



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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**SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT**

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,  
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

## Submission Cover Sheet

### End of Life Choices in the ACT

**Submission Number: 314**

**Date Authorised for Publication: 29/3/18**

# LIVES WORTH LIVING

*We embrace disability as a valid identity*

The Secretary  
Select Committee on End of Life Choices in the ACT,  
Legislative Assembly for the ACT,  
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Dear Secretary

## **End of Life Choices in the ACT**

I am writing to make a submission to the End of Life Choices Inquiry on behalf of Lives Worth Living.

We thank you for the opportunity to submit to the inquiry.

*Lives Worth Living* (LWL) is a national network of senior disability rights advocates and leaders who have concerns about euthanasia and eugenics. We are not a religious or pro-life lobby group. Our views come from a Human Rights basis. We are connected with groups like *Not Dead Yet* in Victoria, WA and the United Kingdom.

We are all people with disabilities including people with degenerative conditions who could come into the orbit of euthanasia legislation.

We include people who have considered or attempted suicide at times in our lives only to realise a better life is possible with the right supports.

We are not a mass membership or representative body, but a network of people who have held senior positions in Disabled Peoples Organisations and who hold concerns about issues including euthanasia, eugenics and violence against people with disabilities.

We are an unincorporated group of volunteer grassroots activists and are not funded by any other group.

We embrace disability as a valid identity and we take pride in the achievements of disabled people.

We reject ableism and attitudes that diminish the lives and worth of disabled people.

Lives Worth Living is a rights based network of Australians with disability speaking up about euthanasia and eugenics founded by Craig Wallace, the late Joan Hume OAM, John Moxon, Sam Connor and Daniel Pask.

Find us on [Facebook](#)

### *Disability Rights and euthanasia*

The disability community does not have a single view on euthanasia. There are those of us who are very concerned about legalised suicide for people with disabilities given the potential for abuse and perverse outcomes, and others who believe in the right to make end of life decisions for people with an illness like inoperable Cancer.

However, there *is* a widely held set of concerns about euthanasia and many disability rights advocates are either neutral, concerned or actively opposed to euthanasia.

The late Stella Young put it well when she said that disabled people do not want death with dignity until we have lives with dignity.

Concerns are held by the national cross disability peak body People With Disability Australia which expressed the view that euthanasia was dangerous and resolved as follows:

“Noting Article 10 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD ) which mandates that ‘people with disability enjoy their inherent right to life on an equal basis with others’ the Board of PWDA:

- i) expresses concern about the introduction of state sanctioned euthanasia for people with disability until people with disability have been fully consulted and possess the same rights, supports and community access as other Australians;
- ii) notes that state sanctioned euthanasia is dangerous while people with disability are denied access to communication supports, advocacy and other supports or are unaware that such supports are available; and
- iii) believes that euthanasia of children with disability and other people unable to give consent is always unacceptable

State sanctioned euthanasia is dangerous while people with disability are denied access to communication supports, advocacy and other supports or are unaware that they are available. We believe that euthanasia of children with disability and other people unable to give consent is always unacceptable”.

11 January 2014

A selection of views by activists concerned about euthanasia can be found below:

A message to Australian Parliamentarians from Liz Carr, a BBC actress and prominent disability actress who represents Not Dead Yet and a growing group disability activists around the world who oppose euthanasia:

<https://www.youtube.com/watch?v=CUvLZIVf0cQ>

This article by Stella Young in The Guardian:

<https://www.theguardian.com/commentisfree/2013/oct/18/disability-euthanasia-assisted-dying>

Craig Wallace’s piece in Crikey:

<https://www.crikey.com.au/2015/08/17/better-off-dead-what-peter-singer-doesnt-get-about-disability-and-euthanasia/>

### *The ACT's right to legislate*

This submission does not take issue with the ACT's maturity as a jurisdiction. We are a mature jurisdiction with quality representatives and a commitment to human rights.

We say that as a human rights jurisdiction the ACT should, if it gets the right to legislate, *strongly reject euthanasia for all disabled people* as dangerous, inappropriate and incompatible with a human rights jurisdiction, starting with Article 10 of the UN Convention on the Rights of People with Disability

Unlike Victoria the ACT should seriously engage with representative disabled people, look at the potential for perverse outcomes and ask whether State sanctioned euthanasia is being introduced in a fair playing field and is a good idea in these times.

This inquiry is a welcome start.

### *Euthanasia and human rights*

Australia is a signatory to the United Nations Convention on the Rights of People with Disability (UNCRPD). The ACT seeks to realise its obligations under Article 10 via the National Disability Strategy.

Article 10 of CRPD provides that States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities *on an equal basis with others*.

