

Submission into the Voluntary Assisted Dying Bill 2021

Submission No.: 1242
Submitted by: Queensland Advocacy Incorporated
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Position: I/We support the Voluntary Assisted Dying Bill but recommend some changes to it.
Comments in relation to: Safeguards
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Submitter Comments:

Voluntary Assisted Dying Bill 2021

**Submission by
Queensland Advocacy Incorporated**

Health and Environment Committee

July 2021

About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (**QAI**) is an independent, community-based advocacy organisation and community legal service that provides individual and systems advocacy for people with disability. Our mission is to promote, protect and defend the fundamental needs and rights of the most vulnerable people with disability in Queensland. QAI's board is comprised of a majority of persons with disability, whose wisdom and lived experience of disability is our foundation and guide.

QAI has been engaged in systems advocacy for over thirty years, advocating for change through campaigns directed at attitudinal, law and policy reform. QAI has also supported the development of a range of advocacy initiatives in this state. For over a decade, QAI has provided highly in-demand individual advocacy services: the Human Rights Legal Service, the Mental Health Legal Service and Justice Support Program and more recently, the National Disability Insurance Scheme Appeals Support Program, Decision Support Pilot Program, Disability Royal Commission Advocacy Program, Education Advocacy Program and Social Work Service. Our individual advocacy experience informs our understanding and prioritisation of systemic advocacy issues.

QAI's recommendations

- QAI is vigilant about the risks for people with disability inherent in schemes that legalise voluntary assisted dying. Voluntary assisted dying must never be a substitute for access to appropriate medical care, disability support services or palliative care, or indeed any other measure that would support the inclusion of a person with disability in society.
- Schemes that seek to legalise voluntary assisted dying must contain unassailable safeguards that identify and protect against coercion, and which ensure the full, free and informed consent of all people with disability seeking to access them.
- QAI supports the narrow application of the proposed scheme and the many safeguards contained therein. QAI also proposes the following additional safeguards for consideration by the Committee:
 - Embedding access to psychosocial support with autonomy of choice into the scheme, to ensure individuals contemplating voluntary assisted dying have access to independent and professional support to optimise their social and psychological well-being. This includes access to independent disability advocacy services where appropriate.
 - Rigorous monitoring of disability support services and palliative care services, both of their efficacy and availability to Queenslanders who request access to the scheme.
 - Regular rotation of healthcare professionals in gatekeeping decision-making roles, for example coordinating and consulting practitioners, to avoid practitioners becoming desensitised to their decision-making and to the gravity of its consequences.
 - Ensuring all professionals working within the model are specifically trained and skilled in working alongside people with a disability, including practicing within a supported decision-making and human rights framework. There must be greater awareness and utilisation of the Queensland Capacity Assessment Guidelines 2020 for example, and greater training in the principles of the CRPD.
 - Ensuring all information regarding voluntary assisted dying, as well as associated disability support services and palliative care information is available to people with a diverse range of communication needs and available in a range of accessible formats and languages.

- Embedding access to culturally appropriate support into the scheme, for Aboriginal and Torres Strait Islander Australians and people from a Culturally and Linguistically Diverse Background.
- Ensuring the oversight board includes people with a disability and lived experience of advanced medical conditions typically associated with uptake of voluntary assisted dying schemes.
- Ensuring certain prescribed information about rights and protections, such as the prohibition on doctors initiating conversations about voluntary assisted dying, is provided to people seeking access to the scheme with a description of appropriate complaint processes.
- Accompanying community awareness campaigns to bring about cultural change that will promote the full inclusion of people with disability in society.

Introduction

Since its inception QAI has maintained a firm opposition to all forms of euthanasia. However contemporary considerations have moved the organisation away from this definitive stance and opposition to euthanasia is no longer contained within our guiding principles. The tabling of this Bill before Parliament, along with a consideration of the developments in medical care, the growth in human rights culture and the lessons learned from other jurisdictions where voluntary assisted dying is legal, have prompted a timely review of QAI's stance. The complexity of the issue and its propensity to ignite fierce debate requires a nuanced response that remains true to QAI's core values whilst acknowledging the varying views of Queenslanders with disability, whose interests, rights and perspectives lie at the very foundation of our work.

