HOUSE OF LORDS

Terminally Ill Adults (End of Life) Bill Committee

Corrected oral evidence

Wednesday 5 November 2025

4.15 pm

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. 13 Heard in Public Questions 165 - 171

Witness

I: Dame Rachel de Souza, Children's Commissioner for England, The Office of the Children's Commissioner.

Examination of witness

Dame Rachel de Souza.

Q165 **The Chair:** Welcome to the 13th session of our inquiry into the Terminally Ill Adults (End of Life) Bill. We are joined at this session by Dame Rachel de Souza. You are very welcome and we look forward to your evidence. We would be grateful if you would introduce yourself briefly, and say whether you would like to add anything to the written material we have received, before you are subjected to the questions by the committee. Today's meeting is being broadcast and a verbatim transcript will be prepared for you to look at and, if you find any errors in it, draw them to our attention. I am going to pass to the first question, which is from Baroness Berridge.

Baroness Berridge: There is an assumption that, because children cannot have assisted suicide under 18, and there is a prohibition on medical practitioners raising it with them, the Bill will not impact children. Do you think the Bill will impact children? Could you particularly comment on those children the law already treats differently—those with special educational needs and disabilities?

Dame Rachel de Souza: The Bill absolutely is impacting on children. Children are fascinated by this, and most children are, up and down the country, debating this in their classroom. I just want to thank the Lords first for having me here to bring children's voices to you. It is really important.

The Baroness is absolutely right to single out, then, those more vulnerable children. They are the children I am worried about: children with special educational needs, children who are already in hospital with life-limiting diseases, children who have EHCPs—education, health and care plans—that provide support for them until the age of 25. The reason they do that is that they are vulnerable, whether it is mental health concerns, whether it is because they have had terrible lives and might have all sorts of problems, including suicidal ideation. It is a real concern.

How you are treated while you are coming to the age of 18 is important to consider. For a child with a life-limiting disease in palliative care, if their treatment is excellent, and many children's treatment is excellent, you would think, yes, over 18, they are clear-headed and more able to make decisions about themselves. But many children are not getting the treatment and care that they need, whether that is children who are in difficult home situations, care situations or with mental health concerns.

When Wes Streeting said he did not support this Bill because palliative care was not good enough, I went and visited pretty much every single children's hospice and all the consultants for palliative care around the country. I saw excellent, brilliant provision, but I also saw massive gaps. There are whole areas of this country where, if you are not on the right pathway, you are not getting any support, even as a child, so I am

worried that that will then affect how children feel about living as they go forward. It will affect them.

Baroness Berridge: In relation to that, the Bill now says that medical practitioners cannot raise it, but, as you have mentioned as well, it does not prohibit teachers, youth group leaders, religious leaders speaking to them. Also, it does not prohibit, we do not think at the moment, video games, social networking and influencers with children. Are you concerned about that for children, and for their parents, of course?

Dame Rachel de Souza: There are two different things there. Children talk to trusted adults about death, dying, life, in their own age-appropriate ways, right through their lives, particularly if they have a disease or an illness. I have vast numbers of quotes from them about how they feel about that.

Now, it is a very different thing to be talking about and raising this as a child with an appropriate, trusted adult than to have—I know we are now saying, with Clause 6, it cannot be raised with you—others intruding on you.

The online world question is a serious problem. I was very instrumental in protecting children with the online harms Bill, and I think we really would need to see any attempts to coerce children around suicide or assisted dying as something that comes under Ofcom's range. It should be banned.

Baroness Berridge: As a final, very specific question, the Bill does not seem to ensure that any next of kin is nominated, and it does not seem to ensure that that next of kin has to be over the age of 18. Does it concern you that a child, we know, could be called by a medical examiner, and that is the first they know that an absent parent has gone down this route?

