeking the Scottish Government's consent to legislate in areas of devolved competence.

The committee's role is to decide whether it agrees with the Scottish Government's proposal to consent to the UK Government making the regulations in areas of devolved competence and in the manner that the UK Government has indicated to the Scottish Government. If members are content for consent to be given, the committee will write accordingly to the Scottish Government. We also have the option to pose questions or to make suggestions and to ask to be kept up to date on relevant developments. However, if the committee is not content with the proposal, it may make one of three recommendations, which are outlined in paragraph 13 of the clerk's note.

In advance of today's meeting, I wrote to the Minister for Public Health and Women's Health on behalf of the committee with a series of questions on the instrument, and the minister submitted a letter in response on Friday 10 January. Both letters are in the annexes to paper 1. Members might now wish to put further questions to the minister about the instrument. The committee could decide to invite the minister to attend its next meeting on Tuesday 21 January. In that case, the committee would defer a final decision on the instrument until after it has taken further evidence from the minister. Do members have any comments?

Gillian Mackay (Central Scotland) (Green): I am in favour of deferring the decision until next week after the committee has taken more evidence. There are concerns about the capacity of Food Standards Scotland and the Food Standards Agency to continually review the evidence, as set out in the proposal, alongside a few other issues that it would be useful to explore with the minister and, potentially, with Food Standards Scotland.

Emma Harper (South Scotland) (SNP): Good morning. Like Gillian Mackay, I would like to defer the decision. I have a long-standing interest in food additives and how food is processed. Ultra-processing means that additives, stabilisers, emulsifiers and lots of different things are added to food, so I am interested in getting more detail to see where we can go with this statutory instrument.

Joe FitzPatrick (Dundee City West) (SNP): It is absolutely appropriate that we hear from the minister. It is a very technical instrument, so it would be helpful to hear from her and from Food Standards Scotland.

Brian Whittle (South Scotland) (Con): We have looked at the issue for a number of years. Generally speaking, the standards to which the UK holds itself are probably not as high as I would like them to be, but they tend to be higher than is the case in much of the European Union. However, it would be appropriate to double-check that that is still the case. As colleagues have said, it would be appropriate to defer the decision on the instrument.

The Convener: I put it to members that we invite the Minister for Public Health and Women's Health to attend the committee's next meeting, on Tuesday 21 January, to answer further questions on the instrument. Do we agree to do so?

Members *indicated agreement.*

The Convener: We will write to the Scottish Government to that effect.

Assisted Dying for Terminally Ill Adults (Scotland) Bill: Stage 1

09:05

The Convener: Under the next item on our agenda, we will take evidence from two panels of witnesses as part of our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill at stage 1. By virtue of rule 12.2.3(a) of standing orders, Liam McArthur may attend the meeting, as the member in charge of the bill.

As part of our scrutiny of the bill, the committee undertook informal engagement with the group called the Scottish Assembly last week to hear from adults with learning disability and autism about their views on the bill. I place on record the committee's gratitude to those who participated in that engagement for sharing their views and experiences with the committee, and I ask members to provide some feedback on what they learned from the session. I will start with Emma Harper.

Emma Harper: I was not sure that I was doing theme 1.

The Convener: This is about feedback from the Scottish Assembly session.

Emma Harper: Of course. Everyone who came to the session had obviously prepared thoroughly and made a great effort. The Parliament's participation and communities team did a fantastic job of organising the session and setting up the room. The people whom I engaged with and heard from were well prepared and well informed. I just wanted to say a huge "Thank you" to them.

Brian Whittle: One of the lessons that I learned from last week was to never pre-empt or pre-judge what you are about to hear. I do not know what the expectations were for the meeting, but it far exceeded what I thought I would get from it. Those who attended were incredibly well prepared and well informed, and were not shy in coming forward. What they said was not what I expected. I put on record my thanks to them.

Paul Sweeney (Glasgow) (Lab): I echo the sentiments expressed by colleagues. The session last week was very effective. I certainly learned a lot from it, and I am sure that colleagues did, too. A perspective that I had not previously considered was the impact on young people of having a supportive structure around them, then, when they transition to adulthood, perhaps having that support removed. That might influence people's outlook on life.

Similarly, there are issues around self-administration for people with significant disabilities. A number of interactions really helped me to understand the practical application of the bill as currently drafted. I appreciate that.

The Convener: An anonymised note of the discussions that took place as part of the informal engagement will be included in the committee's stage 1 report.

We begin today's scrutiny of the bill by taking evidence from organisations that represent individuals with long-term conditions. I welcome to the committee Vicki Cahill, who is policy and public affairs lead at Alzheimer Scotland; Stephanie Fraser, who is chief executive of Cerebral Palsy Scotland; and Susan Webster, who is head of policy and campaigns at MND Scotland.

We move straight to questions.

Carol Mochan (South Scotland) (Lab): The first theme is the definition of terminal illness. A range of views have been expressed about the eligibility criteria used in the bill around the definition. Will you give us your views on that? In particular, do you think that conditions such as motor neurone disease, Alzheimer's and cerebral palsy should or would be covered by that definition?

Stephanie Fraser (Cerebral Palsy Scotland): Thank you for your question. Cerebral palsy is an umbrella condition and is classed as a non-progressive neurological condition. With regard to whether it fits the definition of terminal illness that is in the bill, I note that people do not get better from it. It is lifelong, but it is not a static condition. How people are affected by their cerebral palsy is very much affected not just by how profoundly the condition affects their body but by what access they have to care, support and on-going treatment throughout their lives. If people do not have access to care and support, it is likely that their lives will be shortened.

Our community is concerned about the word "terminal" because we see people whose issues, when they access healthcare, are put down to their condition. They are told, for example, "That is because of your CP", or, "We cannot do anything about that because—". Their life expectancy will worsen because of that lack of access to treatment, but it is not necessarily the case that cerebral palsy will kill them in the end. Our concern is that the definition of "terminal", as set out in the bill, could apply to many long-term conditions. How clinicians ascertain how long someone has to live is an educated best guess.

Carol Mochan: Do you think that it would be helpful to have an expected timeframe for people in relation to their terminal illness diagnosis?

Stephanie Fraser: No, because I think that it is a best guess.

Susan Webster (MND Scotland): We are keen for the definition to stay as it is in the Social Security (Scotland) Act 2018. We and a number of other charities fought hard for its inclusion in that act, so it would be unfortunate if there was a different definition in this bill. Ideally, you do not want different definitions of terminal illness in different pieces of legislation, and we are content with the definition in the 2018 act.

Although we are part of the long-term conditions group, MND is definitely not a long-term condition. Average life expectancy with MND is just 18 months after diagnosis, so it is a bit different from that point of view.

To go back to Ms Mochan's original question, people with MND are covered by the definition of terminal illness that is in the 2018 act.

Vicki Cahill (Alzheimer Scotland): Alzheimer Scotland believes that people with dementia fit within the current definition. However, we seek to ensure that the scope and parameters around the eligibility criteria are clearer and more specific. At the moment, we believe that they could be subject to misinterpretation, and that could be to the detriment of people who seek to access this type of provision under the legislation.

The current definition does not set out clearly the circumstances under which people who are living with progressive terminal conditions, such as dementia, would be able to access this type of provision and when they would be able to do so.

Dementia is a continuum; it continues, progresses and changes, and people's needs and symptoms continue to vary over a period. The Scottish intercollegiate guidelines network guideline for dementia identifies that there are four main stages of dementia: early, moderate, severe and advanced.

Clearly, people with advanced dementia would fit within the definition—as set out in the bill at the moment—of a terminal illness, with regard to how advanced and progressive it is. The symptoms that arise in severe dementia could also be included within that definition. If the legislation uses words such as "advanced" or "progressive", it needs to be much more specific about what they mean. Also, what is included has to be much more descriptive to ensure that those who would be eligible to access this type of provision under the legislation would be able to do so fairly and equitably.

In our view, the definition is much too wide at the moment. It is not specific enough or clear enough to make sure that we are not missing out those individuals who either might be able to or who should not be able to access those provisions.

09:15

Carol Mochan: Okay, that is helpful.

Sandesh Gulhane (Glasgow) (Con): I declare an interest as a practising national health service general practitioner.

Stephanie Fraser, thank you for coming today. Given your answer about the definition, do you think that we should scrap and change the social security definition?

Stephanie Fraser: The definition in the social security legislation was put in place, as Susan Webster said, for very hard-fought reasons. As far as I am concerned, I do not have an issue with the social security definition because it was put in to access particular benefits for people with conditions where there is a timeline. Cerebral palsy is a lifelong condition.

I am not suggesting that I have any issue at all with the social security definition, because that is about accessing benefits. I am concerned about how to assess when somebody's life will come to an end, because people with cerebral palsy struggle to access health and care needs, particularly at the end of life; they struggle to access palliative care; and they struggle to get services from people who understand the impact of their condition on their life. That is why, in this context, I agree with Vicki Cahill—the definition is not descriptive enough and it is vague, whereas it is a separate issue when you are accessing benefits.

Sandesh Gulhane: Obviously, no one can be absolutely certain of the exact time of death. However, in a lot of cases, we can assume some form of timeline and that is how one accesses the DS1500 process, which unlocks a lot of money to allow people to have benefits that they otherwise would not have in their last moments. Should we be getting rid of that as well, because you describe it as a "best guess"?

Stephanie Fraser: We are talking about two different things here. We are not talking about access to care; we are talking about access to when somebody should be able to die. In the context of cerebral palsy, that is complicated, because people will probably have had access to care throughout a lifelong moment. What we are trying to assess is when might that change.

There are no specialists for cerebral palsy in adult services in the NHS. There are neurologists, but I know from my work on the national advisory committee for neurological conditions that most neurologists do not see adult patients with cerebral palsy, because it is not classed as a progressive condition. There are not drugs for the condition that routinely keep people well and people really struggle to access healthcare services. Therefore, when other health issues happen, they might not be addressed or might not be recognised as part of a person's condition, or people might feel that there is no hope because they have no access to support and care.

Therefore, this is not about making a comparison with accessing benefits; this is about how we care for people throughout their lives and ensure that they have a good death.

The Convener: I put on record that I hold a bank nurse contract with NHS Greater Glasgow and Clyde.

In the context of human rights, does the bill contain sufficient protections in relation to vulnerable groups, particularly in relation to the groups that you represent? If you have any concerns, what could be done to address those?

Vicki Cahill: We recognise that the balance of rights is complex and challenging when considering provisions for assisted dying. Finding the balance between the right to life and rights to autonomy, self-determination, equality and dignity is a fine path to tread and is challenging.

The decision to either include people with dementia or exclude them from accessing the bill's provisions will have significant implications for their human rights, regardless of which way we go and the direction of travel on that. For example, excluding people with dementia from accessing provisions for an assisted death could be seen as an erosion of their rights. However, there also has to be a balance between protecting those human rights and the need for protection and safeguarding, because people with dementia are a particularly vulnerable group and we need to ensure that no harm is done.

One area that is not particularly well addressed in the bill is decision making on advance care planning and advance directives. For example, people might draft legitimate and legal advance directives at a time when they have capacity. Capacity is a particularly pertinent issue for people who live with dementia, but not much is said about what happens to the ability to enact a clear request that an individual made at a particular point in their life or their experience of dementia if there are changes to their capacity.

The Convener: We will move on to that. Some of my colleagues have questions about capacity. I am trying to focus more on human rights.

Vicki Cahill: Yes, absolutely. It is about finding the balance. If we do not address the wider issues, there will be a risk of eroding human rights. We have to ensure that we consider the bill and all the wider contexts. We cannot see the matter in isolation; it has to be seen against a much wider framework. We need to consider health and social care to ensure that people's human rights are recognised, respected and upheld.

Stephanie Fraser: We have the same concerns. There are problems about people who might be included and about people who might be excluded.

We have particular concerns about people being able to communicate with anybody as regards assisted dying. We know of people who are non-verbal and end up, for example, in hospital without their communication devices. Those are terrible cases and should not happen, but they do, which worries us.

