

Submission

Queensland Law Reform Commission Consultation Paper - A Legal Framework for Voluntary Assisted Dying

QDN

QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

Submitted to:
Queensland Law Reform Commission

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About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a state-wide network of over 2,000 members and supporters who provide information, feedback and views from a consumer perspective to inform systemic disability policy and disability advocacy.

QDN also operates 21 Peer Support groups across a range of metropolitan, regional and rural and remote locations in the state, run by people with disability for people with diverse disabilities. members and supporters who provide information, feedback and views from a consumer perspective to inform systemic disability policy and disability advocacy.

QDN undertakes a range of work activities and projects as outlined on QDN's website and detailed in our latest [2019-2020 Annual Report](#). Our systemic advocacy work encompasses a range of responses – from community campaigns, formal submissions, evidence to commissions and inquiries, and membership of roundtables and working groups around national, state and local government legislative and policy initiatives.

QDN's work is focused on the rights and full social and economic inclusion of people with disability, along with areas of key importance identified by Queenslanders with disability – the National Disability Insurance Scheme (NDIS), improving mainstream services that people with disability rely on every day, including health, housing employment and transport, and most recently the impact of COVID-19.

Introduction

QDN welcomes the opportunity to make a submission to Queensland Law Reform Commission's Consultation Paper on a *Legal Framework for Voluntary Assisted Dying*. QDN members have provided significant feedback on this issue during previous inquiries and reviews. The feedback can largely be summarised in the following points:

- more accessible information needs to be made available about end of life care, palliative care and voluntary assisted dying (VAD).
- opportunities for people with disability to receive and digest information, ask questions and have the space to come to informed decisions about VAD
- more targeted consultations delivered with a degree of sensitivity and understanding of how the issue of VAD impacts on people with disability.

QDN's response will outline a disability context to end of life care, palliative care and VAD, as well as detail specific issues from the perspective of people with disability. It is important for government and community to understand the disability perspective so everyone can engage in meaningful dialogue about this important issue. It is vital

that people with disability are adequately consulted on this issue and have the opportunity to give considered feedback.

QDN acknowledges that this is a complex issue which elicits diverse opinions and is informed by people's personal values and beliefs. This is no different for people with disability, who will all have individual views on this issue. As such, QDN's submission aims to reflect the complexity of this issue and recommend a range of safeguards for people with disability and mental illness.

A disability context to voluntary assisted dying

The issues around VAD are complex and can be subject to mixed public opinion among everyday Australians. For people with disability there are further layers of complexity to these issues. People with disability historically have been left out of the consultation and may not have been considered a legitimate stakeholder in these issues. People with disability also experience limited choices regarding their everyday care, the settings in which they reside and receive care and support, their health and well-being, and access to quality treatment options, and support and information they can understand.

People with disability who are from Aboriginal and Torres Strait Islander backgrounds, culturally and linguistically diverse backgrounds, women, identify as LGBTIQ+ and who have intellectual and psycho-social disability face additional barriers and need targeted strategies and support in understanding these issues, making informed decisions and contributing their feedback.

People with disability often have a wider range of stakeholders for support such as family, friends, partners, support workers, allied health, medical professionals, informal and formal supports. Some people with disability may also have impaired decision making for particular issues and therefore also have legally appointed decision makers who need to be consulted on issues concerning their health care and end of life decisions. Additionally, some people with disability only have contact and relationships with paid supports and professionals which impacts upon who is in their life to support and safeguard their rights. However, it is critical that all people with disability, including those with impaired decision-making, be supported. People with disability need accessible information and adequate support to understand the full range of choices and complex decisions involved in these matters.

Generally in society, people with disability experience additional barriers to those living without disability, including higher rates of poverty, poorer health outcomes, difficulties accessing and affording appropriate housing and healthcare and higher rates of unemployment¹. People with disability are also be subject to additional attitudinal barriers, commonly held assumptions and myths about disability by professionals in charge of their care and treatment in health settings. These biases

¹ For more information, see the report "Shut out, The experience of people with disabilities and their families in Australia": <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia?HTML>

can often go unchecked and can result in poor health outcomes and limited treatment options being offered to people with disability.

QDN believes it is critical that, as part of any VAD framework, work is undertaken to train doctors, nurses and health professionals, particularly relating to disability-specific curriculum development. This could include:

- the development, piloting and evaluation of model curriculum enhancements to include core intellectual disability, physical and mental health content, in university medical and nursing schools. People with disability need to be involved in the design, implementation, teaching and evaluation of these curriculum enhancements.
- funding education programs and initiatives in Primary Health Networks and universities, to increase capacity of General Practitioners (GPs) and other allied health professionals to better meet the needs of people with disability.
- funding a specific program in Primary Health Networks to enhance the capacity of GPs and other primary health services to respond to the needs of people with intellectual disability and to link them to appropriate healthcare.

In popular culture, people with disability can be confronted with messages and images that reinforce feelings of difference, that they are 'a burden' on loved ones and 'the system' and that their lives are 'worth less' compared to people without disability. A high-profile example of this is the film *Million Dollar Baby* (2004). In the broader context of health, the Chicago Tribune points out:

*"It is true that "Million Dollar Baby" is only a film, but when it comes time for many people to **make health decisions about themselves or a loved one's future**, what experience or knowledge will they fall back on? Few people have personal experience with severe disabilities, and few will take the time to find out about what life is like living with deafness, blindness or disability. No, most people will fall back on what they know -- which is what they have garnered from novels, plays, films and television shows".*

With few positive messages about disability in the public domain, we cannot underestimate the effect these influences have in shaping the self-worth of a person with disability and more broadly, society's views and helping to create a dialogue about what is valued and what is not. Therefore, it is important to consider this context when examining a VAD framework and attitudes toward disability.