On any reasonable assessment we do not enjoy our right to life on an equal basis with others in the choices, decisions, supports and health interventions which would keep us outside of the remit of a euthanasia bill.

People with disabilities continue to lack basic access to preventative and tertiary health systems that enable us to manage their health and avoid illnesses like aggressive cancers.

The health system is hostile to us. As PWD ACT found in their recent consultations people lack access to basic preventative care and fare more poorly in the tertiary system when do get ill. Some of us lack access to full GP check ups because of a lack of height adjustable exam tables and other barriers<sup>1</sup>.

Diagnostic overshadowing is widespread meaning that people with disability are often diagnosed through their disability rather than in the way that other people are. Studies have consistently found higher rates of comorbidity for people with disability especially for people with intellectual disability.

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<sup>1</sup> [https://www.pwdact.org.au/images/stories/articlefiles/Newsletters/CDRV4/CDR\\_4\\_2017\\_WEB-version.pdf](https://www.pwdact.org.au/images/stories/articlefiles/Newsletters/CDRV4/CDR_4_2017_WEB-version.pdf)

*Perverse outcomes – our lack of life choices*

LWL is concerned that euthanasia will bring a host of perverse outcomes for people with a disability. These are covered in various parts of this submission but to summarise:

- People lacking access to healthcare, disability supports or expensive pharmaceuticals might be leverage into suicide as a cheaper, less messy “way out” for all concerned. In California a woman with cancer was told that her insurer would not cover the costs of chemotherapy drugs but would cover the costs of drugs to put her to death<sup>2</sup>.
- There are grey areas between disability and illness – without clear diagnostic definitions we cannot have confidence that euthanasia will not become available to an ever widening group of people.
- Even if the legislation works as intended and only covers conditions like aggressive cancer people with disability will still be far more likely to be in the group of people who are euthanized because we lack a level playing field when it comes to access to the preventative care people need to detect, prevent or halt these conditions.
- In the absence of suicide prevention work with disabled people, legalising euthanasia for people with disability signals to a whole class of people (and to the broader community) that our lives are disposable. Euthanasia creates an authorising climate for suicide for one group in the community based on inherent characteristics.
- There is a grey area between disability and illness. Unless specific conditions are ruled in or out then euthanasia can expand to other groups of people.
- Euthanasia will be occurring in the context of more than 200 years of murder, abuse and neglect of people with disability in state care, in families and in the community. This is documented in the report of the senate inquiry on abuse of people with disability and the White Flower Memorial project. The communities calls for a Royal Commission into disability abuse have been rejected. Allowing people with disabilities to be euthanised perpetuates this violence and opens up a whole new context for the homicide, suicide and death by neglect of our people.
- We cannot discount the idea that a program might be abused or distorted in the future by regimes hostile to people with disability or that the civil norms we hold now will not change. There is reason to be concerned given the rise of populist governments, hate crimes, filicide of disabled children and a general context of global instability. Legalising the killing of sick and disabled people in these times is a dark crevasse we should not fall through.

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<sup>2</sup> <https://nypost.com/2016/10/24/terminally-ill-mom-denied-treatment-coverage-but-gets-suicide-drugs-approved/>

### *Lack of suicide prevention*

Euthanasia creates a double standard in the treatment and interventions around suicide for one group of people in the community based on an inherent personal characteristic.

Research has found that people with disabilities are at greater risk of suicide than other people. About 42% of people aged 16–64 years with severe or profound disability had seriously thought about committing suicide, including 18% who had attempted suicide<sup>3</sup>.

For any other group in the community – young people, LGBTIQ people, rural youth or indigenous people – we do everything we can to avert suicide. Faced with these statistics we would act.

For young LGBTIQ people there is a program called the [It Gets Better Project](#) designed to show young LGBTIQ people that it is possible to overcome the loneliness, rejection and stigma involved in coming out.

Life gets better for many people with disabilities too. LWL knows people with acquired disabilities, such as spinal injuries who assumed that their lives were over and would have accepted euthanasia, were it on offer.

Asked about suicide a year later with the right peer, disability and rehabilitation supports in place, people change their minds.

Yet there are few targeted suicide intervention programs for people with disability. Instead the suicides of disabled people are sometimes presented as understandable or a merciful release. As far as we are aware, the ACT Government has not funded any specific programs to support suicide prevention by people with disability.

Suicidal ideation for people with disability also exists in the context of low incomes, exclusion from social networks, barriers to social and community infrastructure, barriers to transport and an ongoing lack of disability supports that continue despite the NDIS.

Legislation in other jurisdictions has failed to mandate suicide prevention and other counselling which may identify other issues in people's lives which weigh in their decisions. Where counselling is addressed it is an option for the primary practitioner, not mandated.

Our energies should be directed towards making decent disabled lives possible, understanding and preventing our suicides, not creating an authorising climate for us to commit suicide.

