



Submission to the Justice Committee on the End of Life Choice Bill 2017

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Introduction

No safeguards can protect people with disabilities in a world where their lives are not valued¹

1. The purpose of this Bill is to give people with terminal illness or a “grievous and irremediable medical condition” the option of requesting assisted dying.
2. IHC acknowledges that assisted dying is a complex issue and that the Bill is motivated by compassion². However the Bill’s reach extends well beyond people with terminal illness who want to die. It raises fundamental questions about respect for human dignity and autonomy, protection of the vulnerable and the extent to which New Zealand is meeting its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)³.
3. The UNCRPD specifically recognises that every human being has the right to life and it requires government to take all necessary steps to ensure people with disabilities effectively enjoy this right on an equal basis with others⁴.
4. The Bill as it currently stands is silent on human rights. It does not establish either the substantive or procedural mechanisms necessary to balance the complex rights issues involved or provide adequate safeguards. This is particularly problematic for people with intellectual disabilities.
5. There are a number of unarticulated assumptions in the Bill around access to palliative care and disability supports and their importance to issues for people with disabilities in relation to assisted dying.

Key points and recommendations

6. IHC makes the following key points and recommendations:
 - a. This Bill fails to balance the fundamental principles which underpin it; sanctity of life, respect for human dignity and autonomy, and protection of the vulnerable.
 - b. The Bill’s reach extends well beyond people with terminal illness who want to die.
 - c. The dominant social narrative that intellectual disability is a burden and cause for struggle and despair has the potential to impact the interpretation and application of the Bill with serious consequences for people with disabilities.
 - d. Legislative change should not be considered until work is done to ensure equitable access to the highest possible quality of palliative care and disability supports.
 - e. IHC is concerned about possible future extension of the Bill’s application as has happened in overseas jurisdictions.

¹ Tim Stanton, as quoted in CCD and CACL

² End of life Choice Bill, Explanatory Note, purpose

³ United Nations (2006) Convention on the Rights of Persons with Disabilities

⁴ UNCRPD, Article 10

- f. The proposed safeguards do not meet the minimum criteria for a legal framework for assisted dying set out by the Human Rights Commission (2016).

IHC recommends:

- i. The Bill not be passed in its current form.
 - ii. That the scope and intent of the Bill is reviewed and refocused on people with a terminal illness and that eligibility under clause 4 "grievous and irremediable medical conditions" be removed.
 - iii. More work be done, in consultation with the disability community, to ensure any legislation on assisted dying upholds the fundamental principles of sanctity of life, respect for human dignity and autonomy, and promotes the human rights of persons with disability..
 - iv. Government prioritise work to ensure equitable access to the highest possible quality of palliative care and health and disability supports and that this work informs the review of the scope and intent of a refocused Bill.
 - v. Should the Bill be passed into law that clinicians involved in any aspect of the assisted dying processes have extensive training on disability rights and that there is a requirement to consult with disability experts and ethicists.
7. We endorse the submissions and recommendations of the Disabled People's Assembly (DPA) and the New Zealand Human Rights Commission, Disability Commissioner.

About IHC

8. IHC was founded in 1949 by a group of parents who wanted their children with intellectual disabilities to participate in and have equal access to services in their communities. The IHC of today strives for these same rights, advocating for the welfare and inclusion of an estimated 96,800 people with intellectual disabilities and their families/whanau in New Zealand.⁵ Our starting point is that people with intellectual disabilities are able to live valued lives with equal opportunities and equitable outcomes to their non-disabled peers.⁶

Overall comments

*'People with disabilities don't need to die to have dignity'*⁷

9. Although unintended, this Bill raises fundamental concerns for the disability community because of the linkages made between disabilities, what makes life unbearable and assisted dying. It identifies lack of dignity and autonomy as precursors to life being intolerable.

⁵ Statistics New Zealand, *New Zealand Disability Survey 2013*

⁶ IHC. (2016). Making Citizenship and Rights Real in the Lives of People with Intellectual Disabilities, IHC (2017). How's New Zealand doing for people with intellectual disabilities? www.ihc.org.nz/survey , IHC (2017). Valuing All: leave no-one behind.

