HOUSE OF LORDS

Terminally Ill Adults (End of Life) Bill Committee

Corrected oral evidence

Thursday 30 October 2025

11.35 am

Watch the meeting

Members present: Lord Hope of Craighead (The Chair); Baroness Berger; Baroness Berridge; Baroness Finlay of Llandaff; Lord Goddard of Stockport; Lord Goodman of Wycombe; Baroness Hayter of Kentish Town; Lord Markham; The Lord Bishop of Newcastle; Lord Patel; Baroness Scotland of Asthal; Baroness Smith of Newnham; Lord Winston.

Evidence Session No. 9 Heard in Public Questions 110 - 120

Witnesses

I: Baroness Grey-Thompson DBE; Professor Tom Shakespeare CBA FBA, Professor of Disability Research, London School of Hygiene and Tropical Medicine; Alasdair Henderson, Commissioner, Equality and Human Rights Commission; Ken Ross OBE, Founding Officer, The National Down Syndrome Policy Group.

Examination of witnesses

Baroness Grey-Thompson, Professor Tom Shakespeare, Alasdair Henderson and Ken Ross.

Q110 **The Chair:** Welcome to this, the ninth session of our inquiry into the Terminally Ill Adults (End of Life) Bill. We are joined at this session by Alasdair Henderson, Baroness Grey-Thompson, Professor Tom Shakespeare and Ken Ross. You are all very welcome and we look forward to your evidence. You have very kindly provided us with statements, which we have all seen and read.

I would be grateful if, when you introduce yourselves, you would say anything else you would like to add to your statements. Please keep them quite brief, because the whole purpose of this session is to ask you questions and get the answers. Can I begin with Alasdair Henderson and ask you to introduce yourself?

Alasdair Henderson: Thank you very much and good morning. I am Alasdair Henderson. I have been a board member of the Equality and Human Rights Commission since 2018. I am also a barrister specialising in public law, human rights, medical law and equality law. I should say, despite the notice here, I am not actually a KC.

Our chairwoman, Baroness Falkner, gave oral evidence to the Commons Bill Committee in January 2025. She has recused herself from further representations since speaking in a personal capacity at the Lords Second Reading.

The EHRC, in common with a lot of the organisations you have heard from, does not take a position on the issue of assisted dying in principle. However, the Bill raises significant equality and human rights concerns, which we have explored in more detail in our published briefings to Parliamentarians.

The rights of and protections for disabled people must be central to considerations related to this Bill and so I welcome the opportunity to speak about that and some wider equality matters today. If I could emphasise just two main points, they would be the following, and I am then very happy to answer any questions the committee has.

First, it would significantly mitigate the potential risks of discrimination that might arise from this Bill and improve compliance with human rights if an assessment of health and social care, and especially palliative care for terminally ill people, were conducted before the legislation comes into force, not as part of its implementation, as Clause 47 currently provides.

High-quality end-of-life care needs to be available to all and patients properly informed about such services. Inequalities of health access need to be tackled. I note, for instance, the National Audit Office report just yesterday about the state of hospice care, which I am happy to speak a little bit more about, to the extent I can.

Secondly, it is important to consider the risks of discrimination when determining how doctors and the assisted dying review panel would assess a person's desire to choose when and how to end their life. That might mean some further clarity is needed in relation both to the definition of terminal illness in Clause 2 of the Bill and to the provisions relating to the assessment of mental capacity and the role of disability among some other clauses.

In particular, we have emphasised that it is essential to note that coercion or pressure is not always applied directly by another individual, but can result from attitudinal barriers, particularly around disability, and lack of services and support in society as a whole. That needs to be taken into account in designing both the Bill and any regulations and code of practice that follow it.

Professor Tom Shakespeare: I am from the London School of Hygiene and Tropical Medicine. I am a social researcher. I have talked to a lot of disabled people and I support the change to the law. This Bill is far more compassionate and far safer than the current situation. We do not have to choose between good palliative care and assisted dying. I am here to say that the majority of disabled people support assisted dying and this has come through all the polls that I have seen.

Moreover, Professor Colburn at the University of Glasgow did peer-reviewed research, which found that assisted dying did not cause harm to disabled people. Indeed, the practical evidence from those American states and from Australia where assisted dying has been introduced for terminally ill people shows no harm to disabled people. We have debated the issue extensively. Previously Parliaments and this one have expressly debated all the issues.

As a result, it is a good Bill. The safeguards far exceed all other areas of healthcare. There is a longer, four-year, implementation period to iron out any remaining issues. Surely, that is much better than seeking to change the wording at this stage.

Most of us support it. Most disabled people support it. Most members of the public support it. The other House supports it. I would urge you to pass this Bill.

Baroness Grey-Thompson: I have been a Cross-Bench Peer since 2010. I am a Paralympian and I am a director of Living and Dying Well. Many of you will have known my opposition to this Bill. I have spoken extensively in the media and in the Second Reading. If you had asked me when I came to the House of Lords whether I would support this Bill, I would have said yes, but, in my time here and in my research, I have come to believe that it is a danger to disabled people.

I have come to that conclusion because I am treated in three very distinct ways in my life. I am treated one way as a Paralympian, which is generally very nice. I am seen as being a good disabled person, competing for my country.

I am treated in a slightly different way as a Peer. People like or do not like my views. I am slightly upset that, around this debate, one of our colleagues said that I had been "captured". I found that incredibly ableist and very disappointing. I thought I was here as a peer, with both a big P and a small P. It is probably the most upsetting thing that has ever been said about me, because it makes me feel that, as a disabled person, I do not have my own frame of reference to be able to make my own decisions.

The third way I am treated is as a disabled woman. That is where I experience all my discrimination and it is extensive. I come from a place of privilege, either because of my red stripy badge or because of my life as an athlete. I know that people look at me and they pity me. They think they would not want their life to be like mine, which is why I am worried about the safeguards and the way that disabled people will be treated. I have quoted it many times but, in this very building, somebody said to me, "If my life was like yours, I would want to kill myself".