This submission is in response to the Voluntary Assisted Dying Bill 2021 currently before Queensland Parliament's Health and Environment Committee. Specifically, it addresses the proposed legislative right for any person in Queensland who is dying and experiencing intolerable suffering, to choose the timing and circumstances of their own death.

QAI is vigilant about the risks for people with disability inherent in schemes that legalise voluntary assisted dying. The gravity of the consequences of ill-conceived schemes cannot be overstated. Schemes that permit access to voluntary assisted dying on the basis of disability are extremely dangerous, as are schemes with insufficient safeguards to identify abuse by family, carers or service providers. Voluntary assisted dying must never be a substitute for access to appropriate medical care, disability support services or palliative care, or indeed any other measure that would support the inclusion of a person with disability in society. Schemes that seek to legalise voluntary assisted dying must accordingly contain unassailable safeguards that identify and protect against coercion, and which ensure the full, free and informed consent of all people with disability seeking to access them.

The Voluntary Assisted Dying Bill 2021

Following a lengthy inquiry, the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee found that on balance, the Queensland community is supportive of voluntary assisted dying becoming legal in Queensland.¹ The draft Bill subsequently developed by the Queensland Law Reform

¹ Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (March 2020) *Voluntary Assisted Dying: Findings and Recommendations (Report No. 34)*

Commission (QLRC) was introduced into the Queensland Parliament by the Premier on Tuesday 25th May 2021 and is currently before the Health and Environment Committee.

The draft Bill provides individuals who are suffering and dying an additional end of life choice to request medical assistance to end their lives. Its purpose is to establish a lawful process for eligible individuals to choose the timing and circumstances of their death, to limit suffering at the end of life.² Decisions must be *voluntary* and made without coercion; eligible persons will be *assisted* by doctors and nurses, either to self-administer or have a practitioner administer a substance that will hasten their death; and to be eligible, a person must be suffering and *dying*.³

To be eligible for voluntary assisted dying under the proposed law, a person must:

1. Have a disease, illness or medical condition that is advanced, progressive and is expected to cause death within 12 months, and which is causing suffering that the person considers to be intolerable;
2. Have decision-making capacity;
3. Be acting voluntarily and without coercion;
4. Be aged at least 18 years;
5. Fulfil a residency requirement.

To access voluntary assisted dying under the proposed law, a person must be separately and independently assessed by two relevantly trained doctors, both of whom must be satisfied that the person meets all of the eligibility criteria. Three separate requests from the person must be made, with a minimum waiting period of at least 9 days between the first and final request. One such request must be made in writing and witnessed by two eligible witnesses who cannot be anyone who knows or believes they are to be a beneficiary under a will of the person, or who may otherwise benefit financially or in any other material way from the person's death. Doctors cannot initiate conversations about voluntary assisted dying, unless also informing the person about treatment options and palliative care services available to the person, and the person must be told more than once that they may decide at any time not to continue with the voluntary assisted dying process. Self-administration is the default method and practitioner administration is only permitted when self-administration is deemed inappropriate.

The proposed legislative scheme also provides legal protections for health professionals who have a conscientious objection; establishes an oversight board; creates a Statewide Care Navigator Service; proposes seven new criminal offence provisions; establishes scope for Queensland's Civil and Administrative Tribunal (QCAT) to review certain decisions; and provides for a review of the legislative framework 3 years after its commencement.

QAI position

1. QAI's mission is to advocate for the protection and advancement of the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland. QAI believes that every life is of intrinsic value. All human beings are unique and must be afforded equal dignity, respect, and protection.

² Queensland Law Reform Commission, *'A legal framework for voluntary assisted dying in Queensland (4 page summary)*

³ Ibid

2. QAI is guided by the Convention on the Rights of Persons with Disabilities (CRPD) and its General principles. QAI acknowledges the multiple and sometimes conflicting human rights engaged by voluntary assisted dying, including the right to life; the right to freedom from exploitation, violence and abuse; the right to equal recognition before the law; and the right to health.
3. QAI upholds the right of people with disability to exercise individual autonomy, self-determination, and the freedom to make one's own choices. This extends to decision-making regarding end-of-life care, including accessing voluntary assisted dying on an equal basis with others.
4. QAI is conscious of the devaluation of people with disability in Australian society and is vigilant about proposed laws that will further entrench their marginalisation. According to a Social Role Valorisation (SRV) framework, people with disability are excluded and denied access to a 'good, ordinary life' (a life full of richness and meaning) because they hold a devalued status. That is; they have characteristics linked to their impairment that are not typically valued by the wider community, such as being dependent on others or looking different, and are consequently perceived negatively and treated differently. Their rejection from the community is then reinforced through ableist language and imagery and by people with disability internalising the messages around them and adopting the roles that they are given.⁴

Legalising voluntary assisted dying risks further embedding this devaluation by legitimising a connection between traits that are typically associated with disability (such as dependence, pain and illness) with death. A person with disability's decision to access voluntary assisted dying and perception of what constitutes 'intolerable suffering' will undeniably be influenced by these attitudes, in addition to any experience of pain. Palliative care specialists often hear that their patients are concerned about being 'a burden' to their family. In legalising voluntary assisted dying, ableist attitudes that classify people with these attributes as 'less than', are afforded validity rather than challenged. These attitudes risk influencing decision-making, not only of the people seeking to access the scheme, but of those in charge of gatekeeping it. Indeed ableism continues to be prevalent in the actions and decision-making of healthcare professionals. For example, medical professionals who deny people with disability access to life saving treatments such as organ transplants, due to perceptions about the person's presumed poor quality of life. Such decisions must instead be made with reference to the person's right to access healthcare on an equal basis with others. Disability must be understood as a normal part of human diversity, not pathologized under a medical model. Introducing voluntary assisted dying into a community that continues to devalue people with disability creates a risk that decision-making within the context of the scheme will both be influenced by, and will continue to perpetuate, negative and potentially fatal perceptions of people with disability. Proposals to introduce voluntary assisted dying must therefore be accompanied by community awareness campaigns to bring about cultural change that will promote the full inclusion of people with disability in society.

5. QAI fundamentally supports the right to life of people with disability and their right to access supports that will facilitate their full and effective participation in society. QAI is therefore opposed to any scheme that permits access to voluntary assisted dying on the basis of disability alone, such as a mental health

⁴ Sherwin, J (2021) *Submission in response to the rights and attitudes paper, Royal Commission into violence, abuse, neglect and exploitation of people with disability*;
<https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00211.PDF>

diagnosis, in the absence of an advanced medical condition from which death is likely to occur within a twelve-month period. As stated by the Office of the High Commissioner of Human Rights, euthanasia on the basis of disability would institutionalise and legally authorise ableism, and directly violate Article 10 of the CRPD which requires States Parties to ensure people with disabilities can effectively enjoy their inherent right to life on an equal basis with others.⁵ QAI is therefore supportive of the draft Bill restricting access to voluntary assisted dying to individuals who have a disease, illness or medical condition that is advanced, progressive and is expected to cause death within 12 months, and which is causing suffering that the person considers to be intolerable.