We have also seen another issue with our population. Cerebral Palsy Scotland is trying to support people who are non-verbal to have the language to have difficult and challenging conversations and be able to advocate for themselves. We see that challenge throughout everything. In a situation under the bill, it would be even more stressful and challenging. Are the preprogrammed language settings on a device up to giving people the ability to have those difficult conversations?

Those things need to be considered. However, I agree that there is a problem about who is included and, therefore, when we look at the human rights issues, who is not included.

The Convener: Susan, would you like to comment?

Susan Webster: Most of our concerns about human rights relate to the self-administration aspect of the bill. Would you prefer me to address those now or later in the meeting? I can do either.

The Convener: You mentioned human rights. Such issues were specifically raised in our recent private session with members of the Scottish Assembly, when we discussed self-administration as it might apply to people who have capacity but are physically unable to take the medicine. I am keen to hear MND Scotland's views on that aspect of the bill.

Susan Webster: If the bill covers only self-administration, it will inevitably exclude many people with MND because of their inability to use their hands or to swallow at certain stages of their illness. It would therefore limit their ability to choose assisted dying if they wanted to do so. MND is a rapidly progressing illness. If patients wanted to take up the opportunity for assisted dying, they might choose to do so at an earlier stage in their illness than they would ideally want to, so that they can still physically administer the medicine. That is something to consider as regards the bill's interaction with human rights.

The Convener: Stephanie, do you want to come back in?

Stephanie Fraser: The text of the bill is not clear on what "self-administration" actually means. When my colleagues and I were talking about that outside, before the meeting, we assumed that it would have to be done orally, so the person would have to physically take a pill. However, it is possible that it could include operating a head switch, for example. What "self-administration" might mean for patients who are fed by percutaneous endoscopic gastroscopy—PEG—is not clear, either. The way in which it would happen is being left to secondary legislation. We would like to see some aspects of it being explored at this stage rather than left to later direction.

The Convener: Thank you. We will go on to explore many of the themes that we touched on there through other members' questions.

David Torrance (Kirkcaldy) (SNP): Good morning, everyone. What do our witnesses think of the bill's approach to capacity?

Vicki Cahill: It seems pertinent that I should respond, given that people who live with dementia often have their capacity brought into question. Other people often assume that dementia sufferers lack capacity, but they retain the same legal capacity as any other citizens in Scotland.

The Adults with Incapacity (Scotland) Act 2000 clearly sets out that determining whether someone goes on to lack or to lose capacity should be done case by case and decision by decision. Any test of capacity should not involve a blanket approach or a general test. Unfortunately, in our experience, it is often determined that people either have or do not have capacity. We need to be clear that it should be determined decision by decision, and not by adopting a one-size-fits-all approach.

We feel that the bill's current definition of capacity lacks clarity and specificity on what is or is not included. It is taken from the Mental Health (Care and Treatment) (Scotland) Act 2003. However, in practice, that legislation applies only to a small number of people who live with dementia.

09:30

The bill could be improved by clearly defining—in the bill's own terms and within its scope and parameters—exactly what the word "capacity" means, to ensure that that is explicit. That would enable us to understand clearly who would be able to make use of the assisted dying provisions, as set out in the bill, and under what circumstances. That would help those who might choose to access the provisions, but it would also support those who will potentially deliver the provisions. It would remove ambiguity and the potential for misinterpretation or misunderstanding. There is real scope for the bill to be improved by providing those extra parameters and being more specific about the context in which the provisions would operate.

Stephanie Fraser: We are concerned about the vagueness of the wording with regard to capacity. One in two people with cerebral palsy has a learning or intellectual disability, which, as Vicki Cahill said, does not necessarily mean that they do not have capacity.

Our other concern is how capacity is assessed and by whom. I have had several conversations in which people have said that GPs, for example, are perfectly capable of assessing capacity, which could absolutely be the case if the GP knows the person who they are assessing. The financial memorandum refers to people having to attend online courses to be trained in assessing capacity. I very much hope that more thought would be given to how capacity is assessed and that that would involve more than just the provision of a few online training sessions.

Susan Webster: We do not have any comments on capacity for people with MND.

Vicki Cahill: Alzheimer Scotland raised a significant omission with regard to how capacity would be tested, which needs to be addressed in the bill. The omission relates to the ability to act on a decision. At the moment, the test for capacity is based on existing legislation, which sets out how someone's capacity should be tested and the things that they must be able to do. The one part that seems to be missing relates to the ability to act on a decision. Given that self-administration of medication forms part of the bill, it seems that the ability to act on a particular decision is important, so that needs to be addressed in the bill.

David Torrance: To what extent is the bill's approach to capacity compliant with the recommendations of the Scott review? If it is not compliant, how can it be made compliant?

Vicki Cahill: We are undertaking a huge review of the way that we look at different areas of mental health legislation, which involves a huge number of different pieces of legislation. We have just consulted on the Adults with Incapacity (Scotland) Act 2000, including with regard to issues around the testing of capacity.

As I pointed out, the failure to refer to the ability to act on a decision is important. It is not just about understanding and retaining information and being able to communicate it back; the bill's provisions mean that someone must be able to act on the information in order to carry the process right the way through to self-administration of medication. That would probably be our starting point for improving the bill to ensure that it becomes compliant with the recommendations of the Scott review.

Bearing in mind that the Scott review recommendations will be carried out over a period of time, it is important that we make sure that, as we move through them and make changes to legislation to satisfy those recommendations, the bill, if it moves through the legislative process, is also compliant.

David Torrance: Thank you.

Brian Whittle: Good morning. My question is supplementary to David Torrance's questions. I listened to what was said, and I want to clarify something. On testing for capacity, is there the potential for medical staff whose job it is to determine capacity, no matter how well trained they are, to come to a conclusion that is different from that of the person's GP, who has seen them consistently over a period of time and who understands the individual's specific condition? Is there a concern that there could be two different conclusions on capacity?

Stephanie Fraser: I will give you an example to illustrate. Somebody with cerebral palsy who might have been to mainstream school and who physically is not terribly involved—I am thinking of people whom we know—might be assessed as being able to live independently at home, but what has not been picked up are sensory processing issues. For example, somebody physically might be able to live independently but, to make a cup of tea, they need someone to remind them to put water in the kettle, to plug the kettle in, to put the kettle on, to get the cup out, to put the tea bag in and so on.

Capacity is a subtle thing. I can think of people who might present one way but, if you know how they live or what support they need to live, you might assess them slightly differently, exactly as you say. I know that making a cup of tea is a very different thing to what we are discussing here, but that is the kind of example that I can give you. Nobody wants to underestimate the abilities of people—we want to support them to make their own decisions and to live as independently as possible, but their real issues are sometimes overlooked.

Brian Whittle: To take that slightly further, what I am getting at is that a regular healthcare professional who knows the person will notice subtle changes. That is the other way to define capacity—

Stephanie Fraser: For people with CP, what concerns me is that they do not have a regular medical person. That could be their GP, but the days when we all knew our GPs and saw them regularly are not necessarily the days that we live in at the moment.

Brian Whittle: Thank you.

Sandesh Gulhane: I want to explore advance directives a little bit more with Vicki Cahill. To be honest, I am very nervous about the idea of advance directives when it comes to the bill. If somebody has lost their capacity, I do not think that an advance directive should count in this particular instance. That is my opinion at the moment, but I would like to know your opinion and what you believe should happen with an advance directive in the scenario where somebody has perfect capacity when they create their advance directive, but then clearly—not subtly—have no capacity when it comes to potentially using it.

Vicki Cahill: We have adopted a very neutral approach to the bill. We choose to neither support nor oppose the provisions of the bill; we merely raise the concerns and considerations that we believe must be addressed to ensure that, if the bill goes through the legislative process and becomes enacted, it is complete, full and robust and covers absolutely everything.

There are real challenges around advance directives, as you rightly point out. One of the requirements for setting out an advance directive is that the person has capacity at that time. We have to consider what happens as that goes forward. Looking at both sides of that particular coin, there is potential in both directions to really affect an individual's human rights. If someone has set out very clearly their personal wishes for what will happen as their condition progresses, who is to say that it is not right for those wishes to be followed through?

However, the flipside is the issue of how we can test whether someone has changed their mind or has had a change of opinion that has not been tested since the advance directive was completed. For example, if someone is going to create an advance directive, they are more likely to do so early in their diagnosis and may have a preconceived idea of what it is to live with a condition such as dementia. Their actual experience may be different, particularly if they have access to high-quality health and social care—the kind of care and support that enables people to live well with dementia. We suggest that, with the right kind of care and support, it is possible to live well with dementia. Without that, we would have to look at that issue.

Unfortunately, I cannot give you a scenario in which we believe that we should move forward, but I believe that we have to explore these issues much more deeply. We have to engage people on what their views are, to make sure that any decisions that are made on advance directives and advance care planning are made with integrity and manage to uphold rights but provide the right level of support and protection.

Sandesh Gulhane: We are scrutinising the bill to try to find the right thing to do when it comes to advance directives, which is why I am asking what the opinions of experts are.

You talked about the definition of capacity. Could you point to somewhere that has a better definition?

Vicki Cahill: Capacity is really complex, and there are lots of examples of ways in which capacity is considered. On alternatives to the definition in the bill, it is helpful and useful to look at definitions in existing legislation. A good starting point would be to look at the recommendations of the Scott review, which was a thorough review involving a whole range of issues. We need to look at the tools and structures that were recommended by the Scott review and consider capacity in depth and more broadly. The Scott review recommendations would be a good starting point.

Sandesh Gulhane: Unless any of the other panel members has an opinion on advance directives, I will stop there. Thank you.

The Convener: I will probe a bit more on the topic of advance directives. I hear what you say about advance directives with regard to the bill, if it became law. Would you recognise advance directives that someone had put in place and that were about not consenting to treatment, not being put on life support or not being resuscitated, regardless of whether that person had capacity at the time that the intervention might take place?

Vicki Cahill: A lot of that comes down to the subjective decision making that goes on around an individual's care and treatment. When an individual is unable to share or express their views, decision making can be done in conjunction with family members. That is particularly the case if, for example, a power of attorney or guardianship order is in place. A lot of decision making is done at a medical level.

This is not within the scope of today's discussion, but something that could be looked at much more broadly is how advance directives are managed. When people with dementia are looking to access care and support, we encourage them to look to the future. We encourage them to plan ahead and to make the most of the opportunities that they have to think about what provision they would like to receive and how they would like to be treated, cared for and supported in the future.

Societally, we need to think much more widely about how we support individuals to do that. I appreciate that that is not necessarily within the scope of today's discussion, but we could certainly make progress on that.

09:45

Stephanie Fraser: On adults with cerebral palsy, I come back to my point about communication difficulties. We have too many examples of adults who have full capacity but who cannot communicate and do not have the right language on devices or whatever to challenge decisions or to have conversations with people about those decisions. Decisions are often made about their care and support that they are not happy with, but which they find very difficult to challenge. I wanted to add that point.

The Convener: I will take the discussion a step further, and then I will come to Brian Whittle, because I know that he has a supplementary question on the same issue.

An issue that was raised with the committee last week was guardianship and whether guardians who have the legal right to accept or refuse medical interventions on behalf of the person for whom they are guardian should have a right to have a say if the bill were to be enacted. Do you have any thoughts on that?

Stephanie Fraser: I will not respond specifically on guardianship, but we sometimes see a situation in which there is a difference of opinion between the person with cerebral palsy and their nearest and dearest on what is best. It is a really complex area. I come back to my point that, if we could support the person to be able to communicate, to have difficult conversations and to have the right vocabulary and so on, that would be an improvement.

Brian Whittle: I want to clarify a point about advance directives. Am I correct in understanding that you are saying that the problem with advance directives is that, when someone gets to a certain stage in relation to capacity, it is very difficult to understand whether they might have changed their mind on that journey? Are you saying that that is an inherent issue with advance directives, or am I misconstruing you?