We cannot change the law or work through this legislation without understanding the experience of disabled people in wider society and how they are treated in the context of current society. There is no organisation of or for disabled people that supports this legislation and we have to be very careful as we progress. As you will have seen, I have already tabled many amendments to this Bill and I will continue to do so.

Ken Ross: Thank you very much for inviting me here today. I am a founding officer of the National Down Syndrome Policy Group and vice-chair of Portsmouth Down Syndrome Association. I run the southern region for the Special Olympics. I am BAFTA's accessibility and inclusion patron. I have a strong affinity with and closeness to people with Down syndrome and people who have learning disabilities.

I would like to say, to start off with, that I do not have a learning disability and I do not have Down syndrome. It would be important for the committee to hear the voices of those people as well and allow them to represent their own views to you in their own words.

There is a real fear among the people with Down syndrome I have spoken to that this Bill will further target their lives. There are huge health inequalities. If I talk in particular about people with Down syndrome, they typically die 27 years earlier than their peers. The LeDeR report, which came out this year, showed that 37% of deaths among people with a learning disability were from preventable causes.

This continues to highlight a systemic direct and indirect bias shown within the health service, which could also be linked to a lack of understanding of the needs, wishes, health, learning and communication profiles of this particular group. This is something that is there and it will not go away, whether this Bill passes or not.

In Scotland, the most recent report of people with a learning disability dying was listed as Down syndrome. That, in itself, has to be one of the

most damning indictments of the lack of knowledge within the health service around what Down syndrome actually is. I look forward to any questions today. Much of what I would like to say is already within my statement. Thank you again.

The Chair: Thank you very much. Before I move to questions, I should tell you that the evidence you are giving today is being broadcast and is also to be the subject of a transcript, which will be sent to you after the session. I would be very grateful if you would read it through carefully and see that it has accurately recorded the evidence that you wanted to make.

Q111 **The Lord Bishop of Newcastle:** Good morning and thank you very much to each of our panel members for giving us your time today. I have two lines of inquiry that I would like to explore and for each I would like to invite each of our panel members to comment, if they wish to do so.

The first of these is around the theme of discrimination in healthcare decision-making. The Covid-19 pandemic exposed health inequalities and failures in decision-making, most notably the inappropriate application of DNR orders on patients, including disabled people and people with learning disabilities. There have been experiences shared throughout the passage of this Bill of discrimination in healthcare.

In light of the widespread experiences of discrimination for disabled and learning disabled people, do you have concerns about the preliminary discussion being a process in which a doctor can raise assisted dying with patients? I am happy to hear from any panel member, if you wish.

Ken Ross: I am personally very worried about that. Within separate legislation, the Down Syndrome Act, we have pushed since inception for there to be Down syndrome-specific training for health and education processionals. That has been resisted now for three years and is unlikely to come into force.

People with Down syndrome have a very complex and unique speech and communication profile. They are highly suggestible. Even someone wearing a uniform could suggest a position of authority to them and something they should show acquiescence to. The acquiescence bias risk from people with Down syndrome is extraordinary. They could have a seeded view around what they think that person wants to hear and talk about without fully understanding the position.

There is a protection under the Mental Capacity Act, but that Act in itself lists the qualifying example as having a severe learning disability. I have found 23 definitions within the NHS in relation to Down syndrome around learning disability and they described it in various different ways. Essentially, it is defined as either having a learning disability or mild to moderate. That brings every person with Down syndrome into the scope of this Act.

If the physician does not know how to communicate with them and does not understand that leading questions can provide answers the patient

thinks they want to hear, but may not actually represent their views, that is extremely worrying.

Baroness Grey-Thompson: Disabled people experience discrimination in every walk of life. At the moment, there are discussions around benefit cuts, inclusion in transport, education and employment, and Access to Work. Healthcare is one of those areas where there are a lot of assumptions made about ability and disability. When we talked about a disabled person, we are not one homogenous group of people. Everyone has quite a different range of impairments.

Certainly, around Covid, a large number of disabled people got in touch with me to tell me they had had DNR orders put on them without any discussion with them at all. That made a number of disabled people very nervous about accessing the care system. We have seen in Canada and Australia that people are really nervous about accessing healthcare because, certainly in Australia, they think there will be a discussion around euthanasia.

From my own experience, when my father was ill and he had to have his foot amputated, a doctor took me to one side and said, "You might want to have a chat with your dad about continued healthcare because, as a wheelchair user, he will not have any quality of life". That made me and my family extremely nervous about him remaining in that hospital.

It then very easily slips into coercion. Coercion is very variable. As a disabled person, if you already think that you are better off dead, or you are having problems with health and social care, you cannot get the care you need, you are living in poor housing, it will be very easy to have it suggested to you that this is the route to choose.

We are told that it is not for disabled people, but there are a range of conditions that would very easily fit into a terminal diagnosis, such as cystic fibrosis. If somebody like me got a pressure sore and it did not heal, I would very easily fit into a six-month diagnosis. I have had three friends who have died from pressure sores. It absolutely would cover disabled people and we are very poor at determining the difference between sick and disabled or illness and disabled. A lot of our legislation will talk about sick and disabled people.

That is why it is absolutely possible that suggestions will be made to disabled people. "Think of the family. Think of your carer. Think of the people around you". It will be suggested that this is a good route for disabled people to think about.

Professor Tom Shakespeare: I am very concerned about discrimination against disabled people in healthcare. That is why I am one of the co-chairs of the Lancet Commission on Disability and Health, which is all about that. Certainly, there is risk of discrimination. DNACPR is not relevant to this conversation, because this is about assisting dying, which is not DNACPR. It is very different.

It would be discriminatory to say that people could not have this if they are disabled or have learning disabilities. Every healthcare professional now has training in autism and learning disabilities. It is obligatory by law. That may not specifically cover Down syndrome as a specific, separate diagnosis, but there are 5,000 or so single gene disorders. There are many developmental disorders and many chromosomal disorders. You cannot have training on every single one of them.

You can have general training about the fact that, if you seek to influence somebody with learning difficulties, you might be able to do so. That surely covers a lot of people with learning difficulties. It is not about the specific diagnosis. It is about the ways in which a health professional should be careful not to unduly pressurise people who are more biddable or whatever.

