

21 May 2019



Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

David Seymour MP

By email: david.seymour@parliament.govt.nz

Dear Mr Seymour

End of Life Choice Bill

1. I am writing to express my concerns about the implications of the End of Life Choice Bill (**the Bill**) as reported back by the Justice Committee. I consider the Bill as it is currently drafted is problematic for the reasons set out in this letter.
2. People who request assisted dying should have the same protections as others in the health and disability sectors – including the rights and duties provided for in the Code of Health and Disability Services Consumers' Rights (**the Code**). Should the Bill be passed I agree that it is appropriate for HDC to have jurisdiction in respect of assisted dying. However, I am concerned that the Bill does not fully reflect this intent.
3. Bringing assisted dying into HDC's jurisdiction requires careful consideration of how the provisions of the Bill will interact with the Code and the Health and Disability Commissioner Act 1994 (**the Act**). There are a number of areas where it is apparent to us that this interface has not been appropriately addressed. While I have set out a number of specific concerns below, in particular I wish to emphasise that there needs to be greater clarity about how the Code and Act will apply to providers involved in the provision of assisted dying. This is particularly important in relation to questions about competence and informed consent.
4. The proposed amendments to the Act and Code first appeared when the Bill was reported back from the Select Committee. We were not consulted about the changes to the Bill and so have not had an opportunity to comment on how these amendments affect this Office and its work.

Amendments to the Health and Disability Commissioner Act 1994 and Code of Health and Disability Services Consumers' Rights

Services covered

5. As the new definition of services is currently drafted, I consider there is a good argument that it only captures the final steps of assisted dying. I say this because the Bill proposes to amend the definition of services in the Code to include *"the provision of assisted dying under the End of Life Choice Act 2017"*. The definition of 'assisted dying' in the Bill refers to the self-administration or administration by a medical practitioner of a lethal dose of medication.
6. I expect that the policy intent is that the entire process of assisted dying, from the point that a request is made, should be captured by the Code. This is reflected, for instance, in section 30(b)(i)(ia) of the Act, which extends the functions of advocates to include that *"health consumers*

who, under the End of Life Choice Act 2017, request to receive assisted dying" are made aware of the provisions of the Code.

7. In order to address this issue I suggest that the definition of 'services' be expanded to capture the entire process following a request. It might for example be defined as "*services provided to a person who has requested assisted dying under the End of Life Choice Act 2017*", or words to that effect. I also consider that the expanded definition should be moved to become a subset of the definition of "health services" in section 2 of the Act for the reasons set out below.

Health care providers covered

8. There is an issue as to whether all providers involved in the assisted dying process will be covered by the Code.
9. As set out in clause 1(2) of the Code, the duties in the Code are held by providers. Provider is defined in the Code as "*a health care provider or disability services provider*". The definition of health care provider is set out in turn in section 3 of the Act and, in addition to a list of specified providers (including health practitioners), includes a catch-all provision at subsection (k) for "*any other person who provides, or holds himself or herself or itself out as providing, health services to the public or to any section of the public, whether or not any charge is made for those services*".
10. As the definition of 'health services' in the Act is (currently) not proposed to be changed, any providers who would usually fall within section 3(k) could argue that they are not subject to the duties in the Code in respect of assisted dying. This could include people such as health care assistants, counsellors, and administrative staff. While I am not convinced that such an argument would be successful (for example, these individuals would arguably provide other health services in the assisted dying process, and be captured in that way), the proposed amendments introduce an element of ambiguity and risk of legal challenge.
11. One way to ensure these providers are subject to the duties in the Code would be to amend the definition of 'health services' in the Act, to include services provided to a person who has requested assisted dying under the End of Life Choice Act 2017. Doing so would remove the need to amend the definition of 'services' in the Code and 'health consumer' in the Act.¹
12. In respect of any possible policy objections to including assisted dying as a health service, I note that this change would also be consistent with the amendment to section 22B of the Health Act 1956, which (by working through a number of linked definitions) provides that 'health services' in the New Zealand Public Health and Disability Act 2000 includes assisted dying services.

¹ It would also mean that any reference to 'health care procedure' in the Act and Code would include assisted dying services. Consideration would need to be given to the effect of this change, including in respect of the definition of 'advance directive' in the Code.

Informed consent: competence, provision of information, voluntary decision

13. What follows does not purport to be a precise statement of the law of competence/capacity or informed consent. Rather, it is intended to give you a general overview of the issues that give rise to my concerns.

Informed consent

14. The Bill does not refer to informed consent. Further, the process set out in the Bill is prescriptive and does not mirror the requirements for informed consent as set out in the Code. This raises questions as to whether the process requirements in the Bill stand alone, and are a substitute for informed consent, or whether the usual informed consent requirements apply as well.
15. Informed consent is a fundamental pillar of the legal framework applying to the provision of health and disability services. Right 7(1) of the Code requires that:
- Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.*
16. In my view, amendments are needed to ensure that health practitioners, consumers and HDC have clarity as to the requirements that apply and how health practitioners' actions or inactions will be reviewed by complaint bodies. I expand on my view in relation to the key elements of informed consent and how they relate to the Bill below.