Vicki Cahill: There is scope for that. Someone who is living with dementia, whose condition will progress, might have made an advance directive early in their experience of the condition. As their capacity changes and becomes much more diminished, it can be more difficult to ascertain whether they have had a change of mind or whether they are still of the opinion that they would choose to have an assisted death. It is difficult to test that if an individual is unable to express themselves or does not have sufficient capacity to do so. The issue is what measures or limitations could be put in place around advance directives in relation to people's ability to access provision such as assisted death.

Gillian Mackay: We have touched on the issue of fluctuating capacity, but what might we need to include in the bill to adequately address that? What provisions should be added to ensure that individuals such as those with Alzheimer's do not feel as though they are being forced to pursue assisted dying prematurely, because that is when they can demonstrate capacity?

Vicki Cahill: Determining the capacity of people with Alzheimer's or any other form of dementia is really challenging, because capacity can change and move. It is not static and does not stay the same; it can change from day to day. On one day, an individual might struggle to meet the test of capacity but, on a different day, they might be able to do so. We need flexibility in the legislation to allow those with fluctuating conditions to find opportunities to express themselves. It is really important that those who have capacity are supported and enabled to express their views and opinions when their capacity is in place.

We need flexible options for how capacity is tested. Lots of things, including the environment and the time of day or the day of the week, can determine whether an individual manages to satisfy a test of capacity. We need to find opportunities for individuals to be supported, and flexibility must be built in to how we test capacity, because it is really difficult to do that.

An individual might be determined as lacking, or having, capacity, but if that judgment is inappropriate or is made wrongly there is real potential for harm, either because they have not been able to express their views or because they have been involved in making a decision when their capacity might not have been at its strongest.

Gillian Mackay: Stephanie Fraser, do you want to come in?

Stephanie Fraser: If I understand it, your question is about fluctuating conditions. Cerebral palsy is not a progressive condition but, as I said, it is not static. How someone presents can very much depend on the care and treatment to which they have, or have not, had access.

One of my issues with the bill as it stands is that neither the registered medical practitioner nor the independent medical practitioner needs to have any specialist knowledge of the condition that the person says they are going to die of. I think that that is an error. Doctors "may" ask for specialist input, but I suggest that the bill would be stronger if it said that doctors "must" ask for specialist input about particular conditions.

Many conditions, particularly those in the neurological sphere, fluctuate. If specialist knowledge was not part of the assessment process, that would be a glaring omission.

Gillian Mackay: That leads me nicely on to my second question. In specialist services at the moment, do decisions about people's care take their fluctuating capacity into consideration? Can we draw on good practice that is already happening, or do we need improvement across the board?

Vicki Cahill: We need some improvement across the board. Specialist dementia services are few and far between, and there is a postcode lottery regarding the quality of care and the access to care and support for individuals. There are existing small pockets of good practice. Where the system works, it works incredibly well, but that is not everyone's experience, so we need a much broader approach to improving access to care and support.

Stephanie Fraser: I completely agree. There is a concerning lack of access to specialist adult support for people with cerebral palsy, and services in Scotland fall far short of the National Institute for Health and Care Excellence standards and guidelines for adults with CP. We do not have SIGN guidelines, but we try to adhere to the NICE ones, although we fall short of them.

You asked about reviews and about access to specialist care. Particularly for people with neurological conditions, there is too little access to palliative care services and it comes too late. I hugely advocate strengthening both palliative care services and access to palliative care for people with long-term conditions.

Emma Harper: I have a question about eligibility for people with long-term conditions such as Parkinson's. I remind everybody that I am a registered nurse.

Under "Eligibility", in section 3, the bill says:

> "A person has capacity to request lawfully provided assistance if they … are not suffering from any mental disorder which might affect the making of the request".

There are issues around depression. It is considered to be a mental disorder, but is it? How severe is it? A person who has an MND diagnosis might also have a pre-existing depression diagnosis. Parkinson's is a long-term condition, but is it a mental disorder?

Do we need to assess the level of understanding and knowledge of the people who will make the decisions to determine capacity? Does that need to be fleshed out a bit further?

Stephanie Fraser: You hit a number of nails on the head with that question. It absolutely backs up my point about the need for input and specialist knowledge of a condition. Your example about Parkinson's and depression is absolutely spot-on.

With our population and people with neurological conditions in general, we know that access to care, support and continued treatment can colour a person's experience or their view of what the future might be. Section 7, for example, says that the

> "registered medical practitioner"

may

> "discuss ... any palliative or other care available",

but only

> "in so far as the registered medical practitioner considers appropriate".

Is that a real option? Are we giving people a real option if that "palliative or other care" is not available?

Emma Harper: I am interested in whether you think that health professionals have the appropriate skills to assess whether an individual who seeks assisted dying support has been coerced.

Stephanie Fraser: That is why I am concerned about the registered medical practitioner not necessarily having to know the person. In previous discussion, we assumed that the practitioner might be a GP and that they might or might not know the person whom they are assessing and that person's family. The bill omits to say how long somebody who assesses the family circumstances must have known the person and their family circumstances and who can provide evidence.

I will give you another example. An adult with cerebral palsy had a social worker who wanted to change their care package. Given that there are no clinical nurse specialists for CP, Cerebral Palsy Scotland had seen the individual clinically for longer than anyone else. We were asked to provide supporting evidence but, even though we knew the person better than anybody else because of their care circumstances, it was not accepted, because we were not part of the NHS. I give that as an example in relation to who should be able to feed in, who must feed in, in what capacity—although that is probably not the right word to use in this circumstance—how people should know the individual and their family circumstances and who the right people are to provide appropriate evidence.

10:00

Emma Harper: Do Vicki Cahill and Susan Webster believe that there is a risk of coercion for vulnerable people who have Alzheimer's, dementia, MND and so on? How do we safeguard against that?

Vicki Cahill: It is important to understand that, although a specialist might have the knowledge, skills and understanding that are required to test someone's capacity, that does not mean that they automatically have the knowledge and skills to be able to assess the presence or absence of coercion around decision making. In that respect, it is important that we consider who is doing that test to see whether there is coercion. We recognise that people who are living with dementia are a particularly vulnerable group and are at risk of abuse and harm.

Another issue is that we should not look at coercion just in terms of undue influence from an individual in a specific set of circumstances; we should look at it much more widely in terms of undue pressure that might come from elsewhere and influence an individual's decision to seek an assisted death. Examples are the perception of being a burden or being stigmatised or discriminated against in day-to-day living, and someone's experiences of health and social care or social interactions might make them feel that their life is or is not worth living. We need to take a much wider approach to coercion and undue influence overall.

Susan Webster: Our organisation does not have a view on coercion.

Emma Harper: My final question is about overt coercion versus the subtle coercion that Vicki Cahill talked about. We hear talk about people feeling that they are a burden in conversations and emails about how we protect people. Do you have concerns about a wider definition of what coercion and pressure are? How do we protect someone from feeling that they are vulnerable and a burden?

Vicki Cahill: Absolutely. Overt attempts to coerce someone into making a decision that would go against their wishes or personal preferences are easier to identify. The broader test is about understanding the other influences and whether they can be addressed. Looking at ways to remedy and address those influences is a much bigger ask. It is about looking at services and support and at how we address stigma and preconceived ideas about what it is to live with a particular condition or to care for someone who has one.

There are plenty of preconceived ideas about dementia and what it is to live with such a condition. There is a lot of fear and worry about it. We need to look more broadly at how we support individuals through those processes so that they can live well with their condition. We need to broaden the scope of coercion and consider where those influences and that decision making come from.

One of the issues with dementia is the cost of care. Most people who are living with dementia will find themselves not receiving healthcare but having to delve into social care and being expected to pay for their care, particularly as their condition progresses. They find themselves being forced into care homes or residential care because there are no alternatives. We have to look at that much bigger picture, because we do not want the cost of care to influence a decision about whether someone chooses to continue to live or to seek an assisted death.

Brian Whittle: Concerns about palliative care have been raised several times. Should we explore the level of palliative care that is available and whether inability to access palliative care might influence a decision on whether to seek assisted dying as a remedy? Do you have a view on that, Susan?

Susan Webster: I highlight that we, too, are neutral on the question whether assisted dying should be lawful.

We believe that there is much room for improvement in palliative care and social care, regardless of whether assisted dying is available to people by law. For example, we recently responded to the consultation on the palliative care strategy—we ran a focus group for that. The people who took part who had lived experience of MND highlighted issues including the need for equitable access to palliative care across the country; improved funding; holistic palliative care, whether it be physical or psychological; the inclusion of all members of the family, and not just the ill person; care being available from the point of diagnosis, rather than it being an option that is available at the end of life, as is commonly perceived; and the need to work with social care services.

I could talk forever about how I think social care could be improved. As a group, people with terminal illness need to be much better recognised in discussions about the national care service. That group has been largely omitted from that, which must be addressed, especially given what we are discussing today.

Those changes need to be made, and huge improvements must be made to both those areas, regardless of whether assisted dying is introduced.

Stephanie Fraser: I have a figure about children who are under 18, so this would have an effect because the bill seeks to cover people who are aged 16 and above. Around 18 per cent of children with cerebral palsy die in childhood, and only a quarter are able to access specialist palliative care. Cerebral Palsy Scotland agrees with Susan Webster's view that everyone has the right to supportive care throughout their life, and to good-quality end-of-life care when it is needed. That is not available to enough of our population.

Brian Whittle: Does that have the potential to influence somebody's decision on whether to access assisted dying?

Stephanie Fraser: Yes—especially when you include the other factors that Vicki Cahill mentioned, such as lack of independent living accommodation and lack of choices about how care is provided, where people live or what they can do. We see people who struggle to leave their home because their mobility needs are not being provided for. A load of issues can lead to people feeling that things are not worth it.

Vicki Cahill: I agree with Susan Webster and Stephanie Fraser that assisted dying must be seen in the wider context of long-term palliative and end-of-life care. It does not stand alone, but must be seen as part of much wider provision.

We would support the idea that it is the responsibility of the health and social care system to ensure that everyone's physical, psychological, emotional, practical and spiritual needs are met. Palliative care provision, long-term care provision and end-of-life care provision for people living with dementia are very limited. There are positive examples in some areas, but provision is not readily available or universal. We need to ensure that there is high-quality provision for everyone, regardless of their background or circumstances. It should not be limited because of where they live or how much it costs.

Again, that comes down to lack of choice. At the moment, it is very much the case that people have one option, which they can choose to take or not. However, what is currently available does not necessarily meet individuals' needs, wishes and preferences. A huge amount of further work could be done to improve what is on offer. Failure to do so could have an impact on a person's decision making and whether they choose to access the bill's provisions, so it is important that we cover that.

Susan Webster: Can I—

Brian Whittle: If I may, I will bring you in in a little bit. First, I want to add another layer to my line of questioning—just to see whether I can make it more complicated.

If the consensus is that access to palliative care is, at best, patchy across various medical conditions and geographical areas, where is the line on saying that we have reached a level of such care that satisfies our concerns about it influencing a decision to access assisted dying? I suppose that that is an impossible question, but I want to put it out there.

Stephanie Fraser: We have all responded to the consultation on the proposal for a bill on a legal right to palliative care, which has been lodged in the Scottish Parliament. I refer you to that, as a start.

It is interesting that, in Scotland, there is no statutory right to palliative care, as there is now in England. CP Scotland wants to see that being changed.

Another interesting point, which I raise here simply because I do not know where else to raise it, is that much of the palliative care that is available in Scotland, particularly in hospices, is provided by the third sector, which all members will know is currently working under huge constraints.

The only part of the documentation on the Assisted Dying for Terminally Ill Adults (Scotland) Bill that mentions that assisted dying will be provided by the NHS is the financial memorandum. I have read the bill based on the assumption that, if it comes into force, such assistance will be provided by the NHS. However, the question is whether it should it be, or should be done on a par with the palliative care system. I am not suggesting either that it should or should not—I am just saying that the bill is not clear.

The Assisted Dying for Terminally Ill Adults Bill, which will, if it is passed, apply in England, clearly says that the NHS must provide that service. The Scottish bill does not. That is interesting when so much palliative care in Scotland is provided outwith the NHS and is provided instead through third sector organisations. I will leave you with that question about how it should be done.