Within the Bill as it stands, there are safeguards. There are more safeguards here and there should be more amendments to the existing Bill, which would remove that danger.

Alasdair Henderson: Very briefly, I have a couple of points to make. Yes, this is something to be concerned about. There have been good attempts to improve the Bill already in order to deal with some of the issues. The introduction of the independent advocate is one possibility. It is also going to be something that is very important to build into any codes of practice made under the Bill.

This is a known problem. We have already had mention of DNACPR in the context of Covid in particular. That is something that the EHRC looked into during the pandemic.

It is also worth saying that, however good the training is, it can be a difficult thing to get right in practice. There are quite entrenched health inequalities that are difficult to deal with. To give one statistic, the July to August 2025 ONS data from the health insights survey showed that 41% of people with disabilities are on an NHS waiting list, compared to just 10% of those who are not.

Just at that very basic level, you get big inequalities. That can feed through to the way that any particular discussion, particularly the preliminary discussion in this situation, could be affected on quite a wide level. That is, again, why we have made the point about building in concern about wider coercion or pressure, not just individual circumstances of coercion or pressure.

Q112 **Lord Patel:** Thank you, all of you, for coming today. I am very grateful to you for attending today. I will start with a question to Mr Henderson. I then have a very short question for Professor Shakespeare and, if time allows, all of you can comment on the next one.

In your written statement from the Equality and Human Rights Commission, it says, "To ensure that assisted dying is compatible with Article 2 and Article 3 rights, high-quality health and social care"—you do not define this—"including palliative care, should be available to all who

need it. Patients must also be informed about its availability". That suggests that the assisted dying Bill should not be implemented until high-quality healthcare, palliative care and social care is available to all. Would that be correct?

Alasdair Henderson: I need to be careful not to answer the question, if I may, of whether it should be implemented. That is a political question and a question for Parliament, but there is also the question of the way to maximise the chance of compliance with Article 2, 3 and, indeed, 14. Yes, our position would be that the chances of compliance would be maximised—it cannot be said for sure—by undertaking that assessment, to make sure there was good-quality and widespread palliative care available first.

Lord Patel: Apropos of that I have two questions that you might comment on. The first one is commenting on the links between the state of social care and the law change. Dr Mullock said in oral evidence to the Bill Committee, "That is really problematic, because you are then saying, 'We're forcing you to endure this imperfect, substandard system, and we can't allow you to choose an assisted death because the system isn't very good'. It is a really difficult and complicated set of arguments". Would you agree that efforts to improve social care and palliative care, and to increase choices at the end of life, can and must happen in tandem?

Alasdair Henderson: They absolutely could happen in tandem. Whether they must is, again, very much a choice for Parliament. It is possible to do both in tandem, but I would just reiterate our position: the preferable, more human-rights-compliant position would be to try to at least do the assessment of what the issues are, to work out where the inequalities are and where there might need to be improvement first, before bringing a Bill into force.

Lord Patel: Human rights law applies across some countries in Europe, as it applies to us. There are jurisdictions in Europe that have implemented assisted dying legislation. Have any of them been challenged by the Equality and Human Rights Commission, aside from Belgium one time?

Alasdair Henderson: The majority of challenges to the European Court of Human Rights in the area of assisted dying, assisted suicide and euthanasia have been challenges to a ban or a prohibition on it. The clear line of case law in all of those is that a bright line rule, such as we have in our current law, is entirely compatible with the ECHR.

There have been fewer cases dealing with a system once it is in place, but there have been some. My Lord, you mentioned, for example, Belgium. Mortier in Belgium was a recent case dealing with that. The ECHR is then concerned, if a system has been brought in, with the operation of that system and the compliance of that system with the convention. In Mortier, for example, there was a finding of breach of Article 2 on the basis that the post-death review process was not sufficient. There was not enough investigation afterwards.

I hope that answers the question. The short answer is no; there have not been any, in principle, challenges, but the ECHR does have an interest in how these processes work.

Lord Patel: Thank you. You have been most helpful in your comments. Professor Shakespeare, again going back to your written statement, I have a brief question. Do you think the Bill, as it is, provides a balance between autonomy and protection?

Professor Tom Shakespeare: Yes, I do. We must be careful not to be paternalistic. The whole idea of the Bill is to give people at the end of life permission to end their lives. It is not an alternative to palliative care, but rather another tool in the palliative care arsenal. The Bill strikes the right balance. As I have said, there are lots of safeguards, including a cooling-off period and a four-year period of implementation. All of these allow a balance between autonomy and protection, yes.

Lord Patel: My final question is to all of you and I will ask for brief answers. What are your views on the oversight processes in the Bill, which would allow for assisted death, and particularly on the monitoring by the commissioner? Are they adequate?

Baroness Grey-Thompson: Some of the changes that happened in the Commons, in terms of the number of amendments that were tabled and accepted, are interesting. Marie Tidball's amendment around having disabled people on the panel is a step forward. I am tabling some amendments around who that disabled person is and what experience they have, to strengthen that part of it. There should be far greater representation of disabled people, because of the wide range of disabled people and impairments that are out there.

We have to be mindful of other jurisdictions when we are talking about palliative care. Professor David Albert Jones has published an article in the *Journal of Ethics in Mental Health*, which shows that, between 2012 and 2019, in the 20 countries that have no assisted suicide, their palliative care funding went up by 25%. In Belgium, the Netherlands, Luxembourg and Switzerland it also went up, but only by 7.9%. Belgium, Canada and the USA fell out of the top quartile of palliative care.

In Victoria, when they were struggling to get the Bill through, an offer of $9 million was made available to palliative care, which eased the way for the Bill. We have to be mindful of what increases look like and where the actual support goes.

Ken Ross: Some of the issues around the panel assessment will still come down to the people within that panel understanding the much earlier concerns of the people who may be accessing this particular pathway. Again, there might be a miscommunication or a misunderstanding around what that person actually needed and thought they were doing, to get them to the process where a very terminal decision has been made. The people on the panel may not understand that nuance, communication and language. They may potentially still

have a biased view towards disability or even certain types of disability, informing their view around whether they think people are enjoying a quality of life.

