

Response ID ANON-6XVX-YB1A-9

Submitted to A Human Rights Bill for Scotland: Consultation
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Part 4: Incorporating the Treaty Rights

1 What are your views on our proposal to allow for dignity to be considered by courts in interpreting the rights in the Bill?

Allow

Please give us your views:

We strongly support the proposal to allow the courts to consider dignity when interpreting the rights in the Bill. It is the essence of palliative and end of life care to affirm and maintain the dignity of each person in the face of serious illness and dying. No matter whether they have hours, days, weeks or years left to live palliative care aims to maximise wellbeing. As Dame Cicely Saunders, the founder of the modern hospice movement said:

" You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Everyone dies. Everyone loses people they care about. Everyone is deeply affected by these experiences. Everyone has a story about the palliative and end of life care that made the worst of times more bearable. Or a story about a failure of communication, or a lack of compassion and dignity when it was needed most.

Death, dying and bereavement are the most universal human experiences. Over 60,000 people die in Scotland each year, and this is projected to rise significantly. Almost one-third of the people being cared for in a Scottish acute hospital ward today will have died within 12 months . 72% of UK adults report having been bereaved in the last five years . Over 50% of all children in Scotland are bereaved of a parent, sibling, grandparent or other close family member by age 8 and this rises to 62% by age 10.

How Scotland responds to these experiences are a true litmus test of our values and a test of how effectively as a nation we put those values into action.

2 What are your views on our proposal to allow for dignity to be a key threshold for defining the content of minimum core obligation (MCOs)?

Allow

Please give us your views:

We support this.

3 What are your views on the types of international law, materials and mechanisms to be included within the proposed interpretative provision?

If so, please identify these, explain why and how this could be achieved.:

We would like the interpretative provision to include the United Nations Report of the Human Rights Council Thirty-first special session (24 August 2021) Forty-eighth session (13 September–11 October 2021), Resolution 48/3 calling on member states to ensure non-discriminatory access for older people to palliative care.

4 What are your views on the proposed model of incorporation?

Please give us your views.:

Our test for considering the effectiveness of the Bill is whether it will enhance focus on ensuring that people at the end of life have their rights respected, their wellbeing and dignity affirmed and maintained. For example, will people in Scotland be sure that at the end of their life they will get timely access to care and treatment to manage distressing symptoms? Will public bodies recognise and understand a clearly articulated duty to ensure systems, processes and resources are in place to achieve this end.

There is evidence that some groups experience less good access to palliative care or have less positive experiences of that care. These groups include: prisoners, people who are homeless, travelling people, LGBTQI+, BAME, very old people, people experiencing financial hardship.

We have considered the lengthy consultation document which gives a sense of the technical legal complexities which need to be taken into account in choosing the specific model of incorporation. The proposal appears logical.

5 Are there any rights in the equality treaties which you think should be treated differently?

Not Answered

If so, please identify these, explain why and how this could be achieved:

Part 6: Incorporating Further Rights and Embedding Equality

12 Given that the Human Rights Act 1998 is protected from modification under the Scotland Act 1998, how do you think we can best signal that the Human Rights Act (and civil and political rights) form a core pillar of human rights law in Scotland?

Please give us your views:

13 How can we best embed participation in the framework of the Bill?

Please give us your views:

Participation arrangements need to take account of the particular challenges faced by people with serious, life limited advanced illness. The phrase "lived experience" is problematic in relation to end of life care. That said there is evidence that people facing the end of life, and their family carers, appreciate opportunities to share their perspectives and inform decision making.

14 What are your views on the proposed approach to including an equality provision to ensure everyone is able to access rights, in the Bill?

Please give us your views:

We support this in principle.

15 How do you think we should define the groups to be protected by the equality provision?

Please give us your views :

16 Do you agree or disagree that the use of 'other status' in the equality provision would sufficiently protect the rights of LGBTI and older people?

Disagree

17. If you disagree, please provide comments to support your answer.:

Assuming it is not possible to legislate to treat "dying" as a protected characteristic we would like to see specific mention of older people in the equality provisions. Palliative and end of life care is relevant to babies, children, young people and adults. However, the vast majority of people requiring palliative and end of life care are older people and for this reason we would like the equality provision to mention them specifically.

18 Do you think the Bill Framework needs to do anything additionally for LGBTI or older people?

Not Answered

Please give us your views:

Part 7: The Duties

19 What is your view on who the duties in the Bill should apply to?

Please give us your views:

We support the broad approach. However, we have a concern in relation to Third Sector bodies contracted to carry out functions of a public nature. Such contracts need to adequately reflect the resources required to realise people's rights. Resourcing and funding arrangements must be on an equal footing with statutory bodies, including sustainable, longer term funding models.

20 What is your view on the proposed initial procedural duty intended to embed rights in decision making?

Please give us your views:

We support the concept of an initial procedural duty followed after an appropriate interval by a subsequent compliance duty.

21 What is your view on the proposed duty to comply?

Please give us your views:

We support the concept of an initial procedural duty followed after an appropriate interval by a subsequent compliance duty.

22 Do you think certain public authorities should be required to report on what actions they are planning to take, and what actions they have taken, to meet the duties set out in the Bill?