6. QAI is opposed to any form of voluntary assisted dying that represents an alternative to well-funded disability support services or palliative care, or which is in any way a measure to reduce the costs of supporting people with disability to live a full, rich and meaningful life in the community. Voluntary assisted dying must only ever exist alongside well-funded and readily available disability support services and palliative care services. That is, to offer individuals who are dying and who decide continued treatment is not an acceptable option, a mechanism to relieve their suffering and hasten death. However, QAI has concerns regarding the extent to which disability support services and palliative care services are readily available to Queenslanders, including people with a disability. Difficulties accessing support from the National Disability Insurance Scheme (NDIS) are well known and show no sign of abating with current proposals to drastically reform the scheme. Access to palliative care is similarly problematic, particularly for older adults living in residential aged care, many of whom report delayed or inferior access to palliative care specialists.⁶ Schemes for voluntary assisted dying must therefore include rigorous monitoring of disability support services and palliative care services, both of their efficacy and availability to Queenslanders. An individual's experience of intolerable suffering must never stem from a failure to be adequately supported, a reality that would undermine the *voluntary* nature of the scheme.
7. QAI is vigilant about the ongoing abuse of people with disability inflicted by family members, carers, service providers and health professionals. This has been extensively demonstrated at the Disability Royal Commission and continues to occur in many settings throughout the community. Statistics reveal that one person with disability is killed by their carer almost every three months in Australia, yet identification of abuse and responses to it remain inadequate. For example, police who respond to calls about suspected domestic violence often talk to a carer rather than a person with disability and presume people with intellectual or cognitive disabilities to be unreliable witnesses. Such is the level of abuse and the inadequacies of the responses to it, that legitimate fear exists regarding the extent to which voluntary assisted dying schemes will successfully be able to safeguard against it. We are concerned that doctors will have difficulty identifying when a person is being coerced into ending their life through voluntary assisted dying. Power dynamics in abusive relationships are such that victims are often unaware of the level of coercion and control being exercised over them. Self-disclosure of abuse during a formalised assessment process will not expose all situations of undue influence and safeguard against them. QAI is opposed to schemes that contain inadequate safeguards that identify and prevent abuses of power and coercion, including by medical professionals. QAI recommends further consideration of additional

⁵ Office of the High Commissioner of Human Rights (January 2021) *Disability is not a reason to sanction medically assisted dying*; <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=26687&LangID=E>

⁶ Aged and Disability Advocacy Australia (2020) *Submission to the Queensland Parliamentary Inquiry Into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying*; submission no. 1243

safeguard measures that could enhance the protection of vulnerable people from being coerced into accessing voluntary assisted dying, such as those suggested at the end of this submission.

8. The ability of healthcare professionals to communicate effectively and understand the diverse needs of people with disability is integral to the inclusion of people with disability and to the successful delivery of healthcare services, including voluntary assisted dying. Whether a person is listened to, and their views and preferences successfully incorporated into their healthcare, is another critical safeguard against inappropriate recourse to voluntary assisted dying. For example, healthcare professionals might misunderstand the communication needs of people who are non-verbal or who have an intellectual impairment. Such miscommunication can exacerbate a person's poor health or experience of pain, for example by misinterpreting their pain signals, and can therefore inadvertently contribute to their suffering rather than alleviating it. Voluntary assisted dying must therefore only be implemented in settings where healthcare professionals are suitably skilled in communicating with people with a diverse range of communication needs, including ensuring that all information is provided in a variety of accessible formats.
9. QAI considers that supported decision-making practices consistent with the CRPD, must be embedded into the proposed voluntary assisted dying scheme. QAI upholds the legal capacity of all people, including people with disability, and their right to self-determination and autonomy in decision-making. Any scheme that allows requests for voluntary assisted dying by a third party or organisation, are vehemently rejected. People with disability must be supported to exercise their right to legal capacity through the use of supported decision-making in all contexts, including in the healthcare setting. However, paternalistic attitudes that view people with disability as deviating from 'bodily, cognitive and mental norms that require care, treatment and protection', continue to influence the actions of healthcare professionals.⁷ People with disability continue to experience a denial of their legal capacity in healthcare settings, where frequent determinations that they lack decision-making capacity continues to hinder the paradigm shift required by the CRPD. QAI therefore considers that safe and compassionate voluntary assisted dying laws in Queensland will require a greater awareness of, and recourse to, the supported decision-making model outlined in the Queensland Capacity Assessment Guidelines 2020 and in the CRPD.
10. Notwithstanding this, QAI supports restricting access to voluntary assisted dying to individuals deemed to have enduring decision-making capacity. That is, to persons who understand the nature and effect of decisions regarding voluntary assisted dying, who are capable of freely and voluntarily deciding to access voluntary assisted dying, and who can communicate this decision in some way, at each stage of the process. Whilst this denies access to voluntary assisted dying to individuals who have impaired capacity, or who lose capacity during the process, this is a difficult but necessary safeguard that will prevent vulnerable people with impaired capacity from being held to a fatal decision that they might not have fully understood or from which they have since changed their mind. In other words, it will operate to ensure that decisions to access voluntary assisted dying remain *voluntary* at each stage of the process and will ensure the individual has a consistent understanding of the decision and its consequences. This is particularly important given that statistics indicate people who access voluntary assisted dying often just want to have the choice, and that many people who initiate the process choose not to proceed to