My fear is that it will just become another rubberstamping process. When I was thinking about speaking today, it just bothered me. One of the hospitals that is very close to me is the Gosport War Memorial Hospital, and I had not really felt that I had had an update on what happened there, with this extraordinary number of deaths through overmedication of 450-plus people. Some 25 years later, we still do not have a settled view around what happened, what should go on or how we can ever prevent something like this happening again.

If we ended up with a situation where there are multiple panel reviews that do not actually address all the concerns that many people have had, we could have the same situation. It could be Gosport on steroids. One of the things the government report about Gosport came out to say in 2018 was that keeping patients safe requires a team effort. It needs us all to play our part and to support others to make care safer.

If you had that as a tenet all the way through this, you could start to think about the deficiencies in this. Who are the people who are still exposed? I know we are trying to help cover those areas but, if we have not successfully covered those, it does not mean that we just assume that they will be covered in the future.

Q113 **Lord Goodman of Wycombe:** Thank you all for coming to give evidence today. I have a question for Mr Ross following your opening statement and the way in which you explained how people with Down syndrome are particularly vulnerable in certain ways to coercion, pressure and suggestion. I wanted to put to you written evidence given to the Public Bill Committee in the Commons by the Portsmouth Down Syndrome Association, with which I think you said you are associated.

Ken Ross: Yes, that is right.

Lord Goodman of Wycombe: That evidence said there is a risk, even when safeguards are in place, that these are often ignored and abused where people with learning disabilities are concerned. Would you like to expand on that statement for the committee?

Ken Ross: Again, we can look at Covid. Covid is not an isolated time around the use of "do not resuscitate" notices. There is a process for those to be put into place. One of those processes should not be waking someone up in the middle of the night, without anyone familiar with them, to go through the process of whether or not they want to be resuscitated. There is a very real risk that, even with the process in place, it will still be ignored.

Among the only people who were mandated antiviral treatment during Covid were people with Down syndrome. Again, I have personal, direct experience of that not happening. A medical practitioner was effectively trying to diagnose over the phone, without speaking to the patient,

whether that patient thought they needed the antiviral treatment, even though the Government had already said every person with Down syndrome was entitled to this. As a result, that treatment was withheld.

We can go through a plethora of these instances and the 37% of deaths that were treatable and preventable. I know that is England and Wales. If we look in Scotland recently, there was a chap called Derek taken in who had aspiration pneumonia. He was encouraged to sign a DNR. He was told he had days left to live. His family wanted him at home to be treated, so he died somewhere familiar. He is now thriving a year and a half later.

There is this whole process around the presumption, "Should we be trying to provide care and support you or should we be helping you to be less of a burden to the state?" That is what it looks like to a lot of people with Down syndrome. That is what it looks like to a lot of people who care for them.

Lord Goodman of Wycombe: You have explained, first of all, how vulnerable this group is. Then you have set out evidence of how unfairly and unjustly—and, from what you have said, I would say outrageously—they can sometimes be treated. Could the Bill, in your view, be amended in any way that would ensure that people with Down syndrome are protected adequately from coercion and pressure and have sufficient safeguards?

Ken Ross: I take on board comments from Professor Shakespeare. There are lots of conditions. One could think, "How do we provide specialist and meaningful training for every condition?" Down syndrome is the most commonly occurring chromosomal condition. We can always start somewhere and try to make a framework that may work for others as well. It does not need to be discriminatory in doing that.

If we look at every person who could interact with that individual who has Down syndrome, the Bill does not have a provision to ensure that they do not have a casual conversation where someone does not just happen to mention, "Gosh, you're suffering terribly. Have you thought about this? Are you really comfortable with your life?" These are all statements people have raised where quality of life is being discussed.

Again, from personal experience, I had a diagnosis of Down syndrome given to me by a cleaner. The first diagnosis was by a cleaner. I have a colleague who was given the suggestion around termination from an admin worker. That was not from a clinician. These are all happening and probably the clinicians would never get to hear about it. Someone has thought they are doing it from a place of well meaning. They are not thinking about what it is that they are doing.

For someone who is highly suggestible and potentially in quite an emotional state, this can have a devastating outcome. As an individual who does not have Down syndrome, when I was faced with that, it absolutely floored me. It was not something I expected. I did not know

who this person was. They just came in and took it upon themselves to deliver this. If this Bill was to go through, we have to look at mandatory training for everyone who could be involved in the process within the health service. That could be from a receptionist right through to any medical practitioner.

Q114 **Baroness Hayter of Kentish Town:** We are, of course, talking only about people who are dying. We are not talking about the general population that any of you represent. I have a question for all of you. I am going to assume, unless you say to the contrary, that you would not be supportive of the amendment to the Bill that has been put down by Lord Moylan, which would exclude all people with learning difficulties, disabilities, mental health issues or autism from accessing this law entirely.

Professor Tom Shakespeare: No, because that would be discriminatory. I do not think any of us on the panel speaking to you believes in discrimination against people with intellectual disability or any disabled people. We have been talking about safeguards a lot. There will be a multidisciplinary panel. There will be a lawyer. There will be a doctor. There will be a social worker. There will be training for all participating doctors. There will be clear eligibility criteria and there will be independent advocates.

They are the safeguards to allow disabled people access to this. Therefore, their case should be evaluated along with all the others, because they have a relevant reason to want to die, if they have assisted death at the end of life.

Baroness Hayter of Kentish Town: Does anyone perhaps take a different view?

Alasdair Henderson: I agree that a blanket exclusion of a certain group, because of particular disabilities or disorders, would be discriminatory. That raises a broader point. I think this was brought up in the Second Reading debate. One potential issue to look at in the Bill is that there may currently be a potential violation of Article 2 read with Article 14.

There is no specific provision for a person with a particular disability that might give them more likelihood of having suicidal ideation—for example, some of the ones you have mentioned, so autism, bipolar disorder, depression and so on—who expresses a wish to die. It is important to be able to distinguish whether that is a manifestation of their disability or a genuine decision unrelated to their disability.