Please give us your views:

Yes, in principle. In practice reporting needs to avoid being burdensome, and to provide reports which are transparent and useful to rights bearers.

23 How could the proposed duty to report best align with existing reporting obligations on public authorities?

Please give us your views:

24 What are your views on the need to demonstrate compliance with economic, social and cultural rights, as well as the right to a healthy environment, via minimum core obligations (MCOs) and progressive realisation?

Please give us your views:

We support this broad approach.

We have specific views on the minimum core obligations on the right to highest attainable standard of physical and mental health:-

We believe that palliative and end of life care should be put on an equal footing with the other priorities given specific mention in General Comment 14 of the Committee (referenced in the SG Consultation Document).

The dominant paradigms which inform both public health and healthcare policies, plans and priorities emphasise prevention, cure and longevity of life. The experience of irreversibly declining health and dying does not sit easily within this framework, which why it is essential that it be mentioned specifically, otherwise it will risk being missed by duty bearing bodies.

Over 60,000 people die in Scotland each year and 90% of people will have palliative care needs. Everyone dies. Palliative care and end of life care therefore has the characteristics of being of universal relevance and of large scale. It shares these characteristics with the other priorities which are specifically mentioned by the Treaty Body (such as reproductive care, maternal healthcare, child healthcare). It is a significant gap which is receiving significant recognition at international level.

It is not acceptable that the effective and timely treatment of distressing breathlessness, nausea and severe pain at the end of life should be left to a process of progressive realisation. Scotland is a sophisticated and relatively wealthy country capable of delivering a minimum core obligation in this area.

25 What are your views on the right to a healthy environment falling under the same duties as economic, social and cultural rights?

Please give us your views:

26 What is your view on the proposed duty to publish a Human Rights Scheme?

Please give us your views:

Part 8: Ensuring Access to Justice for Rights-Holders

27 What are your views on the most effective ways of supporting advocacy and/or advice services to help rights-holders realise their rights under the Bill?

Please give us your views on advocacy:

Please give us your views on legal aid:

28 What are your views on our proposals in relation to front-line complaints handling mechanisms of public bodies?

Please give us your views:

29 What are your views in relation to our proposed changes to the Scottish Public Services Ombudsman's remit?

Please give us your views:

30 What are your views on our proposals in relation to scrutiny bodies?

Please give us your views:

31 What are your views on additional powers for the Scottish Human Rights Commission?

Please give us your views:

32 What are your views on potentially mirroring these powers for the Children and Young People's Commissioner Scotland where needed?

Please give us your views:

33 What are your views on our proposed approach to 'standing' under the Human Rights Bill?

Please give us your views:

34 What should the approach be to assessing 'reasonableness' under the Human Rights Bill?

Please give us your views:

35 Do you agree or disagree that existing judicial remedies are sufficient in delivering effective remedy for rights-holders?

Not Answered

36. If you do not agree that existing judicial remedies are sufficient in delivering effective remedy for rightsholders, what additional remedies would help to do this?:

37 What are your views on the most appropriate remedy in the event a court finds legislation is incompatible with the rights in the Bill?

Please let us know your views. :

Part 9: Implementing the New Scottish Human Rights Act

38 What are your views on our proposals for bringing the legislation into force?

Please give us your views:

39 What are your views on our proposals to establish minimum core obligations (MCOs) through a participatory process?

Please give us your views:

In principle we welcome the use of a participatory approach to establish minimum core obligations.

However, our experience of how this principle is put into practice gives us serious cause for concern. Despite best intentions it is difficult to see how people with serious illness and who those who may be dying can take part on an equal footing in any participatory process. These perspectives are consequently often marginalised or absent in public policy development.

We therefore believe that any participatory process should start with a presumption that palliative and end of life care be mentioned specifically within the minimum core obligations.

40 What are your views on our proposals for a Human Rights Scheme?

Please give us your views:

41 What are your views on enhancing the assessment and scrutiny of legislation introduced to the Scottish Parliament in relation to the rights in the Human Rights Bill?

Please give us your views:

42 How can the Scottish Government and partners effectively build capacity across the public sector to ensure the rights in the Bill are delivered?

Please give us your views:

43 How can the Scottish Government and partners provide effective information and raise awareness of the rights for rights-holders?

Please give us your views:

44 What are your views on monitoring and reporting?

Please give us your views:

About you

What is your name?

Name:

Mark Hazelwood

What is your email address?

Email:

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Scottish Partnership for Palliative Care (SPPC)

Please tell us which of the following categories best describe you (select all that apply):

Other

If other, please specify:

Scottish Partnership for Palliative Care is a third sector intermediary organisation. Our members include over 100 organisations in Scotland with an interest in improving palliative and end of life care, including all the territorial NHS Boards, all IJBs, all Local authorities, all the hospices, a range of professional associations, many national charities and social care providers. We also lead the public facing alliance Good Life, Good Death, Good Grief supporting community action.

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here.:

This is a tough topic on which to design an accessible public consultation. I found the way the consultation document was structured helpful, and obviously a lot of thought had gone into it.

Despite reading a lot around the subject and spending time getting to grips with human rights language and institutions I still found it hard to answer some of the questions.

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Very satisfied

Please enter comments here.: