



Advocacy for Inclusion

Incorporating People with Disabilities ACT

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The Secretariat
Secretariat, Voluntary Assisted Dying Committee,
ACT Legislative Assembly,
GPO Box 1020, Canberra ACT 2601
Via email: LACommitteeVAD@parliament.act.gov.au

Dear Secretariat

Inquiry into the Voluntary Assisted Dying Bill 2023

Thank you for the opportunity to make a submission to the inquiry on this Bill.

By way of background Advocacy for Inclusion incorporating People with Disabilities ACT is an independent organisation delivering reputable national systemic advocacy informed by our experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the Human Rights Act 2004.

Our position on Voluntary Assisted Dying

AFI does not have a position on whether Voluntary Assisted Dying should be legal in the ACT. We do believe the Territory should be able to legislate in this area. We note that there are members of AFI and people with disabilities generally who are opposed to VAD because of real and perceived risks it poses as well as people who would be strongly supportive of VAD and who might even want to do further than the current Bill in terms of access to euthanasia. There are others who might be supportive in some limited circumstances.

However AFI *does* have a position on the safeguards, supports, regulations and circumstances least likely to do harm to people with disabilities on the introduction of VAD and that we would need to see in a Bill and the surrounding groundwork to its introduction. We set these out in our [substantial submission](#) to Government in its development of VAD. This should be read as a companion to this submission by the Committee.

Namely: we sought work to address unintended consequences in the short and medium terms. We emphasised the need for investments that address gaps in disability support for people in distress and to deliver the ACT Disability Health Strategy and the Disability Strategy and call for packages to mitigate unintended consequences including disability supports, work on suicide prevention and hate speech.

Some key principles outlined in our submission are that having a disability alone should not be grounds for VAD, doctors involved in the VAD process must understand that people with disability can live good lives and no one should be offered VAD in place of disability, health and palliative care supports. We also speak to monitoring and safeguards.

Our key tests for legislation

In our submission on Voluntary Assisted Dying AFI set out a number of preconditions for Voluntary Assisted Dying in the ACT which would need to be met either via the Bill itself or an adjacent government work program. This submission to the inquiry examines the extent to which these are met in the draft Bill and the work which surrounds it.

Eligibility (disability clearly not grounds for VAD)

Our view. Our view is that having a disability alone should not make a person eligible for seeking VAD. Therefore AFI does not support access to VAD being expanded beyond the scope of the Victorian legislation. This only allows VAD for individuals with an incurable, progressive and advanced medical condition and are facing 'unbearable' suffering. Before proceeding with the procedure, two medical practitioners must determine that death is likely to occur *within six months*.

What's in the Bill: The Bill says an individual meets the eligibility requirements if— they are an adult; and they have been diagnosed with a condition that, either on its own or in combination with 1 or more other diagnosed conditions, is advanced,

progressive and expected to cause death (the relevant conditions); and they are suffering intolerably in relation to the relevant conditions.

The Bill does not set a timeframe period where death is likely to occur. Arguably this widens the scope to some disabling conditions well beyond the scope of legislation in Victoria.

Support guarantee for those seeking VAD

What we sought: In Canada people requesting disability supports and healthcare report being offered assisted dying instead of healthcare or supports¹. We therefore sought an emergency pool of supports to be offered to people seeking VAD so this is not an unintended outcome in the ACT. We also sought a legislative trigger in a Bill to require this support be offered. We acknowledge that careful work will be needed in the design of this arrangement so that it does not also trigger unintended consequences.

What's in the Bill and related work program: The Bill does not require that any person seeking Voluntary Assisted Dying should be asked whether there are any disability, healthcare or psychosocial supports that might make their lives bearable. It does not mandate a support offer to avert people, who wish to be averted, from VAD.

Creating an offence around offering VAD in place of disability or other supports

What we sought: In Canada people requesting disability supports and healthcare report being offered assisted dying instead of healthcare or supports. Providers and health professionals are telling people that the State cannot afford disability modifications but it can offer them euthanasia as an alternative. This is unacceptable and in our view it constitutes violence and a serious breach of human rights obligations. We therefore sought that any VAD Bill should create a criminal offence for a provider of disability or healthcare supports to suggest that a person access VAD in the context of a discussion about access to these supports. We do not suggest creating a new criminal offence lightly however we believe that this is warranted given the circumstances over time where VAD has been introduced

What's in the Bill and related work program: The Bill does create an offence around coercion at Section 40.1 which provides that 'a person commits an offence if the person, dishonestly or by coercion, induces an individual into making a request for access to voluntary assisted dying'. We are unclear whether this covers the kinds of situations we are concerned about where a suggestion might be made that a person should consider VAD in the context of a discussion around disability support. We would prefer that a direct prohibition be made.

¹ <https://www.ctvnews.ca/health/chronically-ill-man-releases-audio-of-hospital-staff-offering-assisted-death-1.4038841?cache=kyifhaaa>
<https://thebaffler.com/latest/last-resorts-kislenko>

Mandatory social model and diagnostic overshadowing training for medical professionals

What we sought: We sought mandatory training on diagnostic overshadowing and social model for medical practitioners involved in VAD decisions

Why: People with disability regularly encounter negative assumptions about their prospects and quality of life from medical professionals. This includes people being offered Do Not Resuscitate Orders when they do not want them, assumptions made about quality of life of vulnerable people during COVID 19 and poor self reported health. Diagnostic overshadowing (where a persons disability overshadows their medical condition due to assumptions by practitioners) is a well documented phenomenon.

What's in the Bill and related work program: The Bill provides for training about the operation of VAD but not the specific issues we had highlighted. We also note the Bill also enables a wider group of people to be involved in administering VAD including nurse practitioners which will widen the scope of educative work needed.