At the moment, there is no specific safeguard to make sure that that question is teased out in both directions. They are more likely to seek death because of their disability, but they must also not be excluded from having the choice because of their disability.

Baroness Hayter of Kentish Town: Before I go on to the other two, it is not about choosing to die. They are dying anyway.

Alasdair Henderson: I understand, yes, but—

Baroness Hayter of Kentish Town: It is important, though. One can slip rather easily, as if we are talking about people who want to end their lives. We are talking about people who are dying—

Alasdair Henderson: Yes, but it is a decision to end their life earlier.

Baroness Hayter of Kentish Town: —and whether they are going to bring that forward, probably only by a month, actually. We have heard that, by the time you have been through all of this, we are talking about people really at the very end of their life. You accept that. I do not know whether our other two witnesses want to comment on Lord Moylan's amendment. You may not have seen it. I appreciate that.

Baroness Grey-Thompson: I will probably be speaking to it. It seems like the only time in this building we are really arguing for equality of treatment for disabled people is when we are talking about the Terminally Ill Adults (End of Life) Bill. Disability is completely forgotten, even though it is a protected characteristic, in a lot of the legislation that we do. I feel that I am constantly having to elbow it in.

In Australia, the training around assessing whether someone has voluntarily expressed a wish to end their life is two minutes and 50 seconds long. It is a video that they have to watch. The impact assessment only looked at equality of access. It did not look at the impact. Again, in the society in which we live, we do not have equality. Lord Moylan's amendment is a really interesting place to have a detailed discussion, I presume, around coercion, capacity and what support someone has in their life.

Somebody with exactly the same impairment as I have, which affects them in exactly the same way, but with different financial circumstances, will have a different experience going into this. We do need to take all that into account. The reality is that a lot of disabled people in this country live in poor housing with a lack of transport. They struggle to get employed and already feel excluded from society. I would feel really sad if the first time we genuinely give disabled people equality is over ending their lives.

Baroness Hayter of Kentish Town: Did you want to add to that?

Ken Ross: I did. I just wanted to pick up on one point—

The Chair: I am sorry to interrupt you. Please keep it short, because we have a lot still to cover.

Ken Ross: I fully appreciate that this Bill is about terminally ill people, but the point I made earlier was about an individual who was deemed to be terminally ill who was not. He had a learning disability and there was a lack of understanding in getting to that stage.

Baroness Hayter of Kentish Town: I appreciate that.

Q115 **Baroness Scotland of Asthal:** Taking up that last point, something we have heard from a number of those who have spoken to us is that the whole diagnosis of terminal illness and the length of time that you have is not definitive. It can change. You spoke about somebody who had such a diagnosis for seven years. Others have said the same.

In looking at the vulnerability of those with disability, am I right in saying, from the evidence you are giving us, that there is still real concern as to whether the safeguards in this Bill will have the impact that the sponsors purport?

Ken Ross: The Bill presumes the best, rather than legislates for the worst. That is the real risk with the Bill.

Baroness Grey-Thompson: I agree with that. If we look at ONS data, there is no data on the impact of changing the law. People are more likely to consider this immediately after diagnosis. I sat on the board of Transport for London for 10 years. One of the things we did was to put additional safeguards in and around all the tube stations near hospitals, because that is where there are a higher number of suicides immediately post prognosis.

When you layer that on top of the experiences of many disabled people in this country, where a carer or people around them will say, "This is going to be really difficult", or a doctor tells you, "This is going to be really hard on the people around you, the people you love", there will not be enough around to actually check and go through those processes. Once people go through the stages, it will be fairly rapid.

Baroness Scotland of Asthal: Can I ask you also about the pressure that is going to be put on those caring for people going through this, where there is a drive to ameliorate suicidal tendencies at the same time as raising the possibility that you could choose to end your life earlier, if that was seen to be a way of alleviating your fear and concern?

Baroness Grey-Thompson: We have seen it in other jurisdictions, where burden is pretty high up on the number of reasons that people enter the process. Carers are in a really difficult situation in this country at the moment. Carer support is on its knees. When we talk about the death of a disabled person, it is quite often framed as if it will be a relief for the disabled person to pass away, and a relief for the people around them, so all that is already negative.

I just wanted to pick up on something Ken said. I spoke to a family with a child with Down's, who is now in their late 40s. People with Down's are living longer than ever before, and the family said to me they are really worried about what will happen to their child when they are no longer around. They are terrified of putting their child into care, into support, and they came to me and they said they were worried about the law changing, because it would change the frame of how they think about their child. Yes, they should have done stuff before; they should have looked for independence, but changing the law will change a whole pile of

conversations that we will never know about, because it will just slip under the carpet.

Baroness Scotland of Asthal: It is changing the contextual culture.

Baroness Grey-Thompson: It is a changed relationship with society.

Baroness Scotland of Asthal: If I can then move on to the ECHR impact, you have been relatively clear on the issue in relation to Article 2, but also the issue of choice. I wonder whether you could explore a little further why you think that, unless we do more to make sure that the choice in palliative and other care is real, then the danger of being non-compliant with Article 2 is not theoretical but omnipresent and real.

Alasdair Henderson: As I understand it, there are a range of views on this, but there will be some people, either because of a pre-existing condition—we have already mentioned some: autism, bipolar disorder, depression, et cetera—or because of the immediate response to a diagnosis of some kind of terminal illness, who will have suicidal ideation. It is quite important to work out a system that can disambiguate that response—something to do with either the condition or response to the prognosis—from perhaps, to use the language of the Bill, the clear, settled and informed wish to end their life earlier.

That is not an easy thing to do. It probably requires some kind of specific part of the assessment process to try to work out whether it is that clear, settled and informed wish, or a manifestation of their disability. To give you one way in which that could be done—and this is why one of our major proposals is that palliative care must be central here—currently, Clause 5(5) of the Bill suggests that, as part of the preliminary discussion, there must be an "offer" made to refer to palliative care. It may be worth considering whether that should be a referral to palliative care and having a palliative care assessment, because, if that palliative care assessment takes place, it may well be that, as a matter of course, it has a significant impact on the desire for an earlier assisted death in either direction, but someone does it with much more understanding of what might be available to them, what they are feeling and how they are responding. I hope that helps.