⁷ Nancy Hanson, as quoted in Council of Canadians with Disabilities (CCD) and Canadian Association for Community Living. Media Advisory: Comment on appeal of Carter v. Canada (assisted suicide), 9 October, 2013. Retrieved from <http://www.ccdonline.ca/node/1251>

10. There is despite an enabling government disability strategy a dominant and persistent narrative that the lives of people with disabilities are not of equal value, which is reflected in prevalent negative stereotypes of people with disabilities being tragic and a burden. Stories in the public arena about a lack of access to needed health and disability support services *strengthen* that narrative.
11. A number of assumptions underpinning the Bill are consistent with this narrative. These assumptions are inherent in the terminology used and the inattention to issues that have particular relevance to people with disabilities, those being capacity, supported decision-making, informed consent, and freedom from coercion. By not addressing these issues appropriately the Bill demonstrates a lack of valuing and respect for the dignity and autonomy of people with disabilities, reinforcing and perpetuating the negative stereotypes of disabled people and their lives.
12. Insufficient attention has been paid to the wider issues that impact on the equal application of the proposed legislation. If this Bill were to become law it would not apply equally. This is for two reasons:
 - a. Currently there is inequitable access to and outcomes from quality health, social and disability services. These are essential prerequisites to the fair application of assisted dying laws. Again this is particularly an issue for people with intellectual disability as they experience some of the worst health, social and economic outcomes of any population group in New Zealand.
 - b. The safeguards the Bill proposes are woefully inadequate. IHC is deeply concerned about the potential for un-informed consent, coercion (both direct and indirect) and for “creep” in the scope of the Bill.

We discuss these issues in more detail below.

Human rights of people with disabilities

*‘At the heart of the assisted dying debate are deep misapprehensions about human dignity. If we accept that physical decline and incapacity strip away dignity, that bedpans and feeding tubes are the markers of an undignified life what are we saying about the lives of people with disabilities’.*⁸

13. The above quote has parallels in how we position people with intellectual disabilities and value their lives and dignity.
14. Government’s obligations⁹ under the UNCRPD mean due consideration must be given to how this Bill impacts on the human rights of people with disabilities including the rights to life, dignity and equal recognition before the law.

Having a life of dignity

⁸ Catherine Frazee, as quoted in Council of Canadians with Disabilities (CCD) and Canadian Association for Community Living. Media Advisory: Comment on appeal of Carter v. Canada (assisted suicide), 9 October, 2013. Retrieved from <http://www.ccdonline.ca/node/1251>

⁹ See UNCRPD Article 4

15. People with intellectual disabilities and their families tell us, on a daily basis, they face barriers to living a life of dignity.¹⁰ As Mrs Moody, who recently successfully challenged the government's Funded Family Carers policies in Court, has explained: "Who in their right mind would go minute by minute and tell me how many toilet visits Shane's allowed a day, and for how long? I mean how demeaning is that?"¹¹
16. This Bill does not even acknowledge, let alone advance or protect, the rights and interests of people with disabilities. We are seriously concerned about the implicit messages the Bill sends about the value of the lives of persons with disabilities. It should not proceed until these issues have been worked through, in consultation with people with disabilities and the disability community.

Equal recognition before the law: notions of autonomy and choice

17. Article 12.4 of the UNCRPD is a critical foundation for establishing an assisted dying regime that balances autonomy and protection for people with disabilities. It provides:

States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

18. As noted, people with disabilities struggle to have their basic human rights respected on a daily basis. This undermines their quality of life and freedom of choice on a number of levels. The Bill assumes an even "playing field" that does not exist. People's ability to exercise their own autonomy and have true freedom of choice is compromised by the cumulative impacts of inequitable access to universal services, often inadequate disability support services and lack of respect for inherent dignity. People with intellectual disabilities already face unequal recognition before the law and inequitable access to the supported decision-making resources they are entitled to¹² in order to exercise their own autonomy.
19. Equal recognition before the law was an issue of particular concern when New Zealand last reported on progress on implementing the UNCRPD. It was recommended New Zealand provide a wide range of measures that respects the persons autonomy, will and preferences in conformity with Article 12 of the UNCRPD. Rather than addressing these concerns the Bill, as drafted, could be seen as a backward step.

Scope of Bill and eligibility for assisted dying

¹⁰ See note 6

¹¹ <https://www.radionz.co.nz/news/national/351797/mother-who-took-health-ministry-to-court-refuses-latest-offer>

¹² Article 12, UNCRPD

20. We have strong concern about the Bill's scope, eligibility criteria and safeguards. It is critical that safeguards in any assisted dying legislation set high thresholds, that terminology is clear and well understood, and that there are robust procedures for monitoring and review. IHC does not believe the Bill in its current state meets the acceptable minimum components recommended by the Human Rights Commission 2016.

Unclear terminology: "grievous and irremediable" and "unbearable suffering"

21. The terminology in the Bill is ambiguous and loosely defined.

22. As drafted it is possible that a wide range of physical and medical conditions could be in covered by the phrase "grievous and irremediable medical condition", including psycho-social conditions. Similarly, it is unclear how the phrase "...unbearable suffering that cannot be relieved in a manner that he or she considers tolerable" will be interpreted and applied.