Brian Whittle: Does anyone have anything to add?

The Convener: I see that people are shaking their heads, so we will move on a little, although we will touch on issues that we have already spoken about.

I am interested in whether the bill is sufficiently clear on whether doctors would be expected to offer assisted dying as a reasonable treatment option. From the evidence that we have taken from overseas colleagues, the committee is aware that, in some jurisdictions, it is prohibited for a clinician to raise such an option, and any such conversation must be initiated by the patient, whereas, in other areas, it is not prohibited. I am keen to hear our witnesses' views on that.

Stephanie Fraser: I note that, here, that would not be prohibited. I go back to a comparison with the bill that would apply in England, under which clinicians could raise that option.

Cerebral Palsy Scotland's concern is that, for many people with cerebral palsy, the reality is that they cannot dress themselves, or move, speak, feed or use the toilet without assistance. That does not mean—we get this time and again—that they are suffering, and I use that specific word deliberately. I note that it is not in the bill—the bill is not about people's suffering—but an issue that comes up again and again for people with CP is that their quality of life and the value of their life should be no different to anybody else's just because they cannot do all those things.

10:15

The Convener: I am sorry to interrupt, Stephanie, but I want to come back to what I was asking about specifically, which is whether doctors should be expected to offer assisted dying as a reasonable treatment option.

Stephanie Fraser: We suggest that that should not be the case.

The Convener: Do any other witnesses have an opinion on that?

Susan Webster: We do not have a view on that. Other witnesses would be better placed to give a view on it; I am thinking about the health profession.

Vicki Cahill: Likewise, we would maintain a neutral position on whether to favour that option. Again, I say that others are better placed to answer that question than we are.

The Convener: The flipside of that would be the bill expressly prohibiting doctors or other healthcare professionals from raising assisted dying as an option. Would that provide some reassurance that people with long-term conditions, such as those who access services through your organisations, would not face pressure to have an assisted death when they seek other forms of support?

Stephanie Fraser: I come back to the point that people with CP struggle to access care and support. We are concerned about the change in the doctor-patient relationship if assisted dying were to be proactively suggested.

The Convener: That is helpful. Vicki Cahill or Susan Webster, would either of you like to add anything?

Susan Webster: I have nothing to add.

Joe FitzPatrick: It would be good to hear your thoughts on the section in the bill on conscientious objection. Is the section clear enough, and who do you think the provision applies to? Should the provision extend to organisations—potentially, such as your own—so that you are able to say, "As an organisation, we're having nothing to do with this bill"? We have seen international examples of variation, particularly in Australia, in relation to institutions having a conscientious objection to the legislation. In that wide sense, I would like to hear your thoughts on conscientious objection and institutional objection.

Stephanie Fraser: As an organisation, we have tried to focus on the wording of the bill. Our service provision is about supporting people to live well and to reach their potential, which would not change regardless of whether the bill were enacted.

On conscientious objection, we would be concerned about people doctor shopping, in the sense that people will ask, “If my doctor won’t do this, how do I get another doctor?” We are therefore concerned about inequality, geographically, and the issue of people who already have difficulty with movement needing to travel to wherever they would need to go, in that case.

The real underlying concern is whether, as the wording stands, somebody could go through the assisted dying process with medical professionals who know neither about them nor about their condition. That would be a big concern for us. The bill does not say a huge amount about conscientious objection, other than that an individual can have one. I will not say any more about that from the medical professionals’ side. However, for individuals, the concerns are as I have laid out.

Vicki Cahill: We believe that the best-placed people to respond to conscientious objection would be individual practitioners, their representative organisations and the wider bodies that they work for.

On institutional objection, I can speak only from the Alzheimer Scotland perspective. We are a membership organisation that represents around 8,000 members across Scotland. I am sure that the committee will appreciate that views on the bill are quite polarised to both ends of the debate, and it is not for us, as an organisation, to come down in favour of one side or the other. We would maintain a level of neutrality around that and leave decisions on institutional objection to others who might wish to form a stronger view one way or the other.

Susan Webster: I would reiterate what Vicki Cahill said about institutional objection. Because of our neutrality, we feel as if it is very much a personal choice for individuals, so we would not be giving opinions in favour or against.

Joe FitzPatrick: Institutions that are opting out in Australia include hospices and care homes, many of which, in Australia, are run by religious organisations. In some states in Australia, organisations are able to opt out. The folk who live in those institutions and are under those organisations’ care would be unable to access the provisions in the legislation. Would any of you have concerns about that?

Vicki Cahill: From an equity and accessibility point of view, that would depend on the spread of objection to the provisions in the legislation and on decisions by organisations not to use the provisions. If the bill is to be enacted, we would need to consider ensuring that there is fair and equitable access for everyone, regardless of where they are. There would be a requirement to look at the spread of access and whether it discriminates against any particular group or community. That raises wider questions which, unfortunately, I do not necessarily have answers to.

Joe FitzPatrick: That was still a good answer, though.

Paul Sweeney: I thank the members of the panel for their contributions so far.

I turn to section 15 of the bill, on provision of assistance. Assistance is defined as

> “providing the substance to end the person’s life, staying with the adult until they have decided they wish to use the substance or, removing the substance if they decide they do not wish to use it.”

The bill does not explicitly provide that the substance would have to be self-administered, but self-administration is stressed in the policy memorandum and explanatory notes.

As part of its written submission, MND Scotland has referred to its concern about whether the bill is sufficiently clear in relation to whether people with physical disabilities—with, for example, a progressive condition such as MND—who would find self-administration difficult or impossible, would have access to assistance. I wonder whether Susan Webster would start us off with concerns about the definition of “assistance”.

Susan Webster: That was what we focused on in our evidence. As I say, we are neutral, but this is an issue that we feel we have had to address, because we feel that, if self-administration is the only option, it will, for the reasons that I outlined earlier, impact on whether people with MND are able to access assisted dying. MND is a progressive debilitating illness—it is very quickly progressive. From the outset, people can struggle to use their hands, and others can struggle to speak and swallow, so self-administration is a concern. As Stephanie Fraser touched on earlier, there is not a lot of detail about what self-administration would look like. However, it is a real concern and it jumps out that quite a large population might be unable to access it.

I reiterate the concern that I raised earlier: if self-administration is the only option, people could feel that they have no alternative but to access an assisted death much earlier than they would otherwise choose, so that they are actually physically able to do what is required of them.

Paul Sweeney: That is interesting. Do other witnesses have comments on the current drafting of that section of the bill?

Stephanie Fraser: I agree with Susan. Again, people with cerebral palsy can experience reduced dexterity or swallowing difficulties and might struggle to ingest medication. It is not clear what self-administration actually means—I talked about head switches and so on earlier—so clarity would be great.

The bill is also silent on what the medical practitioner should do if something goes wrong. What is the medical practitioner, either in the room or not in the room, meant to do?

Paul Sweeney: That is an interesting question. Ms Cahill, do you have any points to add?

Vicki Cahill: I reiterate that the bill might create issues with regard to fair and equitable access for those with physical, or perhaps cognitive, impairment that might affect co-ordination, but are able to satisfy the other criteria to reach that particular stage in the process. Again, it is about supporting individuals to exercise their autonomy and how we do that. That could be through alternative approaches—for example, liquid forms or other supports, rather than tablets, such as head or finger switches for individuals. How that might work in those examples should be explored.

I go back to the point about ensuring that part of that capacity is the ability to act. Being able to self-administer requires that ability, so legislation needs to consider that. Any suggestion of an intervention by another individual in any way, shape or form, or of any other type of intervention, might change the scope, parameters or intention of the bill, so the question whether such suggestions would fall within the intention of what has already been set out would need very much to be considered.

Paul Sweeney: I really appreciate your initial thoughts on that.

Section 15(1) of the bill simply mentions someone providing

> "a terminally ill adult with an approved substance with which the adult may end their own life."

The UK bill contains more detail on what is permitted in the definition of self-administration, in that it states that

> "the coordinating doctor may—
>
> (a) prepare that substance for self-administration by that person,
>
> (b) prepare a medical device which will enable that person to self-administer the substance, and
>
> (c) assist that person to ingest or otherwise self-administer the substance."

Would you like to see the bill being amended to have that level of detail or something similar? Is that, in essence, what you are asking for?

Susan Webster: Well, we are not really asking for anything, apart from awareness that the bill, as it stands, could exclude a lot of people. I have listened to previous evidence sessions. Provisions are included in the English bill and perhaps in other countries, too, such that people who cannot self-administer are permitted to seek medical intervention in the process. We would not say what should be done—that decision would be for other people around this table to make. However, as we read it, the bill will clearly exclude many people with MND. There could be more detail around self-administration or the special circumstances in which a medical professional could get involved, but that would be for you guys to decide.

Paul Sweeney: It looks like there are no final comments on the need for amendment to improve the definitions.

Sandesh Gulhane: To touch on some of the things that you have said so far, and following on from Paul's questions, I note that I am not clear whether you would like tighter restrictions on, or greater access to, assisted dying. Could you help me to understand that?

Vicki Cahill: The purpose of the evidence that we have put forward is to present both sides of the argument. Ultimately, it is for people here and our parliamentarians to consider those options. We choose neither to support nor to oppose the bill, but we have decided to raise the issues and concerns that might come about if there is a decision either to include or exclude people with dementia.

We are happy to engage further based on any amendments that might come forward if the bill moves through the legislative process beyond stage 1. We choose to support neither option but, instead, to reflect that opportunities exist in both directions depending on whether, and how, the bill progresses.

The Convener: I thank all three witnesses for their evidence, which has been very helpful to the committee in its scrutiny of the bill.

I briefly suspend the meeting for a changeover of witnesses.

10:31

Meeting suspended.

10:42

On resuming—

The Convener: We continue our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill with a second panel of witnesses from organisations that represent individuals with disabilities. I welcome Tressa Burke, who is chief executive officer of the Glasgow Disability Alliance; Lyn Pornaro, who is chief executive officer of Disability Equality Scotland; and Marianne Scobie, who is depute chief executive officer of the Glasgow Disability Alliance but is here to represent the Glasgow Centre for Inclusive Living. Tressa and Marianne join us online, while Lyn is here with us in person.

We move straight to questions from David Torrance.

David Torrance: Good morning, everyone. Is the definition of terminal illness in the bill drafted sufficiently clearly to apply only to people with terminal illness?

Lyn Pornaro (Disability Equality Scotland): No. Whenever there is a definition, it is open to interpretation. I am sure that we all know individuals who have been given a terminal diagnosis and an estimated time for the remainder of their life, yet they have survived for much longer through the use of different treatments, through new treatments becoming available or just from living their life for longer.

In simple terms, it is not clear. If there has to be a definition, it must have no ambiguity to it and there must be no way that somebody could interpret it in a different manner, because we are talking about people's lives. When medical professionals estimate length of life, they sometimes get it wrong—they say that themselves—because we do not know when a person's life will end in that manner.

The answer is therefore no. The definition is not strong enough or clear enough. We asked Disability Equality Scotland members about the definition, and different people said that it could mean this or it could mean that—straight away, you can see that it needs to be really tight and clear.

10:45

Tressa Burke (Glasgow Disability Alliance): I will build on what Lyn Pornaro has said. I completely agree with her. Glasgow Disability Alliance members are concerned that the definition will apply to many disabled people. I know that Liam McArthur has reassured some disabled people's organisations that the definition would allow only those with advanced and progressive terminal illness and mental capacity the choice of accessing an assisted death. However, we were not aware of that, because the language that is used in the bill's definition of terminal illness makes no mention of advanced and progressive terminal illness. We felt very much that the definition could apply to disabled people.

Glasgow Disability Alliance is a pan-impairment organisation, which means that we have almost 6,000 disabled members with conditions and impairments that span the full range. Many disabled people are born with impairments, but many more acquire illnesses and conditions during their lifespan, possibly through strokes, accidents, cancer or having conditions such as multiple sclerosis, like me, or motor neurone disease, which was covered in the previous evidence session and in the written evidence from the organisation that represents people with MND.