Baroness Scotland of Asthal: We have looked at the UN Committee on the Rights of Persons with Disabilities, and its second and third periodic reports on Canada. There were clear indications there with substantial evidence that the rights of people with disabilities were being eroded in Canada as a result of the medical assistance in dying law and the ableist assumption that underpinned the decisions being made. Does it concern you that, if this was to happen under our Bill, that might be a consequence as well?

Alasdair Henderson: It is probably incumbent on me to note that one of the roles of the EHRC is that we are also the national human rights institution for England and Wales, and we engage with the treaty monitoring processes for the CRPD and the other UN human rights

treaties. It is true that it is a longstanding issue raised by those treaty monitoring bodies of health inequalities particularly around disability, and that is why we have raised it as a concern. I understand that, similarly, a concern has been raised with the CRPD committee about the proposed assisted dying Bill in France on similar grounds, so it is absolutely a concern. That is why it is so important to make sure that this is grappled with specifically if this Bill is to made as human-rights-compliant as possible.

Baroness Scotland of Asthal: I think it was the chief coroner for Ontario who was able to raise issues there about the outcomes of assisted dying, so that is also a matter of concern, is it not?

Alasdair Henderson: Yes, it would be. I know you have already had evidence to this committee from His Honour Judge Teague on the coronial system, so I will not repeat that. I would also just refer to the fact that the European court, as I mentioned earlier, has started to grapple with this issue. The Mortier case was about post-death investigation and review, and grappling with some of those issues.

Professor Tom Shakespeare: Sir, we must make clear that the law as proposed in this country in the Bill is very different from Canada. It is about terminal illness. It is not all about all disabled people—all people—as Canada's is. It moved from terminal illness to all disabled people.

In terms of the safeguards that exist, the Government's own equality impact assessment confirmed, "The safeguards provided for in the Bill, which apply at every stage of the process for seeking an assisted death, would help to minimise the risk of any eligible person, including disabled people, from being coerced or pressured into requesting or proceeding with an assisted death", so there are safeguards, and it is different from Canada.

Baroness Scotland of Asthal: I should make clear that one thing this committee is really interested in is to test whether those safeguards are robust or are not. There is a lot of concern, and that is why we are asking the question, so I am very grateful to you for the answers that you have each given.

Professor Tom Shakespeare: You are quite right to bring up the Committee on the Rights of Persons with Disabilities, which has made no comments or recommendations about Belgium and Switzerland, two jurisdictions that do allow assisted dying at the end of life. It is not all concluding observations that raise that.

Baroness Scotland of Asthal: We do know, because we have had evidence today, that, in relation to Belgium, there has been a case raised, and this is the beginning, so we are being appropriately cautious to understand what exactly we may be letting ourselves in for. Better to prepare now to prevent than to regret later when it is too late.

Q116 **Lord Markham:** I am aware of the concerns about safeguarding for

disabled people, and you have all put it very eloquently today. I am also aware that, overall, there are high levels of public support—70%—for this, and I believe, among disabled people, that is even higher. It is 79%.

The challenge for us as parliamentarians is that, as I see it, we have three choices here. I would like your advice. If you were in our shoes—and Tanni is in our shoes—we have only three choices. First, we can pass the assisted dying Bill with the sorts of safeguards that have been discussed here. Secondly, we can accept the amendment that would say that disabled groups should be excluded from the assisted dying Bill. Thirdly, we can vote against the assisted dying Bill for everyone and vote it down. Those are the three choices that we have on the table that we face as parliamentarians. Given those three choices, I would welcome the views of each committee member on which one of those three they would advise.

Ken Ross: On disability and the stats that you have said, disability covers a very wide range. As the National Down Syndrome Policy Group, we speak specifically for over 60 Down syndrome groups and their thousands of members, all of whom have raised significant concerns around this. We can look at majorities in different cases, but we are still talking about significant numbers of people—the 21%, say, using your own figures—who do not want this. That is still a large number of people where things could potentially go wrong.

Lord Markham: My question was—I am really asking your advice here—about those three choices I have. Which one of those three would you advise me to do?

Ken Ross: This Bill has helped bring into the light a lot of deficiencies in other areas, and it gives us an opportunity to have a look at those deficiencies and go beyond theory and suggested training to practical delivery on the ground. If we are not confident that what we think is happening in terms of process is actually happening, it is very tricky to pass the Bill in its current form, assuming that all the safeguards, all the training, all the knowledge that we think is being applied in a whole host of areas is being robustly applied.

Lord Markham: Understood. So your advice would be against, of those three.

Ken Ross: The Bill in its current format, yes.

Lord Markham: Thank you. Any other views, please? Yes, Tanni, please, because, again, you are in our shoes.

Baroness Grey-Thompson: There is tons of data that shows different levels of support. There is data that shows that the public are very much in support until they understand what assisted dying is. When you call it assisted suicide, they have a different view. Support drops the more people understand about it, certainly when you start talking about complications, time to death, change in jurisdictions.

There is still no organisation of or for disabled people that supports this. A lot of the time, in the surveys that have been done, it is about self-selecting on disability, so that could be somebody who is a quadriplegic or it could technically be someone with repetitive strain injury whose life is impacted by their impairment, so we have to be slightly careful around data.

I am probably going to give a very political answer until we get to the end, until we know what has been accepted or not. If we look at the amendments that were accepted in the Commons and at those who voted against the Bill, only 18% of amendments were accepted by those who disagree with the Bill as it was introduced and as it went through its stages.

I am afraid I would need to feel assured that there were enough safeguards in place, but also we need to be looking at what else we do for disabled people. We should not stop or not have a conversation about palliative care, the reform of welfare, or everything else we need to do, while we are doing this as well. My personal preference is that we need to do a lot more in society to make disabled people feel included than rush this Bill.