23. We agree with DPA that these loose definitions leave open the possibility that people may qualify for physician-assisted dying merely on the grounds that they are disabled.

24. Also of concern is the potential for the Bill's loose terminology to result in its extension. IHC questions the claim 'that analysis of overseas jurisdictions where assisted dying is permitted demonstrates that concerns about abuse of the vulnerable, have not materialised and that risks can be properly managed through appropriate legislative safeguards' (Bill p.2). There is evidence from Belgium and Netherlands that overtime it becomes an increasingly used option, extending acceptable reasons for assisted suicide to vague conditions such as 'tired of living' and 'loneliness' with disproportionate access by disadvantaged groups including women and those over 80.¹³

Capacity and consent

25. The Bill defines a person as eligible for assisted dying if he or she has 'the ability to understand the nature and consequence of assisted dying'¹⁴. This definition of competency falls well short of common legal and clinical definitions.

26. There are specific issues for people with intellectual disability around capacity and consent. The wording of the Bill could be read as implying that people with intellectual disabilities would be excluded because of their ability to understand the nature and consequences of assisted dying. (We note that, unlike Oregon, there is not specific exclusion of disability within the Bill). Although this is an area that needs further research a recent New Zealand study¹⁵ indicates that some people with intellectual disabilities, with the right support and information, are able to understand the nature and consequences of dying.

¹³ Dierickx, S., Deliëns, L., Cohen, J., & Perlick, D.A. (2015), Kim, S.Y.H., De Vries, R.G., & Peteet, J.R. (2016).

¹⁴ Clause 4(1)(f)

¹⁵ McKenzie, N., Mirfin-Veitch, Conder, J., Brandford, S. (2017)

27. IHC believes the Bill fails to adequately address New Zealand's UNCRPD article 12 obligations. That failure perpetuates the notion that decision-making capacity can be assessed and that there is a point where a person's right to autonomy does not apply. The knock on effect is to validate substitute decision-making. This is at odds with New Zealand's obligations to move towards supported decision-making in law, policy and practice

Adequacy of safeguards

28. In IHC's view the legal, procedural and systemic safeguards provided in the Bill are far from adequate.

29. The adequacy of safeguards depends upon their proportionality; how well they balance respect for the autonomy of people with intellectual disabilities while at the same time protecting them from coercion. Vulnerability to coercion may stem from individual circumstances or systemic factors.

30. People with intellectual disability can be particularly susceptible to coercion. Many of those with intellectual disability live lives with very limited opportunities to express their will and preference as to, for example, what they eat, where they live and who they live with, what time they go to bed or how they spend their time. Lack of opportunities to exercise their will and preference, and lack of practice to develop and express personal agency can make them more susceptible to coercion. A tendency for some people with intellectual disability to acquiesce or comply with what they think others want can compound their vulnerability to influence and coercion. Also, people with disabilities are more likely than their non-disabled peers to experience personal violence and abuse making them vulnerable in situations where they experience a lack of power.

31. There is also a need to guard against people with intellectual disability being positioned to feel as if they are a burden and indirectly coerced by the messages society sends. Long term data from the Oregon assisted death regimes suggests that it is the fear of losing autonomy and dignity, and being a burden on others that motivates most requests.¹⁶ Given the negative stereotypes and fears of becoming a burden often experienced by people with disability they are potentially more susceptible to this reasoning and therefore require better safeguards.

32. IHC is also concerned that the lack of adequate safeguards will lead to "creep". There is evidence that vulnerable persons are coerced and induced to use the system to commit suicide. A growing number of people with intellectual disabilities, autism and psychosocial disabilities now getting approved for assisted death in the Netherlands with an overrepresentation among women with psychosocial disabilities.¹⁷ (Bach)

Processes, monitoring and review

¹⁶ Oregon Public Health Division, 2014

¹⁷ Canadian Association for Community Living 2016, Kim, De Vries & Peteet 2016

33. We have specific concerns around the robustness of the procedures established under the Bill.
34. The procedures for actioning a request for assisted dying are very “light” given the gravity and complexity of the issues concerned. For example the requirement (Clause 8(2)(h)) that the attending medical practitioner must “do his or her best” is disturbingly inadequate and open to broad and subjective interpretation.
35. This is especially concerning given that the Bill is premised on assumptions that medical professionals will have appropriate knowledge and attitudes about disability and what enhances or detracts from quality of life. On the contrary, data on poor health outcomes for people with intellectual disabilities suggests variable levels of understanding within the health system about disability. For example, IHC is aware of cases where death certificates have noted disability as the cause of death. The data accords with what people with intellectual disabilities and their families tell us of their experiences.
36. We are concerned that at all stages the procedures under the Bill are over-reliant on the expertise of medical practitioners and do not include any requirements for seeking additional expertise such as an ethicist. This concern extends to the proposed Support and Consultation for End of Life in New Zealand Group. Also, the name of the Bill is ambiguous and could be read as ending all life in New Zealand. Should the Bill proceed we recommend this wording be changed.