Level of competence

17. It is not clear whether the Bill sets a different level of competence to that applied to the provision of other services or, whether it is intended to operate separately to the law currently.
18. New Zealand relies on the Code and common law when assessing whether a consumer is competent to make decisions regarding the provision of health and disability services.²
19. Relevantly, the Code provides that:
- (a) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent (Right 7(2)).
 - (b) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence (Right 7(3)).
20. As illustrated in Right 7, assessing competence is a complex matter. Assessing capacity is an on-going process rather than a one-off event. It is not an exercise in 'ticking the boxes'. On one view, the Bill sets the level of competence required in order to access assisted dying by clause 4(f): that is, to be eligible for assisted dying, the person must have the ability to understand:
- (a) the nature of assisted dying; and

² Notable exceptions include section 9 of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 and section 5 of the Protection of Personal and Property Rights Act 1988.

- (b) the consequences for them of assisted dying.
21. This is reinforced by the fact that the attending medical practitioner and the independent medical practitioner, are directed by clauses 10(2) and 11(3) to consider whether the consumer is eligible under clause 4(f) (and clause 4(f) is the only criterion that relates to the level of understanding that the person must have). As such, it appears that the question of "competence" is restricted to an assessment against this standard.
22. However, issues relevant to a consumer's competence are also addressed elsewhere in the Bill and are inconsistent with clause 4(f) being the required level of competence. In particular:
- (a) Under clause 8, a medical practitioner who is approached by a person who wishes to have the option of receiving assisted dying must do those things set out in subclauses (2)(a) to (h). This includes providing certain information about the consumer's prognosis but also imposes an obligation on the practitioner to "*ensure that the person understands their other options for end of life care*" (clause 8(2)(c)). This requires a greater level of competence than that expressed in clause 4(f) – it would, for instance, require the person to have a sufficient level of understanding about their condition and prognosis, as well as the stated need to understand available options for end of life care.³
- (b) A medical practitioner must also "*ensure that the person knows that he or she can change their mind at any time before the administration of the medication*" (clause 8(2)(d) and clause 15(3)(c)). Again, this suggests a level of competence that touches on matters beyond those expressed in clause 4(f). It also suggests that the requirement to be competent extends beyond the initial assessment of eligibility, and will continue from the time the person decides to exercise the option of receiving assisted dying (in clause 15(2)) until the time the medication is administered (in clause 16(2)). I discuss this later point in more detail below.
23. In my view, it is necessary for this matter to be clarified. In order for HDC to be able to apply the provisions of the Bill, it needs to be clear what the policy and requirements are.

When is competence assessed?

24. The Bill is unclear currently with regard to when competence must be assessed.
25. Under the Code and Act, the assessment as to whether a consumer has provided informed consent is made at the time that the health care procedure is carried out. This means that the provider must be satisfied that the person consenting is competent to make that particular decision at that time.
26. The Bill requires issues of competence to be assessed when the medical practitioners undertake their assessments of eligibility (under clauses 10, 11 and 12). In contrast, competence is not expressly required to be assessed when the consumer advises that they wish to exercise the option

³ I also note that clause 8(2)(c) appears to be impose a higher standard – to ensure that the person understands their other option – than that which is imposed under the Code. In particular, Code provides a consumer has a right to effective communication that "enables the consumer to understand the information provided" (Right 5, and Right 6).

of receiving assisted dying (clause 15(2)), chooses a method of assisted dying (clause 3(b)), or chooses to receive the medication (clause 16(2)).

27. It could be argued that it is implicit competence must be assessed at these stages. For example:
- (a) As noted above, the medical practitioner must "*ensure that the person knows that he or she can change their mind at any time before the administration of the medication*" (clause 8(2)(d) and clause 15(3)(c)).
 - (b) The person must 'choose' a method of administration (clause 15(3)(b)), must 'choose' the time for administration (clause 15(3)(c)), and must 'choose' to receive the medication (clause 16(3)).
28. However, it could also be argued that a further assessment of competence is not required at these stages. For example:
- (a) The absence of an express requirement to reassess competence (or indeed, reassess eligibility in general) can be contrasted with the express requirement that a medical practitioner take no further action if, at any stage during the process, they have reasonable grounds to suspect that the person is not expressing their wish for assisted dying "*free from pressure from any other person*" (clause 22A).
 - (b) A person's condition may be expected to degenerate to the point where the individual is not competent to make all decisions regarding their care and welfare, including medical treatment. The absence of the requirement for an ongoing assessment of competence (and instead requiring that it be assessed only at an earlier stage) may be viewed as a policy decision designed to reflect this situation, similar to an advance directive. In line with this, the policy may be that there is a requirement for the person to maintain consistency in choice, or that the level of competence required is limited to being able to 'choose' the method, and 'choose' to receive the medication. Whether this is the case is not clear.
29. In my view, this should be clarified.