There are so many conditions that could fit under the definition, and our worry at this point is that discrimination and prejudice are endemic in society and, despite all best efforts, no law is immune from that. We are very concerned that the definition is too wide and that many disabled people will fall under it.

Marianne Scobie (Glasgow Centre for Inclusive Living): I echo what Tressa Burke and Lyn Pornaro have said on behalf of their organisations. The Glasgow Centre for Inclusive Living also feels that the definition of terminal illness is not correct and not understandable enough. We feel that it would apply to many disabled people who have life-limiting conditions that they are unlikely to recover from and that would reasonably be expected to cause premature death.

Sorry—I should have said that, like Tressa Burke's organisation, we are a pan-impairment organisation.

Within the bounds of the Equality Act 2010, people with terminal illness are also defined as disabled people, and because of co-morbidities, many disabled people develop terminal conditions as well as their existing conditions. Studies have shown that doctors and other health professionals are not very accurate when predicting how long someone has left to live. Accuracy can range from 23 per cent to 78 per cent, which is a range of accuracy—or inaccuracy—in relation to predicting how long someone has left to live.

Many people live with terminal conditions for many months or even many years, and we are concerned that people might make decisions to end their life based on an inaccurate prognosis of their condition and situation and without any mental health or other support to enable them to process and cope with their diagnosis. When given a terminal diagnosis, many people's immediate thought is, "I don't want to live any more—I'd rather die than go through a terminal illness." However, with the right healthcare, mental health care and peer support, many people can live with a terminal condition, and live well. We promote the idea that people should be supported to live well while they are dying, including from a terminal illness.

In addition, we are concerned that the legislation might widen out to include people who are not terminally ill. I am sure that we will go on to talk about that.

David Torrance: Many of the submissions from those who are against the bill say that it would be the start of a slippery slope. Do you think that the bill, if passed, could be expanded without parliamentary oversight to include people with disabilities? If so, are there additional safeguards that you would like to see to prevent that from happening?

Lyn Pornaro: There has been talk about countries where similar bills have been passed. There is an argument that we cannot look at other countries because they have different laws. However, when we look at countries that have brought in some kind of assisted dying legislation, their bills have been expanded.

I would hope that the bill could not be officially expanded without going through parliamentary scrutiny, because I hope that none of our bills could be amended without that happening.

There is concern from our members and from disabled people. There is a little bit of—I am not sure what word I am looking for because I am quite tired today—interpretation of laws and bills. We see that all the time. Disabled people are concerned that they will be directed towards assisted dying rather than looking at palliative care during terminal illness, whatever the definition ends up being if the bill goes through. There is a small sidestep from that to saying that something might not be a terminal illness but that it might be causing a person challenges in life and that assisted dying might be an option.

We are all aware of situations during the Covid pandemic when a lot of disabled people had "do not resuscitate" notes put on their files without any consultation or approval. We heard of one case recently where an individual who did not have capacity had that note put on his file because doctors had asked the question and the person had said that was okay, but without the legal situation being considered.

Those slippery slopes could become the norm, making it so much easier to widen that out. There is a lot of evidence from people who have lived in other countries and have been offered assisted dying as an option because of that slippery slope, but who refused it and are now against the whole idea of that progressing more widely.

Marianne Scobie: We are absolutely certain that the approval of legislation to legalise assisted dying will very quickly open the door to widening the eligibility criteria. We have seen that in other countries where assisted dying is legal and eligibility has been widened out to include children and young people, as well as other adults. The legislation might not be widened, but the practice and implementation of that legislation is widened. We firmly believe that legislative creep is an inevitable consequence of legalising assisted dying.

Campaigners for assisted dying highlight the personal stories and tragedies of disabled people's lives to promote the assisted dying cause. There is clear evidence that disabled people's lives and lived experience have been used to promote assisted dying by campaigners who support such legislation. It is extremely naive and dangerous to expect that those campaigners would be satisfied with the eligibility criteria as proposed in the current bill.

Very soon after the recent vote at Westminster, there were already calls to widen the scope of the legislation and reduce safeguards such as the need for a judge to make a ruling. Those who were not eligible for assisted dying under the original legislation might claim that they are being discriminated against because they are prevented from accessing it. We heard about that from the previous panel. That would include people who cannot self-administer drugs, which would open up the scope for people who are currently excluded, including disabled people.

Guidance and implementation have been widened in every country or state where assisted dying is legal, so there is no reason to believe that that would not happen in Scotland. There are other pieces of legislation in Scotland that seem quite tight on paper but are not tight in how they are administered and put into practice. I point to the self-directed support legislation as an example of that.

There are numerous examples of eligibility criteria being widened. In Oregon, for example, cancer remains the main qualifying diagnosis, but it fell from being a qualifying diagnosis in 80 per cent of cases in the first five years to being a qualifying diagnosis in only 64 per cent of cases in 2022. Other diagnoses have been listed as making people eligible for assisted dying, such as arthritis and other non-terminal illnesses, as have people experiencing extreme socioeconomic disadvantage such as homelessness, people not being able to find mobility equipment and so on.

Also, the doctor-patient relationship timeline has lessened. It reduced from 18 weeks to an average of five weeks in 2022. That means that people could be doctor shopping to find a doctor who will classify them as eligible, which shows that the safeguards become widened and nullified over time. It is our opinion and the opinion of all the DPOs in Scotland that that would be an inevitable consequence of enacting such legislation for assisted dying.

Tressa Burke: As you have heard from Marianne Scobie from the Glasgow Centre for Inclusive Living and from Disability Equality Scotland, Inclusion Scotland and other DPOs, disabled people are incredibly strong in their opposition to the bill because we feel that we will be the ones at the thin end of the wedge when it comes to assisted dying.

This perhaps crosses over into other areas, but Marianne Scobie touched on what happened during the pandemic. Glasgow Disability Alliance members were terrified by what happened with “do not resuscitate” orders being found on their medical notes, and by being asked to co-operate or comply with those while not fully understanding what they meant. Very inappropriate conversations were had at very inappropriate life stages, and not at the point of terminal illness or end of life. Disabled people’s lives were relegated to being of little value and it was increasingly apparent that some people had the attitude that it did not really matter if disabled people died, because we were already vulnerable.

When we heard reports of who had been dying every week from Covid, there was analysis that said that people who might have had an underlying condition or who were old would not otherwise have enjoyed a good or full life. That made disabled people feel that they were worth less and that our lives had less value, less currency and less meaning. That evidence was enough for our members—we had 5,000 at that time and the number now approaches 6,000—to take the approach of campaigning and lobbying us to do work on assisted dying. We ran workshops, showed films and did what Glasgow Disability Alliance and other DPOs do—we provided support and information so that people had the space to talk, ask questions, find out information and deliberate on this really emotive subject.

Unlike some of the organisations in the previous evidence session, we take a very clear stand against assisted dying. We simply believe that it will creep and that disabled people will be at the thin end of the wedge. All the threats that have come, such as austerity, cuts to services, Covid, the cost of living crisis and now the ruthless warnings that we hear about cuts to disability benefits, make disabled people feel that they will be at the thin end of the wedge.

The Convener: I call Liam McArthur.

Liam McArthur (Orkney Islands) (LD): I will not touch on the arguments about a slippery slope; all the evidence shows that there is not a jurisdiction with a terminal illness and mental capacity model in which the eligibility criteria has been expanded over time.

Rather, I want to highlight that, while the point is being made that disabled people are uniformly against assisted dying, all the polling evidence suggests that support for it among the disabled community as a whole broadly maps the position of the population at large.

11:00

I am aware that, back in 2022, Disability Scotland undertook a survey of its membership, which showed strong support for assisted dying among 57 per cent of its members and support among 20 per cent, with opposition at just over 10 per cent. I understand that there are anxieties in the disabled community, but I am interested in hearing the witnesses’ response to the argument that support, or interest in finding out more about the issue, is unlikely to be helped if the view of the legislation that is presented comes from the perspective of opposition, rather than challenging neutrality.

In the light of the position that members of the disabled community appear to take on the issue, is that not a more reasonable way of eliciting the views of disabled people? I put that question to Tressa Burke, because she spoke last, but I am sure that others will have a view on it, too.

Tressa Burke: Thank you for your comments, Liam. I can understand that a lot of what is driving the agenda for assisted dying among many people will be about compassion and an end to unnecessary suffering, and people’s autonomy and choices at a particularly difficult point of life. For disabled people, however, I struggle to believe that the groundswell of support that you describe would exist among Glasgow Disability Alliance members. I know for a fact that the people with whom we have engaged have almost universally been against it.

I am not saying that that view is unanimous; there are extremely small numbers of people—a handful—to whom we have spoken in meetings, but it is never more than one person among a couple of hundred people at a time who might have concerns for exactly the reasons that you state. However, we believe that disabled people’s lives have been devalued and deprioritised. During the pandemic, when we spoke to disabled people at wellbeing check-ins, we uncovered that 90 per cent of our members at that time felt lonely and isolated. People were concerned about their access to services, and 55 per cent who participated in one particular piece of mental health research expressed having suicidal feelings in the past two years. A whole range of exclusion was uncovered during that time.

We subsequently repeated an in-depth survey with 30 questions for disabled people who were members of the GDA; it was restricted to our membership. A total of 621 people responded to that survey. People spoke about feeling forgotten about by Government, and about having concerns around money—that was 93 per cent of people, with about 71 per cent saying that they could not afford to manage their bills. A total of 91 per cent were experiencing social isolation and loneliness and 89 per cent of people were experiencing difficulties with mental health.

Those are statistics, but there are people behind all of them, and the overwhelming fact is that people do not know where to get support and are not able to access the service and supports that they need. Where there are services, they are often available but not accessible to disabled people. It is clear that disabled people are experiencing exponential interrelated barriers that sometimes make them feel that their lives are not worth living.

Disabled people feel that—as I described earlier—they will be at the thin end of the wedge, for all those reasons. I do not think that there are any safeguards that we feel could be put in place, because of the slippage that has occurred in other countries and the evidence that we are seeing around this issue with regard to austerity. When things get tough for Governments, Governments get tough on disabled people. If we had not seen the evidence during Covid, we are seeing it with the UK Government's cut in the winter fuel payment, and now with its threats to benefits specifically for disabled people. Unfortunately, that is often replicated in cuts across the devolved Administrations, simply because money is so tight.

When we say, therefore, that we are concerned that we are at the thin end of the wedge, we are using evidence to say that—it is not just a gut feeling or sense of intuition. We are saying it on the basis of evidence of extreme disadvantage, and of disabled people dying not only from Covid, but as a result of health inequalities. I cannot tell you the number of funerals that I have been to over the past couple of years. That is partly because of Covid, and partly as a result of health inequalities, and sometimes suicide. Disabled people have taken their own lives, not necessarily because they were in a state of mental ill health before the pandemic, but because the cumulative impact of disabled people not having the services and support that they need, and the isolation that they experience, is so bad that their lives become unbearable and not worth living.

However, our disabled members who access the independent living fund, for example, and get the support that they need to live the lives that they want to live tell a very different story. We want service and supports for disabled people so that everybody can enjoy that kind of life.

The Convener: I call Brian Whittle.

Brian Whittle: I am listening to the witnesses—you are obviously very passionate in your views, Tressa. However, I am wondering whether your comments are not so much about the bill but more about the way in which society—and Governments, potentially—currently treat disability and disabled people in terms of access to services. Would it be fair to say that it is more a comment on that, rather than specifically about the bill?

Tressa Burke: Thank you for your question. In response, I would say that it is both a comment on the bill and a wider comment about disabled people's place in society. Historically, disabled people have been put at the bottom of society whenever there are problems and whenever money is tight. As I said, when things get tough for Governments, Governments get tough on disabled people. However, we are also concerned about the bill, including a potential widening of the scope and the definitions not being clear enough.