Professor Tom Shakespeare: I would support the Bill. I would include disabled people as eligible for it. There are lots of safeguards here. People talk about inequality. We live in a very unequal society. If we are to wait until there is no inequality, we are going to wait for an awful long time. I think that people who are dying cannot wait and they should have access through the Bill. It does not affect, in any negative way, disabled people. I am disabled. I agree with Tanni most of the time, but not on this.

Alasdair Henderson: You will understand if I do not express a view one way or the other, given my role here, but I would make a few comments. First, there are other options than the three, respectfully, you have set out. There is the option to introduce new amendments or changes to the Bill. There is also the option to, as we have suggested, do a thorough review of the state of health and social care, and particularly palliative care, before the Bill comes into force, so I would commend those to the House.

Then it does very much come down to each Peer once considering it. If you are sure the safeguards will be sufficient, then vote in support. If you have any doubts that those safeguards will work, then you should vote against.

Q117 **Baroness Berger:** I have two relatively, I hope, short questions for Alasdair Henderson, and then one question at the end. We have here the equality impact assessment that was produced in relation to the Bill. I note that it came after the Bill completed its Committee stage in the House of Commons, and it is just 21 pages long. Can I ask you whether this is regular or acceptable for a Bill of this magnitude?

Alasdair Henderson: You will note that one thing we raised in our briefing is that, while we welcome the fact that there is now an impact assessment, it is unfortunate that it was not available for most of the passage through the Commons. It is helpful in so far as it goes, but there are still various issues that it does not deal with, or issues where Peers could benefit from significantly more detail. We tried to raise some of them in our briefing and just now, so a much more thorough understanding of the impact in terms of health inequalities for disabled people.

Just to name one other, for example, there may be an issue around the protection for freedom of conscience. We welcome the extension to Clause 31 to protect freedom of conscience. Nobody has to participate in an assisted dying system, but it is not clear, for example, what would happen to an organisation—a religious organisation or other organisation, such as the hospice that had an objection to being involved—and whether they could say, "We're not going to be involved in this at all" and be protected. There are various issues that still need to be gone into.

Baroness Berger: I note that, in the written statement you shared with us, you focus on five specific protected characteristics where you would want to furnish us with more information, and I am sure all Members of the House of Lords would warmly welcome receiving that.

If I can just pick up on a point that Baroness Grey-Thompson alluded to, this equality impact assessment focuses very heavily on the issue of equality of access, but much less on the protections needed to keep vulnerable groups of people safe. In fact, the word "access" appears more than twice as many times in this document as the word "safeguard" or any variation of "coerce" or "coercion". Does the EHRC believe that this equality impact assessment properly balances these issues? If not, what are the gaps that we should be considering?

Alasdair Henderson: I would not be as blunt in saying it does not deal with it adequately at all. It is important to deal with access. As I have previously discussed and, I hope, made clear in my answers, we do not want to discriminate against disabled people if this is going to become law, but there seems to be insufficient analysis particularly of the point we raised in our briefing for the Second Reading in the Lords about this wider issue of coercion or pressure at a societal level or an attitudinal level.

The extent to which both the Bill and the impact assessment consider coercion and pressure, it is primarily focused on, for example, the criminal offences in the Bill, the protections against particular coercion or pressure on the individual facts of a particular individual's case, but does not really engage with the broader trends or cultural issues that might also need to be worked out in some way.

Baroness Berger: Again, I would just reiterate the point that we would really like to receive that information from the EHRC. If I can direct my last question, please, to Mr Ross and Baroness Grey-Thompson, we have

had a lot of discussion, including in this session, about the reliability of a diagnosis of six months to live.

I am also interested in the idea some have put forward that a six-month diagnosis to live is, in itself, a kind of safeguard. We heard this on a number of occasions. For example, at Second Reading in the other place, there was a Member who said, "The limit in the Bill, however, is that someone must have only six months to live … which I genuinely believe massively reduces the risk of coercion".

I am concerned that what some proponents of the Bill mean is that coercion no longer matters if you have six months or less to live. In your experience, where disabled and learning disabled people have become terminally ill, does a terminal diagnosis make them immune to coercion? If not, are there sufficient safeguards in this Bill to ward against coercion of disabled and learning disabled people?

Baroness Grey-Thompson: We know that prognosis is really difficult. I would probably defer to colleagues who are medics, but six months is quite arbitrary in terms of what it means. Doctors are taking the best guess they can. Talking to a disabled person, she said her real fear around it is that doctors treat the illness and not the patient. We have this arbitrary figure of six months, so why can it not be seven months? Why should it not be four months? It feels like six months sounds reasonable, but we know from equality legislation that "reasonable" in the term "reasonable adjustment" means next to nothing. I do not think it protects disabled people in any way at all.

We have to be mindful of other jurisdictions that have changed from six months to 12 months. They have expanded either through the court system or through legislation. It will be eroded, and there will be doctors who will—I cannot think of a better phrase—turn a blind eye to what that six-month diagnosis might mean for disabled people, because of the inherent nature of discrimination against disabled people.

Ken Ross: I still feel uncomfortable where there are so many preventable deaths among learning disabled people and people with Down syndrome. That pathway towards the final six months could be predetermined by the practitioners itself. I am very aware, again going back to the "do not resuscitate" notices, of family members who felt that they had to sign the DNRs on behalf of their family member, because they thought that was part of the way that their whole condition was going to be managed, rather than realising that there could be potentially be another course of action which could have a much better outcome.

The level of coercion, not just for the individual but potentially the people that individual may wish to speak to and to take counsel from, could be very live all the time, because they could feel under pressure to end suffering of their child or loved one, and the individual themselves could think, "I don't want to see this person feeling under pressure who loves me". I just think there are so many levels of coercion that could be felt

right up to the point where there could be an avoidance of even getting to that situation in many cases.

The Chair: We have just under 10 minutes to go. Baroness Berridge?

Q118 **Baroness Berridge:** Baroness Grey-Thompson, I just have a particular question. It is interesting to hear the voice and opinion of Professor Shakespeare, but you mentioned at the beginning that there is not a disability organisation that supports the Bill. How large is that sector? Sorry, you might not have a precise figure, but how many organisations are we talking about here?

Baroness Grey-Thompson: Oh, gosh.