Information provision

30. The Bill is prescriptive as to what information must be provided to the person at various stages of the assisted dying process. This raises a question as to whether the general information requirements set out in Right 6 will apply.
31. While my view is that the Bill ought to be interpreted so that the specific information requirements supplement the general obligation to ensure that the person receives information that a reasonable consumer in their circumstances would expect to receive (similar to those specific examples set out in Right 6(1)), it is not clear from the Bill whether this interpretation would apply.

32. I also note that by specifying information that the medical practitioner must discuss at various stages in the process, a question arises as to whether this information is information that a reasonable person, in that person's circumstances, would expect to receive earlier in the process.
33. For example, the Bill does not contemplate a provider giving a consumer information about assisted dying in advance of a request from that consumer. Information provision is only triggered where a consumer requests assisted dying. Given the requirements under Right 6(1)(b) of the Code, it is arguable that providers should tell consumers about the option of assisted dying when informing them about their diagnosis and treatment options (which may well be before the consumer requests assisted dying). In this regard, I note that:
- (a) the Bill does not specifically prohibit providers from offering information about assisted dying where the consumer has not requested assisted dying;
 - (b) there is a risk that providing information could constitute an offence under section 179 of the Crimes Act (aiding and abetting suicide) as it is not an action that is "in accordance with the requirements of this Act" (so would not be covered by the immunity provision in clause 26 of the Bill); and
 - (c) there is a policy question about the appropriateness of a provider raising assisted dying as an option, given the considerable influence that providers have over consumers.
34. In my view, this should be clarified in order to remove any confusion or risk of legal challenge.

Voluntary decision

35. There is some ambiguity with clause 22A with respect to the title and the wording of the clause itself. The title of the clause states: "Attending medical practitioner to take no further action if coercion is suspected". This is different from the wording of the clause which provides that, if the practitioner "has reasonable grounds to suspect that a person... is not expressing their wish free from pressure of any other person", then they must take no further action under the Act. Pressure and coercion are different concepts. It is important for this to be clarified.

Advance directives

36. The Bill does not address advance directives. The Bill requires the medical practitioner to "*ask the person if they choose to receive the medication*" prior to its provision (clause 16(2)), which on its face excludes the availability of advance directives. However, given my comments regarding competence above, it is at least arguable that the medical practitioner is required to assess consistency of choice at this stage, as opposed to undertaking a further assessment of competence.

37. Right 7(5) of the Code permits the use of advance directives, although only *"in accordance with the common law"*.⁴ If it is not intended that advance directives be available for assisted dying, this must be set out explicitly in the Bill.

Registrar and complaints

38. It is unclear whether the registrar⁵ is able to refer to other agencies information shared by the end-of-life review committee, including reports and "follow up" requirements. In the absence of requirements set out in legislation to refer this information, privacy and jurisdictional issues may arise. I understand that section 118(f) of the Health Practitioner's Competence Assurance Act 2003 was amended recently to address concerns about the information that registration authorities could receive and act on.⁶ Similar amendments to clause 21(4) of the Bill would enable the registrar to receive and act on any information, not just 'complaints'.
39. I also note that, as currently drafted, the registrar must come to a view about whether a complaint *"relates to a breach of the Code..."* This requires the registrar to make an assessment of the complaint in respect of the Code, which may be outside their expertise and would duplicate the work that HDC would do upon receipt of the complaint. Drafting clause 20 in a similar manner to the referral provision at section 64(1) of the Health Practitioner's Competence Assurance Act 2003 may address these concerns.
40. As currently drafted, the registrar is only able to refer matters that it considers are "more properly" within the jurisdiction of other organisations. What is properly in the jurisdiction of the registrar is unclear. The Bill should clarify the registrar's powers, including whether the registrar can take action on complaints other than just referring them to another agency.
41. In light of the issues discussed above, I consider the Bill as it is currently drafted is problematic. Those who seek assisted dying should at least be afforded the same protections as others in the health and disability sectors, including the rights and duties provided for in the Code.
42. I trust these comments are helpful. I would be happy to meet with you to discuss any of the issues I have raised.

Yours sincerely



Anthony Hill
Health and Disability Commissioner

⁴ Clause 4 of the Code defines an "Advance directive" to mean a written or oral directive by which a consumer makes a choice about a possible future health care procedure and that is intended to be effective only when he or she is not competent.

⁵ As created by clause 21 of the Bill.

⁶ Section 118 was originally "to receive and act on information from health practitioners, employers, and the Health and Disability Commissioner about the competence of health practitioners", and was amended to "to receive information from any person about the practice, conduct, or competence of health practitioners and, if it is appropriate to do so, act on that information". The Select Committee report stated change was necessary to widen the original provision so that "any person ... could raise issues with an authority if they have concerns about a practitioner's practice, conduct or competence."

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