Unlike the organisations that gave evidence in the previous session this morning, Glasgow Disability Alliance is not neutral. We are not saying that, if the bill goes through, we want to work with you on the wording of it; we are saying that the timing is completely wrong. How can we pass such a bill, at this time of complete austerity, with all the cuts to services?

We are on the phone to social workers who are crying because they cannot uphold disabled people's human rights—in fact, they are being forced to erode those rights. The very people who got into their job—I say this as someone who trained in social work myself—to try to uphold rights and make people's lives better are actually having to undermine that. How can we introduce such a bill at this time, when we should be looking at how to help people to live a better life? We should also be looking at investment in public services and in palliative and end-of-life care and support.

The Convener: Marianne, do you want to come in on Mr Whittle's question?

Marianne Scobie: From our perspective, it is important to remember that, as Tressa Burke said, there are very few disabled people who are part of our organisations who have said that they support the bill. When we have asked those few people why they support the bill, every single one of them has said, "It's because I don't want to be a burden on my family", rather than because they fear dying in pain, or suffering. That is completely different from the intention of the bill. The reasons that people give involve their current living situation.

I go back to the survey that Liam McArthur mentioned, because it is important to clarify that point. Lyn Pornaro is the chief executive of the organisation that came from the previous organisation that was mentioned—Disability Scotland no longer exists. When the survey that Liam McArthur highlighted was completed, we, as a group of disabled people's organisations, interrogated that data and found that there was no way to check back on whether it was disabled people who were members of the organisation who had completed the survey.

The situation is similar with other surveys—60 per cent of disabled people face digital exclusion, which means that they are not able to go online and put forward their views in surveys, via online comments and so on, including in relation to this particular bill. Disabled people are actually disengaged from being able to participate in capacity building, which affects our understanding of their views on legislation, including on this particular bill. Disabled people cannot put forward their views in the way that non-disabled people can because they do not have the information, skills, capacity or opportunity to contribute.

The reason why our organisations have become opposed to the bill is that we have done significant in-depth capacity building with disabled people, presenting all sides of the arguments and helping people to discuss and debate, and deliberate on, their views and opinions and come to these conclusions. We absolutely have supported disabled people to come to these viewpoints, and it is because of the strong views of disabled people that our organisations have come to these views.

Other surveys have taken place with regard to the views of disabled people's organisations across the UK. Again, however, those surveys were quite disingenuous—if organisations did not have it on their website that they were opposed to the legislation on assisted dying, it was assumed that they were either neutral or pro the legislation. Some of the survey results that have been published, therefore, do not present the real, genuine views of disabled people and their organisations.

I will finish on another point: when we do speak up, we are targeted for abuse. Many of us are involved in campaigning either outside or as part of our organisations, and when we speak up, in particular on social media, we are targeted personally for abuse and harassment, and there is hostility in relation to our views, which makes us reluctant to speak up against this sort of legislation.

We have to think about the fact that disabled people want to have their views heard, and they want to be part of the collective voice of disabled people as part of our organisations. Some of that is about protecting themselves from the abuse and harassment that they get when they speak up as individuals. We need to remember that that is the reality for disabled people.

Tressa Burke and I are attending the committee online today because we are not fit and able to appear in person. We are confident and articulate disabled people who are leading organisations, yet we are not able to be there in person. We cannot always present ourselves in front of you, apart from appearing online. It is really difficult and challenging for disabled people to have their voices heard, and we need to remember that.

Emma Harper: I thank Lyn Pornaro, Tressa Burke and Marianne Scobie for being here this morning.

I remind everybody that I am a registered nurse. To continue on a similar trajectory, I am thinking about autonomy. We have talked about the definition of "terminal illness". The bill is designed to apply to individuals with a terminal illness, and the definition of that might need to be altered. How can we address the concerns of disability groups while respecting the autonomy of those who are seeking to access assisted dying?

I am looking at Lyn first, but only because she is in the room—I am sure that Tressa and Marianne will want to answer, too.

Lyn Pornaro: I am happy to speak to that. We need to look at disabled people's lives in full, as we would for any citizens in Scotland. Opinions and thoughts change as people develop new knowledge and understanding of their conditions, their terminal illness and so on.

Last year, we held a focus group with members, and we had phone calls with them, as well. Individuals who said that they were supportive of the bill made it clear that their support was always subject to there being sufficient safeguards and to the autonomy of all individuals being upheld. One person said:

> "Persons living with disabilities are not having their rights listened to currently. Their views and rights regarding assisted dying may be ignored—or not even asked about!"

That was a concern that people raised.

In respect of autonomy, we have to consider a raft of issues, starting with individuals who receive a terminal diagnosis and who require, as Tressa Burke mentioned, the time to absorb the news and understand what that might mean for them.

11:15

We are concerned about individuals who do not have, but are seen as having, capacity and about individuals who are not seen as having capacity but do have it. There are issues around autonomy not only in making the decision but in going through the process of having conversations and taking medication—whatever that looks like at that point in time. What about individuals who physically cannot administer medication themselves? What if they change their mind?

There is a raft of things for individuals to consider, as we do in our day-to-day lives. We have different thoughts on different days, and we sometimes have different opinions about things on different days. Our members feel clearly that there needs to be something in the bill about allowing reasonable adjustments for people who cannot administer medication themselves.

We have had one person say to us that there needs to be an opportunity for people to make the right health decisions for themselves and that that should be done by keeping people informed, not just by saying, “This is an option for you—this is roughly what happens; make your decision.” There needs to be support and counselling, and there needs to be help in order for people to understand what other options are available to them. Some of our members are concerned that, should the bill be passed, assisted dying would be the automatic option rather than other options, such as palliative care support or treatments, being available.

There needs to be a specified amount of time between receiving a diagnosis and, should the bill be passed, requesting assisted dying. There needs to be full understanding of what that means. We talk about choice and control, and people should absolutely have that. However, our choices are not usually so final. In life, we have choices, but we can change our mind and go back, whereas assisted dying is a final choice.

One question that was brought up, on which our members had a big discussion, was on what constitutes unbearable suffering and what constitutes dignity. That will be different for every person, and our discussion went through those considerations. How do we determine that when what is right for one person might not be right for someone else? If we are looking at the definitions, how can we define that for someone who is suffering as a result of their terminal illness or condition? On one day, they might feel that it is unbearable; the next day, it might be a different scenario.

Marianne Scobie: It is difficult for someone to make a truly informed decision about their own care and treatment when they are limited from the beginning. It is difficult for someone to make a choice when they are not supported in the right way with their mental health. As Tressa Burke said, 55 per cent of disabled people who were surveyed by the GDA said that they had had suicidal thoughts in the past two years. Importantly, that survey was a survey of disabled people who did not have a diagnosed mental health condition—they were simply disabled people who were experiencing mental health challenges. It also excluded people who were currently undergoing a mental health crisis. That is an important point to consider.

Our lives as disabled people are portrayed as tragic and worthless all the time on television, in literature and in the media, and many people start to internalise those feelings and think that they would be better off dead if they cannot walk, talk, feed themselves or go to the toilet. Many people who become disabled through illness or accident, including terminal illness, do not receive the mental health support or access to peer support to enable them to come to terms with their diagnosis.

There is no provision in the bill for mental health assessments, as far as we understand it. We have seen from the review of what has happened in Oregon that, over 25 years, just 1 per cent of those opting for assisted dying underwent any psychiatric evaluation. Many members of our organisations tell us that they have contemplated or attempted suicide prior to joining the organisation because they felt that their life was not worth living. A lot of that is due to the fact that people are forced into living really undignified lives. Someone told us, “I’ve been forced into using adult nappies, even though I’m not incontinent, because my social care package has been cut so much.” We see that more and more often.

As I said earlier, many disabled people who say that they might support the bill say that they would do so because they would not want to be a burden on their family. We argue that that in itself demonstrates that disabled people would be affected should assisted dying become legal, because its supporters will push for eligibility extensions, and the lack of available support for disabled people further intensifies the burden that disabled people feel that they represent. In short, when someone’s life is so dire and tragic, it is not a choice if they feel that they have no choice but to opt for assisted dying.

As a society, we should prioritise assistance to enable people to live well and die well with the support that they need, rather than prioritising assisted dying from a medical perspective. We should prioritise funding and resources for health and social care, particularly for palliative care, so that people can live and die well, and we should not prioritise medical assistance to end life.

Emma Harper: I have a final question. Is assisted dying any different, in principle, from a person's right to refuse treatment or intervention such as artificial hydration and nutrition? In my experience of looking after people at the end of their life, they sometimes choose no further methods that would support them, such as subcutaneous fluids.

Lyn Pornaro: I am just getting the words right in my head to answer you.

Yes, people have a right to ask for no more fluids and so on, although that is sometimes forced on them, too. However, they also have the right to turn round and say, "Actually, no—I want fluids again", or that they want food or medication. At that point, they are choosing to go through a natural death and to allow their body to survive as it will for as long as that needs to be.

We hear the message that assisted dying is an option for people, and it has been spoken about as a treatment option, but it is not—it is an option to end someone's life, and that is suicide. When people choose to take their own lives, it causes so much pain and distress for family members and others, and assisted dying is no different. In Scotland, we spend quite a lot of time, energy and money on preventing suicide. It feels incongruent, therefore, to turn round and say, "But you can choose to end your own life in this manner."

In addition, the choice that people make when they decide that they do not want any more treatment or any further assistance—whether they are in palliative care, in hospital or at home—is based on being faced with the fact that they know that their death is absolutely 100 per cent imminent within, more than likely, a few days or a week or so. In the bill, we are talking about people who receive a terminal illness diagnosis of six months to live, but they have a choice of when the end is actually going to be. As a society, we either acknowledge the sanctity of life or move away from what actually makes us human.

Some disabled people have a fight on their hands from the moment that they are born. They have to fight to get the support that they need, to be heard, to be listened to, to be valued and, sometimes, to be educated. They have to fight to live life and have opportunities in the same way as non-disabled people do—they have to fight for fairness. They are neglected, and they have their human rights taken away from them. In Scotland, we cannot even incorporate the full rights of disabled people into our laws because of the challenges that are faced.

Do we have the right to recommend that people consider assisted dying as an option—that is how it will be presented—rather than allowing them to go forward and refuse that option when they know that things are imminent?

As you said, people sometimes refuse further treatment and so on when they are at the end of life. Sometimes, treatment is forced on people—they still receive hydration and so on even if they are refusing it. We know that there is no perfect solution or system for individuals at the end of life. However, given that we already have systems that do not uphold the rights and autonomy of individuals to make the decisions that they want to make, how can we introduce something that is even more final and will not allow people to have their rights or wishes upheld?

Tressa Burke: On the question of autonomy, which, broadly speaking, is about being able to act without having to consider other influences, we feel that the impact of structural inequality is absent from the bill. That relates to all the things that we are talking about. The decisions of people living with long-term or terminal illnesses could, for the reasons that have been outlined, be influenced by their need for support, by the barriers that they face in getting the support that they need to live a full life and participate in society, and by the exceptional poverty that they face.

We know that 62 per cent of disabled families are more likely to fall into deep poverty and that 25 per cent are having to sell household belongings to make ends meet. According to the Joseph Rowntree Foundation, in total, 70 per cent of disabled families have had to cut back on essentials. Those are external influences, but they are factors that might influence the decisions of disabled people about assisted dying, because of the failure to tackle structural inequalities and help people to live.

The Convener: I call Sandesh Gulhane.

Sandesh Gulhane: I declare an interest as a practising GP.

I turn to the people online. From what I have heard, disabled people are universally opposed to the bill. You spoke about gross societal inequalities for disabled people, Tressa. Before we go to the stage where the bill can pass, would you like to see an amendment lodged that specifically excludes people with disabilities from being able to access assisted dying?

Tressa Burke: I need to give that some thought. Do you have a response, Marianne?

Marianne Scobie: The question is an example of why the issue would be quickly left open to legislative creep, because if you exclude disabled people from being to participate in the process then you are discriminating against them.