Baroness Berridge: Under 100? Over 100?

Baroness Grey-Thompson: Hundreds. Sorry, I have not counted them before.

Baroness Berridge: Could you provide us with that evidence coming back?

Baroness Grey-Thompson: I will[1].

Baroness Berridge: To Mr Henderson, I have a legal question—and colleagues will know I like these. In the Equality and Human Rights Commission briefing on the Bill ahead of Second Reading in the Commons, you state, "Article 14 of the ECHR provides for all people to enjoy their rights without discrimination". It is an important consideration for Parliament about whether the Bill would lead to discrimination. We have heard much criticism from royal colleges and from other organisations about the Bill as drafted.

The Bill could be legally challenged. Are you concerned, for example, at the possibility for someone to mount a successful challenge on the basis that the provisions in the Bill for eligibility are discriminatory and that might widen the criteria? It is for you, Mr Henderson. We heard this from Mind as well. Its witness in the session before you was concerned about expansion of the Bill.

Alasdair Henderson: Yes. The short answer is that we cannot exclude that possibility. If I just expand that very briefly—I am conscious of time—as I mentioned before, the European court is very clear that a bright line law prohibiting assisted dying is compatible with the convention. That was recently reaffirmed in the case of Karsai and Hungary last year.

However, if member states do implement some form of assisted dying, the court grapples with the extent and the process. This was raised in the Second Reading debate. The argument would go something like this. Having more than six months to live is a personal status for the purpose

[1] Baroness Grey-Thompson subsequently clarified that the figure is between 300 and 400 depending on the definition.

of Article 14. The law on assisted dying discriminates against people who have more than six months to live, contrary to Article 14. There is no obvious reason for setting the limit at six months as opposed to nine months, 12 months, 24 months, or whatever, particularly because someone who has longer to live might suffer more and, therefore, you need to justify that somehow.

It is important to say there is a range of views on whether that argument would succeed. I know that the government memorandum, for example, said the Government's view is that it is unlikely to succeed because of the wide margin of appreciation given by the court, so that is important to say. No one can tell you whether that argument will succeed. It is important for me to say that argument could be made—and almost certainly will be made by somebody—and it cannot be guaranteed that, whatever Parliament says, it will not be expanded by the courts. It is a possibility.

Professor Tom Shakespeare: It is quite important that this Bill did not include the word "suffering". That was why Canada has expanded, because, as soon as you have suffering people, then you could say dying is a form of suffering, but so is living and, therefore, it should be covered by the Bill. That is not in this Bill. Quite rightly, it is for terminally ill people. It is true—six months, seven months, whatever—but it is very, very difficult for medical practitioners to diagnose. If people have cancer or motor neurone disease in the end stage, they are likely to die of that.

Baroness Berridge: Can I just put a reference to you? Jamilla Hussain, who is a consultant palliative doctor up in the north of the country, and is pro assisted dying in principle, wrote to the *Guardian* newspaper on 18 May 2025. She is concerned about the impact of the Bill particularly on minoritised communities around Bradford. She stated this. She has said that assisted dying legislation must "not shift the risk of bad deaths"—which is a small group—"to much larger and more vulnerable groups of people". Professor Shakespeare, the royal colleges are not in support of that Bill. Are you not concerned that, in fact, we will be shifting the risk of these bad deaths on to much larger and more vulnerable groups, including some disabled people?

Professor Tom Shakespeare: I am not concerned, because it has been very effective in Oregon and Washington. There have not been these sorts of fears. There have not been these sorts of outcomes. Therefore, I am not concerned. I think it would be tightly defined with lots of safeguards. It is the will of the people as well as the will of the Commons.

The Chair: We have time for just one more question, Baroness Hayter. Could you keep it quite short, please, in your answers?

Q119 **Baroness Hayter of Kentish Town:** It is particularly to the EHRC, because you have mentioned equality. I just wonder what your views are about the current legal system, where those who are rich enough can go abroad with absolutely no safeguards that they are even dying let alone all the other issues, or, indeed, can starve themselves to death here

under coercion, under pain, under whatever reason, with no safeguards at all. Given your interest as EHRC in inequality, is it not unequal at the moment for those who can go abroad to bring their death forward?

Alasdair Henderson: No, because, first of all, wealth is not a protected characteristic under the Equality Act. Secondly, there are so many other factors involved that I am not sure it is a straight question of discrimination of any kind. There might be, I guess, a sort of indirectly discriminatory impact in some ways, but that could be justified as protecting other vulnerable people from feeling forced into an assisted death. I do not want to advise on the hoof, or give a clear position on the hoof, but the clear answer to that is not yes. It is probably no.

The Chair: Baroness Smith, we can squeeze you in.

Q120 **Baroness Smith of Newnham:** Thank you very much indeed. Professor Shakespeare, you seem to think that this Bill does not create any threats for disabled people and that, essentially, they should be, as you say, not discriminated against if the legislation were passed. You also said that assisted dying should go alongside better support for disabled people, and we have also heard a lot of support for stronger support for palliative care. Do you not think there is a risk that, if we introduced assisted dying, rather than going alongside better support for disabled people and for palliative care, the danger is that decisions would be taken for financial reasons that would preclude improving those other services?

Professor Tom Shakespeare: That is a theoretical possibility, but it is not what has happened in Oregon; it is not what has happened in Washington. I do believe in palliative care very much. People should have a choice, and it should be better funded, for sure, but the problems for palliative care or disability are not consequential on this Bill. In other words, because they have not pertained in other jurisdictions—in Oregon, Washington or whatever—there are not those objections.

Alasdair Henderson: If I could just mention again, I would encourage Peers to read the National Audit Office report from yesterday, which has some rather worrying things to say about the current state of palliative care in this country, not necessarily the other jurisdictions.

The Chair: I am afraid I have to bring this session to an end, but I want, on behalf of all members of the committee, to thank you very much indeed for coming and for your very helpful answers to our questions on these very, very important issues. I remind you that the evidence will be transcribed. Please look very carefully at the transcription that we will send to you, in case there are any errors you would like to point out. That having been said, can I thank you all very much indeed and wish you a good afternoon?