Importance of right supports at the right time

37. End of life takes place within a social context. That social context is crucial for the support of, and outcomes experienced by the dying person, family, friends, disability support staff and professionals.¹⁸
38. There are several things that need to happen before New Zealand legislates for an assisted dying regime. A priority must be, ensuring palliative care is a viable option and freely available for all, including those with disabilities. This work should be done in consultation with the disability community.
39. There is sparse literature combining end of life and intellectual disability with the complex debate about assisted dying. However, a recent New Zealand study has shown that people with intellectual disabilities can be involved in decisions about end of life.¹⁹ Participants in the study gave strong feedback about how being involved in planning and decision making was helpful to them and gave rich information on ways to continue this support. They all strongly agreed that they wanted Advanced Care Planning to be about living, not just dying. This is consistent with research with the general population.
40. Improvements must also be made in the health system for people with intellectual disabilities who experience some of the highest health needs, greatest disparities

¹⁸ Stancliffe et al P.977

¹⁹ See note 15 above

and poorest health outcomes of any population group in New Zealand.²⁰ Men and women with intellectual disability live, respectively, 18 and 23 years fewer than the general population. Compared to the general population people with intellectual disabilities have higher rates of: potential preventable deaths; mental health conditions; polypharmacy; and aging and age related problems occurring earlier. We know that people with intellectual disability are less likely to be included in public health initiatives and routine screening such as women having mammograms and pap smears. Too often health issues, including mental health issues, are either under recognised or inadequately managed.

Conclusion

IHC acknowledges the growing international and national trend and call for laws to assist people with terminal illness to choose how and when they die. The End of Life Choice Bill in its current form proposes to do that and more. The Bill makes clear and unfortunate linkages, between assisted dying and what might make life “unbearable” which has triggered concern across the disability community. Given the lack of legal and procedural safeguards combined with unclear terminology IHC shares the view of the Human Rights Disability Commissioner that the Bill “undermines the position of disabled and vulnerable members of our community and poses significant risks to them, as individuals and as a group. IHC also stresses that the intent and scope of the Bill is somewhat premature without full consideration of palliative care provision and evidence that the health and disability support systems meet need and enhance the quality of life for people with disabilities.

²⁰ Ministry of Health, 2011, *Health Indicators for New Zealanders with intellectual disability*; Mirfin-Veitch, B. & Paris, A. (2013). *Primary health and disability: A review of the literature*. Auckland: Te Pou o Te Whakaaro Nui.

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Appendix 1.

Who are the population of people with intellectual disabilities?

People with intellectual disabilities are a diverse group with a wide range of skills and abilities. Having an intellectual impairment means it is harder to learn new things and understand complicated information; support may be needed with everyday activities and that the impairment is evident from birth or childhood and affects someone for their whole life.

An estimated 96,800 people with intellectual disabilities (2 per cent of the population) in New Zealand.²¹

- Children with intellectual disabilities make up 5 per cent of the children's 0-14 population.
- Adults with intellectual disabilities aged 15-44 make up three per cent, and those over 45 make up one per cent of the adult population.
- Maori and Pacific people have higher than average disability rates after adjusting for differences in ethnic population groups.
- There are more males living with intellectual disability, both as children and adults.
- Between 20 per cent and 30 per cent of people with intellectual disability also have autism.
- People with intellectual disability are the largest group using Ministry of Health (MoH) Disability Support Services,²² with around half identifying intellectual disability as their primary disability. Many of this group also have a physical disability.

In the future it is likely there will be increased numbers of people with intellectual disability due to:

- Increased in survival rates for pre-term babies and in numbers of people with high and complex needs.
- Increased in awareness and identification of autism spectrum disorder, foetal alcohol syndrome along with a growing number of syndrome specific conditions being identified.
- The ageing population which means, as with the general population, people with intellectual disability living longer.

²¹ Statistics New Zealand, *New Zealand Disability Survey 2013*

²² Ministry of Health, Demographic report on clients allocated Ministry of Health's Disability Support Services as at September 2016 – released July 2017.