11:30

When we are talking about our organisations, we are talking about disabled people who are connected to our organisations and who have had the time, capacity and support to recognise the discrimination that they face and to understand the social model of disability, which is basically talking about the barriers that we face as disabled people not being ingrained in us but being society's barriers.

Sometimes, when disabled people do not understand their own oppression or recognise the discrimination that they face, they might feel like they would be better off dead—and many people feel like that. However, when disabled people begin to understand that the social inequality and the structural inequalities that they face are not their fault and can be addressed by different policies and by Governments doing things differently, their opinions change. It is difficult—

Sandesh Gulhane: Can I just go back to the question? You have made your point very clear about the structural inequalities and the real problems that people with disabilities are facing. However, my question was not about legislative creep or about what could happen; it was specifically about whether a member of the Scottish Parliament should introduce an amendment to exclude disabled people from accessing assisted dying.

Marianne Scobie: Yes, but I was saying that, if you were to lodge such an amendment, there would be calls for its scope to be widened so that disabled people who become terminally ill, for example, would be excluded. How can you possibly have an amendment that says that disabled people would be excluded when people who are terminally ill are defined as disabled people under the Equality Act 2010? That legislation would cancel that out.

When someone has a terminal diagnosis, they are defined as disabled people under the 2010 act, so you cannot put in a provision in another piece of legislation that would exclude disabled people. That would not make any sense. It would not fit from a legal perspective.

Sandesh Gulhane: Okay. You would not want such an amendment to be lodged, then.

Marianne Scobie: We did not want the bill to be put forward at all.

Sandesh Gulhane: Okay. Tressa Burke, do you have a view on whether somebody could lodge an amendment to specifically exclude people with disabilities?

Tressa Burke: Thank you for asking me that again. I initially hesitated, as what was in my mind was exactly what Marianne Scobie said. How can you exclude disabled people when the definition of disabled people would include people with a terminal illness? I was confused by your question, although I think that I understand the sentiment behind what you are saying.

The problem is that doing that would create inequalities and the unintended consequence would itself be discriminatory, and that might be problematic from the point of view of the 2010 act as well. A technical problem would arise from doing that.

As Marianne said, our position is that we would rather not have seen the bill's introduction.

Sandesh Gulhane: Okay. I turn to Lyn Pornaro. You talked about the sanctity of life. That seems to me to be a religious discussion and argument. Is that your position or was that just a turn of phrase?

Lyn Pornaro: It was just a phrase. As a society that is part of the western world, we have always upheld life. Our medical professionals might take the Hippocratic oath, which refers to upholding ethical standards and doing no harm. My point is that life is important. I was not making a religious point. All our lives should be valued and they should hold value regardless of who we are or whether we are disabled or non-disabled. My view, which is based on how I have been brought up and what I have experienced in Scotland, is that we all have value to bring and that every life is important.

If we saw someone who was in distress and looked as if they were going to attempt to take their own life, we would do all that we could to stop that and to give them support. I am not sure why we would spend so much time trying to prevent people from committing suicide if, on the other hand, we are saying that it is okay to end your life. That is where I am coming from when I referred to the sanctity of life.

Sandesh Gulhane: I have a final question. We have just now received an email from somebody whose husband went to the Dignitas clinic in Zurich, expressing their support for that person being able to choose what happened to them.

Given that there is opposition to the bill from disability groups, what would you say to people on the other side of the issue who would like the legislation brought in for them—for their autonomy and their choice?

Lyn Pornaro: I can see the other side; I think that we all can. We have members who support the bill in principle, subject to sufficient safeguards, more definitions and so on, and we have other members who are totally against it. We had a very good focus group, in which people actually listened to conversations. Some of the individuals in it were living with terminal illnesses; again, there was a mixture of viewpoints in that regard.

When it comes to how someone else lives and what they choose in their lives, I do not think that any of us have the right to say what someone can or cannot do in that regard—that is a personal viewpoint. If the bill comes into effect, that would be the law, so people would have that choice, as they have a choice, perhaps, of where they stay or what job they do or that kind of thing. Obviously, we would support people.

The argument is that, as the bill stands, disabled people cannot just look at the bill in terms of one thing. It is about people's full lives, and they have faced challenges, whether throughout their lives or for a period of time, as my colleagues here have said, around getting support, around poverty, and around barriers that they face day after day. That is the challenge that we have with the bill.

For a variety of reasons, disabled people often do not have the capacity to fully understand and to express their viewpoints, and they are often pigeonholed into square holes and told "We know what is best for you." The medical model that our society adopts is wrong. It is seen as saying, "This is what is wrong with you."

I am here today. I have been a disabled person all my life; however, I did not know that. Because I had long-term conditions that affected me, I was disabled according to the Equality Act 2010, but I did not know that. I only really started talking to myself as, and identifying as, a disabled person after catching Covid, because then I had breathing issues and was not able to walk any distance and so on.

When I look back at what I experienced—my challenges, what I faced over my life and what I would have said about it—I see that the challenges were there, but I did not always see them. As Marianne Scobie mentioned, sometimes we do not see the barriers, the discrimination and the challenges that we face until they are brought to the forefront and our eyes are opened in that regard.

For individuals who are choosing to end their life, such as the person who you were emailed about who chose to go to Dignitas, that was their choice at that moment in time. We do not know what that person's life has been like. Have they been a disabled person? Have they faced adversity or poverty? Have they been ignored? Have they had their dignity, their choice and their control taken away from them over and over again, before they got to the point where they chose to go to Dignitas? We do not know that scenario.

We are representing individuals who have had choice and control taken away from them, day after day. They have faced barriers, discrimination and, as Marianne mentioned, abuse for standing up for their own rights—not necessarily in relation to the right to assisted dying, but any rights. Therefore, their choice when they are coming towards the end of life is a completely different scenario than it is for non-disabled people.

The Convener: I am conscious of time and we still have a lot of questions to get through, so I ask members and witnesses to be succinct. I call Gillian Mackay.

Gillian Mackay: Thank you, convener. You will be pleased to know that I will ask only one question. I will go to Tressa Burke first. We have already explored quite extensively the structural and societal barriers that disabled people face. As a disabled person, I recognise many of the things that have been spoken about. In terms of those structural barriers, could services ever reach a point where the witnesses would be satisfied that a decision to have an assisted death was entirely free from pressure and that the introduction of assisted dying legislation was taking place at the right time for disabled people? I appreciate that you might not have been able to put that to your members and you might be speaking in a personal capacity.

Tressa Burke: Thank you for your question, which is an incredibly complicated philosophical question. I would push back and ask whether politicians could ever adequately fund services so that disabled people and people who need them across Scotland are not in dire straits and facing all those potential influences.

However, separate from that, there will always be risks around coercion. At the best of times, if the legislation had been introduced, we would be urging safeguards around coercion, because coercion is one of our biggest fears. The creep in eligibility is the number 1 issue, but coercion is pretty high up there with all the things that we have talked about, for all the reasons that we have mentioned, which I will not rehearse. There needs to be more progressive taxation and better investment in services, and disabled people must be valued as part of society more equally than we are, rather than pretending that we are ever going to be equal.

As one of the previous speakers said, we are devastated that the humans rights legislation has been paused and that there will be no incorporation of the United Nations Convention on the Rights of Persons with Disabilities.

In relation to Lyn Pornaro's point, as disabled people or DPOs, it is not about religion for us—certainly not for the three of us on this call, although it might be for some of our members. For us, it is about human rights, and it is also definitely about human rights for our members. It is about the protection of disabled people's human rights by the European convention on human rights and the UNCRPD. The erosion of those rights that we have described has being happening for 15 years and it has got worse and worse.

Even at the best of times, there would be the risk of creep and coercion, which I think is more about what you are getting at—influential factors that might make people make those decisions. We cannot ever fully know what those factors might be in relation to people who have limited capacity, whether it is because of mental health, learning difficulties, or even physical impairments that restrict their lives, and how much they could be undermined by families or people who do not have good intentions towards them. That would not be our experience. Most family support is powerful and important.

Your question is a really complicated philosophical one and it requires an awful lot of thinking through.

Gillian Mackay: Does anyone else want to come in?

Marianne Scobie: To echo what Tressa Burke said, I cannot imagine a world in which disabled people have full human rights.

Carol Mochan: My question relates to the situation if the bill became law, so I will try to make it brief. Lyn Pornaro talked about assisted dying as a treatment option. I suppose that my question can be quite straightforward.

Under the Montgomery ruling, people should, rightly, have all the options put to them. In this case, as disabled people's organisations, would it help with the issue of pressure, in the way that you have described it, if that was not the case—that is, if assisted dying was not seen as a reasonable treatment option, and so was not discussed at that stage? Alternatively, do you feel, as you expressed before, that that might mean that people did not have all the options placed in front of them? If the bill was enacted and became law, how would you feel about that?

11:45

Lyn Pornaro: Our members do not feel that assisted dying is a treatment option. For them, treatments are about palliative care, which might be medication, physiotherapy, pain support and so on, to make them comfortable. They do not see this as a treatment option, and they do not want it described as a treatment option.

For the people who were supportive, subject to sufficient safeguards, it was clear that it should be the very, very last thing that is discussed. There should always be other options available. They did not see it as an either/or. If the bill goes through, they would run alongside each other. If individuals require palliative care, that would be their choice. Some people might be in palliative care and then make a choice around assisted dying, or vice versa.

It comes back to the fact that, currently, the assisted dying options—Dignitas has been spoken about—are there for people who can afford to pay for them. I assume that, under the bill, people would not be paying for it, and there would be that equality there.

If the bill comes in, we need to ensure that individuals have the options available to them, but also that they fully understand those options. We have spoken about the need for support so that they can understand what the terminal illness actually means for them. It is also about ensuring that the options available to them are not thrown at them all at once, because they need time to process and think things through.

Our members are clear that it is not a treatment option, but an option that people may have at full end of life and once they have explored all their other options.

Carol Mochan: In theory, though, people should be aware of the option.

Lyn Pornaro: They should be aware of the option, but other options should be fully discussed first—that is what our members were saying—rather than people being given all the information about assisted dying at the same time as all the other information. That would give people time to gradually process that and have their questions answered, as and when they need that.

Carol Mochan: Marianne, do you have a view?

Marianne Scobie: I think that Tressa requested to speak before I did, if that is okay.

Carol Mochan: Yes, of course.

Tressa Burke: Thanks.

Very quickly, although we have spoken a lot about structural barriers and inequalities, we have not spoken about the growing hostility and negative attitudes that disabled people face. Directly in relation to the idea of treatment options, we have been experiencing more and more uncaring attitudes across health and social care, and in other areas. With limited resources and capacity to deliver services, it is no wonder that people feel frustration and extreme stress and anxiety at their work.

We are very concerned that, in those circumstances, normalising assisted dying as a treatment option would further desensitise people who would normally be working not only to prevent death but to enhance life and make people's lives better. We are therefore really concerned about it being seen as a treatment option.

Carol Mochan: Given what you have said throughout today's evidence session, I absolutely understand.

If the bill became law, would your organisation find it helpful if assisted dying was not discussed at all, or should people have the right to have that option placed in front of them when they discussed their options?

Tressa Burke: If the bill was law, people would have that right, and it would not matter what I felt or what my members felt. As Lyn Pornaro said, if the bill became law and that was an option, it should be the last option, rather than something high up the agenda. We would much prefer that the bill did not become law.

Earlier, somebody—it might have been yourself—asked how I would feel. I would feel absolutely terrified—and I say that as somebody who was diagnosed with MS 35 years ago. I am very lucky and I have done well, although I experience a lot of different things that you cannot see. I thought that assisted dying would be the last absolute self-determination, and the greatest exercise of autonomy and choice, giving control at the end-of-life stage. Having now worked with disabled people for 30 years, I am terrified by the thought of it.

I am not thinking about myself, as a very empowered and privileged disabled person, who is more likely to have access to information, support and services; I am thinking about my members. There is no guarantee about it, but I am genuinely thinking about the people who do not have a voice, who cannot speak for themselves and who cannot agree, but who will experience coercion and pressures and all the influences that we have spoken about.