Dame Rachel de Souza: We need to be hugely careful about this. When I was in Canada recently—and I know the system we are proposing here is nothing like the Canadian system—I asked the equivalent of GOSH, SickKids, to pull together its MAID team, the MAID consultants and its ethicists. They were talking to me about bringing mature children on next. I know we are not near there, but the interesting thing was that the ethicists' concern was, "Under a rights perspective, if a child decides they want to have assisted dying without telling their parents, should we do it?" I do not want us to be anywhere near that with children's one precious childhood. We have to make sure that we absolutely do not go anywhere near that. I know nobody here is proposing that, but the unintended consequence of a quickly pushed-through PMB is that we just do not have the time to consider those things, and I worry about it.

Q166 **Lord Goddard of Stockport:** Just to try to reverse that and turn it entirely on its head, what about the rights of parents who have children but do not want them to know that they have six months to live and are on palliative care? They do not want them to see them suffering. They do

not want them worrying. They will pass and then, "Your mother has passed" or, "Your father has passed".

Where do the feelings of the parents come into this, then? They are trying to shield their children from the horrors of whatever they are going through at the end of life. Is that perhaps why the Bill says that no professional should raise assisted dying with a person under 18? I am trying to use my words carefully, but do you think that line was put in for a different reason?

Dame Rachel de Souza: The problem is that we are talking about deeply personal familial relationships, childhood, children, and we are trying to legislate about it. Now, that is your job, not mine. I have heard from our best children's palliative care consultants, absolutely brilliant people. I have looked at how they engage with families, with parents, with children, and manage deaths of children, which are very rare—outside of accidents, it is a very small number—with such sensitivity and care, and at home. When the professionals are therapeutic, we often have a high level of trust in that, do we not?

Q167 **Baroness Berger:** It was more than a decade ago that the Department of Health, in its document *Future in Mind*, recommended an extension of child and adolescent mental health services up until the age of 25 to, essentially, end the practice of discharging young people out of mental health services at 18.

The rationale for that was because of two reasons. First, this cliff edge meant that children entering mental health services had to go through the process all again, and adult mental health services were not really appropriate for children and young people. The second of the rationales given at the time was that the prefrontal cortex of the brain, responsible for executive functions such as planning and decision-making, is one of the last parts of our brain to fully develop and typically does so around the age of 25.

Do you think it is right that the Bill allows assisted dying to be suggested from the age of 18? Do you foresee any circumstances where young people with a history specifically of mental health issues, possibly perhaps related to an eating disorder or suicidal ideation, and without appropriate support, could at 18 be exposed to even more harm through this Bill?

Dame Rachel de Souza: The reality of life on the ground, as those of you who work with health will know, is that 18 is not really a thing. You look at lots of 16 year-olds in the NHS going straight into adult services. You are absolutely right. I have responsibility for vulnerable children in this country, a statutory duty to have oversight for them, but, when it comes to the most vulnerable, that is extended to 25. EHCPs are extended to 25 for all the reasons that you point out.

I could give you multiple examples of children for whom that absolutely is the case, and I have vast numbers of case studies about it. I would far rather that we erred on the side of caution, protecting those who have

had terrible lives, terrible experiences, have been abused, have had their families turn them out, protecting those who are suffering from extreme mental illness, protecting those with special educational needs and disabilities, protecting anorexic children who are heading into adulthood, and saying, "Let's err on the side of caution and go for 25".

Basically, anyone who would be considered for this Bill should have an EHCP if they were coming from childhood. Those children are protected in law to 25, and I think that we are missing a trick by thinking somehow 18 is the cut-off. I really do strongly think that. I would like the committee to consider that.

Baroness Berger: You have touched on quite a few issues to do with safeguards and specific areas where you think things are missing. Can you share with us anything else, if you believe that there are gaps, in terms of what is missing in this Bill, specifically relating to children and safeguards?