Suicide prevention work amongst people with disability

What we sought: We sought a commitment to funding for suicide prevention work to show life gets better for people with disability and address harmful perceptions and stereotypes of life with disability amplified by VAD debate. A model could be the It Gets Better project.

Why: For any other group of people in the community there is an overwhelming focus on prevention ahead of suicide, especially based on inherent personal characteristics. VAD changes that for some people with disabilities both in legislation and through the public discourse surrounding the legislation. Studies have shown that people with disabilities are up to twice as likely to experience suicidal ideation. Debates on Voluntary Assisted Dying create an authorizing environment for discussion suicide by a vulnerable group in the community. Some people with disability who consider or attempt suicide early in their diagnosis change their minds after receiving improved quality of life or better disability supports.

What's in the Bill and related work program: The Government has not flagged any intent to consider or implement additional suicide prevention work or programs which respond to VAD for people with disability.

Advocacy support to deal with trauma, harm and hate speech

What we sought: Advocacy support is needed for people impacted by community debate around VAD and effected by hate speech and traumatised be negative attitudes which have emerged through the pandemic

Why: Debates on VAD in other jurisdictions have lead to a rise in hate speech, trauma and discussions about other forms of violence against people with disabilities (such as filicide). Governments have in the past supported communities experiencing trauma due to policy debates such as the same sex marriage poll.

VAD in the ACT bookends an extended harmful conversation about the value assigned to the lives of people with disability and underlying health conditions across three years of the COVID19 pandemic which has left a trail of negative attitudes in the community and trauma for disabled people.

What's in the Bill and related work program: The Government has not flagged any intent to consider or implement additional measures which respond to the risks of adverse outcomes from VAD for people with disability.

A VAD review board

What we sought: A funded Voluntary Assisted Dying Review Board would provide an independent and impartial body to review end-of-life decisions in the ACT. The board would be responsible to assess current legislation and regulations to ensure that standards of care are being met and that safeguards are being observed and effective.

This board should include a mix of medical professional and others with expertise and knowledge around end-of-life issues and the ethical issues surrounding them as well as disability rights. The Board should include a person with a disability able to apply a critical and inquiring lens on end of life issues working from a disability rights perspective nominated by the peak Disabled Peoples Organisation. The board should have unhindered access to all documents, date and decision making around VAD applications in the ACT.

There should be an annual report on the operation of the legislation including recommendations which is publicly available.

Why: Voluntary Assisted Dying is a major reform impacting vulnerable people and requires oversight. A lack of oversight and accountability, especially to the disability community, has been a feature of VAD regimes overseas especially in Canada which have in turn created distrust of VAD's ability to operate safely by people with disability.

What's in the Bill: The Bill does provide for a Voluntary assisted dying oversight board but it's not clear if that will include a person with a disability able to apply a critical and inquiring lens on end of life issues working from a disability rights perspective nominated by the peak Disabled Peoples Organisation.

A fully funded ACT Disability Health Strategy and access to preventative health

What: A funded Strategy is required to address issues of health care access, financial barriers, training, poor infrastructure, a lack of diagnostic services, culture and workforce issues which prevent people with disability from receiving quality health care.

Why: A lack of access to preventative health care and accessible screening for serious conditions like cancer, means that people with disability are more likely to be in the group of people who acquire other aggressive conditions.



To prevent people with disability being in the pathway of VAD we argue its introduction should trigger urgent priority investments in accessible infrastructure to ensure that people with disability have the same access to preventative health, screening and treatment for serious health conditions as other Canberrans.

What's in the Bill and related work program: There is progress towards a Disability Health Strategy but we have not yet seen investments or a significant focus on preventative health. We would prefer to see substantial progress prior to VAD being introduced.

Fund an ACT Disability Strategy

What: AFI recommends the Budget include a funding package to deliver, monitor and implement the ACT Disability Strategy – the ACT's commitment to Australia's Disability Strategy and to meet obligations under CRPD.

Why: Too many people with disabilities live lives that are intolerable because of poverty, homelessness and isolation caused by barriers and a lack of goods, services and incomes.

What's in the Bill and related work program: There is progress towards a Disability Strategy but we have not yet seen the Strategy or its investments

Properly fund Disability supports

In our submission to Government AFI called for proper funding for disability supports through the NDIS and the CASP program to guard against gaps in access to services can emerge, as well as inadequate transition and mental health supports for people facing a crisis. We also noted that The ACT's CASP program fills important ongoing gaps for people ineligible for the NDIS and people in NDIS transition that have been widely highlighted including in the NDIS review and hearings of the Royal Commission.

What's in the Bill and related work program: AFI is concerned that funding and support in some of these areas has become constricted in the transition from CASP to a new Community Assistance and Temporary Supports (CATS) program. There are gaps in long term supports for people with complex lives needing case management support.

Conclusions

On balance, we feel that the Bill currently before the Assembly does not meet the tests we set out in our submission to Government. It widens eligibility for VAD well beyond the Victorian legislation.

It does not provide for a support guarantee, mandate social model training of practitioners or provide sufficient assurances, through its widened scope and definition of terminal illness that disability will not be grounds for VAD. It does not appear to create an offence around 'soft coercion' which might see people nudged towards VAD rather than disability supports (as occurs in Canada).

Moreover there are no signs or serious indications that the Government intends to undertake work to mitigate unintended consequences, like disability specific suicide prevention work or early action on access to preventative health.

If anything, there are now fewer functional supports at the disability and health interface than there were when we lodged our submission in April.

AFI believes the Bill should be either substantially amended or rejected by the Assembly.

We would also be happy to discuss this submission at the inquiry. Our contact is Craig Wallace, Head of Policy on 0477 200 755

Regards

Nicolas Lawler

Chief Executive Officer