The answer to the question is that I feel absolutely terrified about it.

Marianne Scobie: I do not want to repeat what Lyn Pornaro and Tressa Burke have said, other than to say that I would echo it.

Just to pick up on one thing that Tressa said, as disabled people, we often have multiple comorbidities, and it is often difficult to get treatment for one part of your medical condition. Someone may present with one thing, and it is assumed to be linked to their existing medical condition, while other things and comorbidities can be missed. Disabled people do not necessarily get the treatment that they need or that they ask for.

It would be difficult to ensure that assisted dying is not presented as an option, with people being pushed towards particular options. Tressa mentioned the coercion that may result. As disabled people, we already see that we can be pushed towards particular options. There is denial of medical treatment, and people are denied treatments that work because they are so expensive. We would not want assisted dying to become an option on the table at the expense of other options that would treat people's conditions, even a terminal illness, and that would allow them to continue to live with that illness.

We seem to have skipped over the coercion aspect a wee bit. One of the issues arising from the bill is about people seeing their GP. People struggle to see their GP. They struggled to see their GP before the pandemic, and they struggle even more to see them now. Most GPs are not seeing people face to face; they are holding telephone appointments, and so on. How will GPs have any meaningful relationships with their patients?

Many disabled people have not been able to see their GP for some years. Even now, they are not able to see a GP even when they are quite ill. How can the GP build a relationship? How would they know whether there is any coercion in the patient's family? How would they know whether there is any coercive control going on in a person's particular situation? GPs have told us that they already feel that they are not in a position to determine that at this point, never mind at a point when someone might be asking about assisted dying.

There is no public health policy in relation to disabled people who need hoists to access screening programmes, so many disabled people become ill with cancer because they cannot access screening programmes. Way down the line, preventative measures are not in place to prevent disabled people from becoming terminally ill. It seems a bit difficult to be discussing end-of-life care and assisted dying, including for disabled people, when we cannot even get preventative measures in place.

We have not been able to find any GP surgeries in Glasgow with a hoist to support someone so that they can have an examination. There are disabled women who have not had smear tests for over 20 years because they cannot get a hoist. One of our members recently died because the female cancer that she had was not picked up, despite the fact that she was repeatedly telling various people in her life about her symptoms.

We have to think about preventative care, but we do not seem to be having those conversations. That is why disabled people are so worried and scared. If you put all the energy into assisted dying, where will the momentum be to fund, resource and promote preventative measures for disabled people? At the moment, we do not see any of that happening.

Joe FitzPatrick: Bearing in mind that all three witnesses in today's session have said that they fundamentally do not support the bill, they might not have much to say on this question, which is about the conscientious objection provision in the bill. What are your views on whether the bill is clear enough on that issue? Should it go further? Do you have any thoughts on institutional objections, where an organisation could say that it is not going to be part of the process?

Lyn Pornaro: We discussed that provision with our members, and they felt that it could lead to a reduction in the number of terminal diagnoses being made by doctors who are against the bill, because they might want to wait before making such a diagnosis, and that could result in individuals not having all the information that they need to discuss full treatment and so on.

Our members were also clear that medical professionals should have the opportunity to opt out of the process. However, there was discussion about whether, if the bill comes into place and it becomes more widely known about, it might become the norm and then individuals who are training to be medical professionals might not get the option to opt out.

Members felt that a lot of people have gone into the medical profession to support people to live well, be healthy and so on. We understand that those who are involved in palliative care are there to help the end-of-life process to be as easy and calm as possible, but they still may not wish to be involved in assisted dying. It is important that it is made clear that medical professionals can stay out of it at any point in time.

Joe FitzPatrick: Does anyone else want to come in?

Marianne Scobie: I have a quick point. Obviously, we support palliative care doctors, the majority of whom have made it clear that they would not wish to administer such medication, with a huge percentage saying that they would leave the profession.

Our concern is that doctors with a conscientious objection would leave the profession, and that those remaining would be more likely to support assisted dying. That would shift the balance among doctors towards those who are for assisted dying, which would further compromise the doctor-patient relationship and erode trust in the medical profession. That would make it even more difficult for seriously ill patients to trust the very people who are there to support them when they are at their most vulnerable.

Paul Sweeney: I thank the members of the panel for their contributions so far today. A key part of monitoring the appropriate implementation of assisted dying would come in the shape of the bill's reporting provisions. Are the reporting and monitoring requirements that are set out in the bill suitably robust to pick up on any potential misapplication of the law? Do you have any views on the current provisions?

Marianne Scobie: Obviously, we do not support the bill as a matter of principle, but we have some comments in relation to practical things. For example, death certificates should report that an assisted death took place. Under the bill as drafted, there would be no record of socioeconomic elements, such as whether someone had financial difficulties prior to when they sought support and services; similarly, social care or palliative care elements or what their main reason was in opting for assisted dying would not be recorded. Our main concern is that there would no monitoring or reporting of whether the person had had a mental health assessment, or any counselling or support, before they made the decision to go ahead with the decision to end their life.

I think that Tressa Burke wants to come in, as well.

Paul Sweeney: Please do, Tressa.

12:00

Tressa Burke: No, I do not have anything to add—I simply echo everything that Marianne Scobie has said.

Paul Sweeney: That is great.

Lyn Pornaro, do you have any comments?

Lyn Pornaro: Reporting and monitoring was the one area that our focus group did not spend a lot of time talking about, because we ran out of time. However, our members were clear that the reporting cannot be a tick-box exercise. There needs to be someone looking at that, and there needs to be support—as Marianne Scobie and Tressa Burke indicated—to ensure that people are making an informed choice.

Some of our members felt that the bill as it is currently drafted assumes that there is no abuse or neglect of disabled people happening. It needs to be made clear that the disabled person's voice—whether they are under a guardianship order or power of attorney or have learning disabilities—is still listened to regardless of what other individuals, who might have the legal power to make a decision for them, are saying. They absolutely need to be heard.

Paul Sweeney: Thank you—that is helpful.

I note that the Terminally Ill Adults (End of Life) Bill in England stipulates that a review should include an assessment of palliative care services, which seems to be roughly what you were suggesting, Ms Scobie. We can certainly look at that.

I know that there is a requirement in the bill for reporting within five years, but would you favour a sunset clause and/or a statutory review period that is shorter than five years following the legislation's entry into force? Is five years too far out for you? What is your view on the timescale?

If you do not want to comment, or if there are no strong views about the five-year period, that is fine.

Marianne Scobie: To go back to your previous question, there is no indication of there being an independent review body or of how much scrutiny power such a body would have in relation to the bill. We would need to see much more on that before we would say something in relation to a review of the whole bill itself. Does that make sense?

Paul Sweeney: Yes.

Marianne Scobie: There is no independent review body in relation to how the bill has been implemented from the beginning, so waiting for five years before anything is reviewed would seem to be rather a long time. Ultimately, we are opposed to the bill, so it is not something on which we would wish to comment further.

Paul Sweeney: Okay—we can certainly note the point about an independent review. The obligation is on the Scottish Government to review the legislation and report to the Parliament, so we can perhaps take a view on who would be best placed to conduct an independent review. I thank you for that feedback—it is helpful.

The Convener: I call Brian Whittle.

Brian Whittle: The witnesses have spoken passionately and eloquently about the lack of rights for the disability community, and about concerns around the impact that the bill would have on that community. They have highlighted strongly how society is currently not necessarily giving the disability community the services that they deserve and to which they have the right.

There is a flipside to that—I will offer the devil's advocate's view, if you like. You may have an objection to the bill because of the way in which society treats the disabled community, and because you feel that disability rights would be eroded. What about the rights of those people who—as my colleague Sandesh Gulhane highlighted—are suffering long term, in the way that the bill is intended to address, and who are currently looking to go to Switzerland or whatever to access that end-of-life option? Is there not a case that, in protecting disabled rights, we are eroding the rights of others?

Lyn Pornaro: On paper, protecting one group means that the rights of others might not be upheld—you cannot dispute that. However, why do we have the Equality Act 2010, with our protected groups? That is to protect those individuals because they face constant discrimination and their rights being taken away from them—in all aspects of life, not just in this one area.

Individuals have a choice to make with regard to some things, but we do not have free choice all the time. There are laws that we need to uphold and there is criteria that we just would not go against morally. That might mean that, for some people, they cannot express their rights.

Right now, disabled people are not able to express their rights to treatments, education, housing, work and training and, at times, life. I am sure that we can all give lots of examples of where rights are taken away from disabled people but not from non-disabled people or where non-disabled people are not excluded.

We are saying that society is geared to be against disabled people. Even though every person could become a disabled person at any time in their life, society is still geared towards non-disabled people. We need to look out for those in society who are classed as being more vulnerable. Unfortunately, that might mean that choices need to be made and that some people's choices are taken away.

Right now, none of us has the right to assisted dying, so we are already eroding the rights of people who go to Dignitas or who are positive about that. We want to make sure that those individuals who are facing a really vulnerable time in their life are as protected as possible to make the choice that they want to make.

Right now, our society is geared towards not allowing disabled people to really be heard or to make their choice if they are against something. We have heard that GDA members, GCIL members and some Disability Equality Scotland members are against the proposals, yet it already feels like we are being told, "That's because you're disabled people and everybody else should have the right." Apparently, there are more non-disabled people in the world than there are disabled people. We know that that is true, but we also know that every individual will age, could have an accident or could develop a terminal illness and, therefore, could become a disabled person and part of that community.

The Convener: Tressa Burke wants to come in.

Tressa Burke: I think that Marianne had her hand up first, so she can go before me.

Marianne Scobie: It is our firm belief that any assisted dying legislation would further erode the rights of disabled people and cause more harm. Nobody wants to see someone suffering and in pain at the end of their life. We are not completely heartless; that is not what we want. We want to see properly resourced and funded palliative care for people who are at the end of life.

It is absolutely abhorrent that palliative care is not funded by the state and that the funding of palliative care relies on the third sector, charities and people having fundraising drives. We do not have a right to palliative care in this country. We do not have a right to independent living. We do not have human rights for disabled people.

For many people who are choosing to end their lives via Dignitas, for example, were those rights in place, they might not choose to end their lives, because many of them are not terminally ill. As I said at the beginning of the evidence session, many of the people who are pushing for the measures are disabled people who are not terminally ill. Those tend to be the people who are the faces of the campaigns.

For the very small number of people who have a bad death, for want of a better phrase, it does not seem right to put in place legislation to make it easier for a majority of people to end their lives through assisted dying when we do not have in place the legislation to ensure that everybody has the right to palliative care, the right to independent living and the right to have their full human rights upheld. That is our firm belief.

As we have said, disabled people are already living the lives that supporters of this bill fear, and we need to make sure not only that our lives as disabled people are valued and that we get the support that we need as disabled people, but that people who are dying and at the end of their life get properly resourced palliative care without question and without waiting for it.

The Convener: Tressa Burke, do you have anything to add to that?

Tressa Burke: Just a variation on a theme. Marianne Scobie and Lyn Pornaro mentioned that we all have human rights. We have protections because we are human beings. There is a minimum standard for how everybody should be treated, but disabled people just do not have that. We do not have dignity. We do not have autonomy. We do not have freedom. We do not have equality.

I know that we have protections in law, but there is a massive implementation gap, which goes back to the United Nations Universal Declaration of Human Rights in 1949 and all the way through to the UN Convention on Rights of Persons with Disabilities, the Human Rights Act 1998, the Disability Discrimination Act 1995 and all the other different pieces of legislation.

As Marianne Scobie said, we are compassionate, and we completely understand that people who might sit at the opposite end of the table from us are looking to uphold people's rights in the same way that we are, but, unfortunately, disabled people just do not have access to all those rights. It should not be a case of either/or or a race to the bottom. As Marianne said, if services were invested in and palliative care was better funded and resourced, people would have access to better end-of-life care.

The Convener: I thank all the panel members for their evidence today. Next week, the committee will continue its stage 1 scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill with two further panels of witnesses.

12:12

Meeting continued in private until 12:34.

Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

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