Dame Rachel de Souza: Let me just tell you what the children say. There is a girl with osteosarcoma, a 16 year-old, who is an amputee. She has won the golden boot for our Amputee Lionesses. This is a sensitive topic for me. Sometimes doctors get it wrong. Sometimes you are told you have six months to live, and you have a couple of years. I think they are missing out. I think this Bill will influence them. It is difficult to explain.

I have one child who says, "I'm in care. I've got disabilities. The Government will pay for me to die under this Bill, but it won't pay for me to live". There are some deep concerns from children, and we need to hear them, listen to them and answer them.

Q168 **Lord Winston:** I do not quite understand. Are you talking for children who might need assisted dying, or are you talking about children who are reacting to assisted dying?

Dame Rachel de Souza: I have tried to answer differently in both of those cases. I opened speaking about all children and their interest in this; then I talked about vulnerable children, children with special educational needs and disabilities, and children in hospital with life-limiting diseases. That latter category all have, or should have, education, health and care plans that give them protection and support, and positive therapeutic support, to the age of 25.

Lord Winston: So you would be against assisted dying. Is that what you are saying?

Dame Rachel de Souza: For adults and for those who are not vulnerable, it is not my place to have a view. It is the children I am responsible for.

Lord Winston: Adults who are childless.

Dame Rachel de Souza: It is the children that I am responsible for, and the children up to 25 who are extremely vulnerable and have an EHCP that I have a statutory responsibility for.

Lord Winston: My father died as a result of assisted dying through medical negligence—I think negligence anyway—when I was just eight, or actually the end of seven. I do not recognise anything that you say, and I have a problem with that because I think every child is different. No doubt you will be familiar with the evidence from Colombia—I hope you are, because, of course, it is on record—where they have even had legislation about children on assisted dying. One point that is made is that most children, they recognise, do not have really any conception of death, surprisingly far on into life. That is reported by Ben White in his book, and there are other examples of that.

Dame Rachel de Souza: I was a head teacher for 20 years. I taught personal, social and health education and religious education for 32 years. I have had lots of conversations and discussions with children. It is part of the curriculum. You are absolutely right. There is a developmental process, and our understanding of death changes throughout life, does it not? There is a difference between the kind of conversations you are having in school, in RSE lessons and those things, and children who are facing these experiences themselves. We have taken the views from vulnerable children here.

Q169 **Baroness Scotland of Asthal:** There has been a suggestion that this Bill will not affect children. From what I hear you saying, your answer is, "Yes, it will".

Dame Rachel de Souza: Yes.

Baroness Scotland of Asthal: It will affect how they think of themselves, how they think of life and how they will understand the end of life. I see you nodding, so the answer to that is yes, but I want to ask you about a particularly vulnerable group—that is children who are living in domestic violence homes where the level of harm to the parent being subjected to it is high—and how much children see. From the evidence we have heard from this committee, there is a higher degree of suicide in those who are victims, a higher incidence where the perpetrator will manufacture a suicide, and an escalation in the abuse where someone is ill, particularly when they are terminally ill. I think that is in accordance with your experience.

Dame Rachel de Souza: Yes, absolutely, and deeply concerning. We would not want any child to be in that situation.

Baroness Scotland of Asthal: The issue with these children who are living in domestic violence homes is that they are subject to far greater pressure in terms of their response to the level of dysfunction. They are overrepresented in the prison population, overrepresented in those who take drugs, overrepresented in those who, therefore, subsequently suffer mental illness, and overrepresented in the suicide figures themselves.

That is correct, is it not?

Dame Rachel de Souza: Absolutely.

Baroness Scotland of Asthal: For those children whose parent commits suicide, if we look at the figures, there is a heightened risk that they themselves will take that as a way out. That is just fact.

Dame Rachel de Souza: Yes.

Baroness Scotland of Asthal: For anyone to think that this will not affect children, would you agree that they are gravely mistaken?

Dame Rachel de Souza: Gravely mistaken. Our QOL work, which I have shared, shows that children, especially our vulnerable children, are absolutely affected by what is going on. They live in 24/7 worlds. They will be watching us.