⁷ Kayess, R. & Sands, T. (2020) *Convention on the Rights of Persons with Disabilities: Shining a light on Social Transformation*. Sydney: UNSW Social Policy Research Centre, p1

the administration stage until much later, if at all.⁸ Accordingly, QAI is opposed to any model that would enable individuals to access voluntary assisted dying through an advanced health directive. We acknowledge this is not part of the current proposals but offer our opposition to any such potential amendment for the sake of clarity. Advanced health directives must, however, continue to be used as a mechanism for people with impaired decision-making capacity to exercise autonomy over other key health care and end of life decisions.

11. QAI supports the narrow application of the proposed scheme and the many safeguards contained therein, including those listed at the beginning of the submission. QAI also proposes the following additional safeguards for consideration by the Committee:

- Embedding access to psychosocial support with autonomy of choice into the scheme, to ensure individuals contemplating voluntary assisted dying have access to independent and professional support to optimise their social and psychological well-being. This should not be mandatory but could be integrated into a holistic model of care that seeks to address pain and suffering of all kinds. Specialised psychological or social work support could assist individuals to explore the underlying reasoning behind their decision and support the person to identify situations where they might be experiencing coercion or abuse. People should have autonomy of choice for support, including access to independent disability advocacy services where appropriate. Embedding this into the model of care is necessary due to inequitable access to allied health services between public and private hospitals, with public hospitals typically offering more allied health services than private hospitals. Such support could also help address the inevitable power imbalance between patients and health professionals in medical settings, particularly with the presence of an independent advocate.
- Rigorous monitoring of disability support services and palliative care services, both of their efficacy and availability to Queenslanders who request access to the scheme.
- Regular rotation of healthcare professionals in gatekeeping decision-making roles, for example coordinating and consulting practitioners, in order to avoid practitioners becoming desensitised to their decision-making and to the gravity of its consequences.
- Ensuring all professionals working within the model are specifically trained and skilled in working alongside people with a disability, including practicing within a supported decision-making and human rights framework. There must be greater awareness and utilisation of the Queensland Capacity Assessment Guidelines 2020 for example, and greater training in the principles of the CRPD.
- Ensuring all information regarding voluntary assisted dying, as well as associated disability support services and palliative care information is available to people with a diverse range of communication needs and available in a range of accessible formats and languages.
- Embedding access to culturally appropriate support into the scheme, for Aboriginal and Torres Strait Islander Australians and people from a Culturally and Linguistically Diverse Background. Providing access to culturally appropriate supports will uphold the rights of these populations to enjoy their culture, use their language and to make decisions in accordance with their cultural beliefs.
- Ensuring the oversight board includes people with a disability and lived experience of advanced medical conditions typically associated with uptake of voluntary assisted dying schemes.

⁸ Queensland Law Reform Commission, *A Legal Framework for Voluntary Assisted Dying: Report Summary*, p20

- Certain prescribed information about rights and protections, such as the prohibition on doctors initiating conversations, should be provided to people seeking access to the scheme with a description of appropriate complaint processes.
- Accompanying community awareness campaigns to bring about cultural change that will promote the full inclusion of people with disability in society.

Conclusion

QAI thanks the Health and Environment Committee for the opportunity to make a submission and is happy to provide further detail upon request.