End of Life and Palliative Care

QDN believes people with disability have the right to access the full range and highest available standards of end of life and palliative care services offered to all people in Queensland. People with disability should be consulted as much as possible about the planning and delivery of services provided to them, including accessible information on all available treatment options, medications and other approaches used in their care. People with disability, like other patients, have the right at any time throughout their treatment to seek further information, cease a treatment option, seek second opinions by qualified medical professionals. explore

and have reasonable access to alternative therapies and treatments and give their own opinions about their healthcare in a Palliative Care environment. It is also important that consideration is given to children and young people with disability with regards to end of life and palliative care.

People with disability must continue to have access to any disability related aids and equipment during their care. This may also include acknowledging the role of assistance animals and/ or pets, and consulting the people closest to them (including family members, partners and support workers) about what their personal care needs are and allowing those people to provide aspects of their personal care if it is the expressed wish of the person.

QDN believes any legal framework around VAD should be founded in Palliative Care Australia's (PCA) "*Guiding principles for those providing care to people living with a life-limiting illness*"², including:

- People living with a life-limiting illness are supported and respected whether or not they choose to explore or access voluntary assisted dying
- People exploring voluntary assisted dying will not be abandoned
- Respectful and professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying
- Effective communication is an important part of quality care
- Ongoing development of knowledge, skill and confidence is required to provide competent and safe care to people living with a life-limiting illness
- Self-care practice is a shared responsibility between individuals, colleagues and organisations
- Continue to learn from evidence and evolving practice to drive quality improvement in voluntary assisted dying.

In preparing this submission, QDN members have also reflected on the importance of palliative care staff acknowledging the needs and wishes of people with disability who may be family members, partners, friends, supporters and informal carers of people using palliative care services.

Voluntary Assisted Dying

QDN supports an open, transparent discussion and development of a legal mechanism for VAD that is reflective of contemporary societal views on choice concerning end of life and which has at its core best practices in healthcare within an ethical and legal framework. Given concerns expressed earlier in QDN's submission about the intrinsic value of the lives of people with disability and the messages people with disability receive about their worth, QDN believes special provisions need to exist which include safeguards for people with disability and mental illness.

² Palliative Care Australia, "*Guiding principles for those providing care to people living with a life-limiting illness*", (June 2019): https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/06/PCA-Guiding-Principles-Voluntary-Assisted-Dying.pdf.

QDN strongly supports Queensland developing a set of core values for end of life care to guide practice similar to Victoria's³, which include:

- Every human life has value – every individual has inherent value
- Open discussion about death and dying should be encouraged and promoted
- People should be able to make informed choices about the end of their life
- End of life care should be person-centred
- End of life care should address the needs of families and carers
- Pain and suffering should be alleviated for those who are unwell
- Palliative care is an invaluable, life-enhancing part of end of life care
- High quality end of life care should be available to all people in all settings
- Each person should be entitled to core rights in end of life care
- Vulnerable people should be supported and protected - safeguards need to be in place to ensure that vulnerable people are not pressured or coerced into making decisions that they do not want to
- The law should be coherent and transparent - Health practitioners and patients should be fully aware of their legal rights and responsibilities in end of life care
- The law should be followed and enforced - the purpose of end of life legislation should be to provide for end of life choices for patients and protection for doctors.
- Breaches of laws should be penalised appropriately.

QDN believes safeguards are required to protect vulnerable people and supports the approach to people with mental illness or disability having access to VAD detailed in Chapter 4 Sections 4.19 to 4.23 of the framework.

In relation to Question 6 in the consultation paper, QDN agrees with the principle in Victorian legislation that a mental illness or disability is not an eligible disease, illness or medical condition for the purposes of accessing VAD. Having a mental illness or disability should not however exclude a person from accessing VAD if they have decision making capacity and meet all the eligibility criteria.

We support the approach detailed in 4.21 as it ensures that people with mental illness or disability have equitable access in the same way as others and will not be discriminated against or denied access to VAD.

Other safeguards could include but are not limited to:

- Only allowing VAD to be made available to terminally ill people for whom there is no hope of recovery (in line with Victoria's Bill)
- Providing mediation or assisted and supported decision-making processes for people who are vulnerable
- Providing targeted user-friendly information to vulnerable people in a variety of formats that outlines options and treatment plans in relation to end of life treatment

³ See: <https://www2.health.vic.gov.au/.../%7BB5260B7D-C28B-4772-AFF0-871CFEA23ED...>

- Providing counselling services delivered by professionals who are trained in the specific needs of vulnerable populations
- Providing peer support and safe places, and increased time for people to think through their options and come to informed decisions
- Seeking the views of family members, loved ones, informal and formal decision-makers, advocates and other professionals in the person's life and encouraging them to form a circle of support around the person.

For extremely vulnerable people, there may be advantages to separating the process out to be independent of the medical system (or a requirement to document the steps taken to demonstrate independence) to avoid the risk or the perception of coercion.

QDN strongly recommends that the introduction of a VAD framework in Queensland is supported by specific targeted consultation with people with disability and mental illness, their families and the organisations that support them.

Conclusion

QDN welcomes the opportunity to provide a disability perspective to the *Consultation Paper – A legal framework for voluntary assisted dying*.

Further targeted consultation and information targeted at people with disability and mental illness would be strongly recommended to enable people with disability and mental illness to come to an informed decision on these matters. Additionally, strategies to safeguard vulnerable people are required.

QDN looks forward to further engagement in the process of developing Queensland legislation on VAD.