Baroness Scotland of Asthal: If we now look at the children of prisoners, that group of children are particularly vulnerable both during their childhood and thereafter.

Dame Rachel de Souza: Yes, absolutely.

Baroness Scotland of Asthal: So the risk for them is particularly heightened.

Dame Rachel de Souza: Yes, the intergenerational experience, absolutely. I meet every child in prison. I speak to every child in prison. The stories of the percentage of care leavers, those who have experienced poverty, domestic violence, the suicide attempts, are a matter of record.

Q170 **Lord Goodman of Wycombe:** I just have a quick follow-up question to the one that Elizabeth Berridge originally asked you. There has been a lot of concern in this session about TikTok videos, what AI might say, video games and all that, and the effects on children. In the last session we had with the Minister, I asked the Minister whether those things would be caught by the prohibition on advertising in the Bill. The Minister said that he thought it would be.

I would have thought—and I am not a lawyer—this is at least arguable, because the Bill bans advertising in relation to the promotion of a voluntary assisted dying service. TikTok video is not a service. A video game is not a service. An AI machine giving you an answer is not a service. Have your lawyers looked at this clause? If you do not have an answer to hand, and I would be surprised if you did, might you be able to give us a view?

Dame Rachel de Souza: We will look at it. The complexity of how, say, Instagram influencers make their money is not straightforward. I do think a productive route for a very tricky Bill—the online harms Bill—might be that it was set up so that it could expand and take things such as this in.

This would be a fruitful place to look. I will be speaking to Ofcom about it, and I will talk to its lawyers as well.

Q171 **Baroness Hayter of Kentish Town:** Death affects children. Not just assisted death, but death affects children. Like Lord Winston, I was younger than 10 when my mother was killed. Far more children are going to lose parents than through assisted dying. My concern is that you seem to be saying that you did not want assisted dying to be available to someone, even at 18, who would not be reaching their 19th birthday. You are saying, I think, that that group, no matter how much suffering, pain, whatever, they are going through, just have to suck it up, basically.

Dame Rachel de Souza: No. What I am saying is, working with those most vulnerable groups of children that we talk about, I am concerned that, if they have not had good experiences, proper support, we should be supporting them to try to live that one precious life they have got as well as they can.

Baroness Hayter of Kentish Town: However much distress, however much pain, and however much they beg, "Just finish it", you would say no, they cannot.

Dame Rachel de Souza: I have seen so many young people who tell me, 10 years later, 15 years later, "I am pleased I didn't act on that".

Baroness Hayter of Kentish Town: I am talking about someone who is dying within six months. They are 18. They are not going to get to their 19th birthday. No matter, I think you are saying, however ill, how much suffering, how much they are under oxygen, you would deny them the ability to finish their life early.

Dame Rachel de Souza: I am saying, "Let's be cautious", because my experience in Canada made me think, if you are cautious and pull back, that is different to starting in a place that can take you places you do not want to go. I am worried about that. I am worried. I think this is really serious, really important, as you do, and I have great respect for everybody around this table, whatever their position. We need to try to make the right decision. With vulnerable young people, I worry, because they tell me they changed their minds.

Baroness Hayter of Kentish Town: But they are dying. We are only talking about dying. We have to be really clear on this. We are talking about people dying.

Dame Rachel de Souza: I know you are. I know, yes. It is going through so quickly that I am worried about the unintended consequences of how those decisions are made, how the support is made, how poor support early makes those last months different for you. I just want us to consider them really carefully so the child's rights and experience are really protected.

The Chair: I am going to have to leave it there. Thank you very much indeed. I am having to bring this session to an end, with some regret, but

it is necessary for other reasons. Thank you very much indeed for coming to see us. I remind you that there will be a transcript that will be shown to you. Could you check it, please, to see that it is accurate and, if there is anything wrong with it, do let us know? Thank you very much indeed.