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<sup>3</sup> Health of Australians with disability: health status and risk factors, AIHW September 2010

### *Eligibility and scope*

Lives Worth Living is concerned about the failure of euthanasia bills in other States and Territories to clearly define eligibility for euthanasia and to exclude disability.

Here are some of the common issues

- Most Bills do not name the disabilities or conditions covered or exclude any disabilities, illnesses or chronic conditions instead focussing on how the condition is experienced and perceived by the individual.
- The communities common view of euthanasia is that it is about cancer, but the Bills do not specify cancer or any specific diagnostic illness.
- Most legislation, including the successful Victorian Bill, does not diagnostically define a terminal medical condition and imagines that you can make a clear distinction between a person with a medical condition and a person with a disability.
- Most disabilities shorten the lifespan and there is no clearly defined boundary between a shortened life span and a terminal illness.
- All people with disability have medical conditions that cause a disability, meaning that disability is in scope at the outset. The disability arising from a condition is caused by a lack of access to rights, access, treatments and disability.
- Further, people with disability are not necessarily “suffering” from our conditions, we suffer from a lack of rights, access and disability supports. Euthanasia does nothing to address these underlying issues or provide people with the advocacy supports they might need to address them in their own lives.
- In the absence of a clear definition of terminal medical condition (there is no specific timeframe) we are not satisfied euthanasia legislation would not encompass people with disabilities like Muscular Dystrophy, Motor Neurone Disease or Quadriplegia.
- Euthanasia bills do not recognise that a person’s disability is *not* the only factor that determines the quality of their lives in the same way that a person’s race, gender, sexual orientation, social background or other inherent characteristic may be only one hinge factor in their life experiences
- A person's enjoyment of life can be impeded by poverty, poor supports, inappropriate housing, relationship breakdowns, experience of domestic violence or abuse, carer abuse, poor allied health care and people subjecting us to psychological, sexual, economic or physical neglect and abuse. These issues aren't intractable or hopeless – they can be changed.
- There are many examples of these multi-faceted barriers in [SHUT OUT: The Experience of People with Disabilities and their Families in Australia](#) – the consultation report by the National People with Disability and Carers Council.

- We would prefer that Parliaments addressed secondary comorbidity, barriers and lack of supports experienced by people with a disability rather than provide a mechanism for suicide because of them. Instead of safeguards, we need to be talking about preconditions. Like the precondition that half of us no longer live in poverty, have good access to medical treatment and palliative care, that we have the care and support to live a good life.

### *The experience overseas*

The overseas experience is that assisted dying laws, once introduced, expand to include people with disability, people with mental illness and people who want to commit suicide for all kinds of reasons. People are also subject to coercion.

For people with disability euthanasia isn't a slippery slope – it's a free-fall off a cliff.

For instance:

- Two deaf twins who were going blind, but did not have a terminal illness, were euthanised in Belgium in 2013<sup>4</sup>
- A Dutch woman with dementia was granted euthanasia in 2015<sup>5</sup>
- In 2016 a sexual abuse victim in her 20s was euthanized as she was suffering from "incurable" post-traumatic-stress disorder (PTSD), according to the Dutch Euthanasia Commission<sup>6</sup>.
- Euthanasia has been extended to children in Belgium<sup>7</sup>
- There is discussion about extending euthanasia to people with psychiatric disability in Canada, Belgium and Holland<sup>8</sup>.
- A Dutch clinic was reprimanded after granting euthanasia to a woman with tinnitus (ear ringing) in 2015<sup>9</sup>
- A woman in the United States was told that her insurer wouldn't pay for cancer treatment drugs but they could supply her with a cheaper drug to commit suicide<sup>10</sup>.

There is no evidence that euthanasia can be contained and we have every reason to be concerned about slippage and definition creep.

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<sup>4</sup> [https://www.huffingtonpost.com/2013/01/14/marc-eddy-verbesssem-belgium-euthanasia\\_n\\_2472320.html](https://www.huffingtonpost.com/2013/01/14/marc-eddy-verbesssem-belgium-euthanasia_n_2472320.html)

<sup>5</sup> <http://archive.no euthanasia.org.au/blog/2292-court-tussle-over-right-to-euthanase-dutch-woman-with-dementia.html>

<sup>6</sup> <http://www.news.com.au/lifestyle/real-life/sex-abuse-victim-in-her-20s-allowed-by-doctors-to-choose-euthanasia-due-to-incurable-ptsd/news-story/33d67a4ee6e5980d0c8f6c38147f1576>

<sup>7</sup> <https://edition.cnn.com/2016/09/17/health/belgium-minor-euthanasia/index.html>

<sup>8</sup> <http://archive.no euthanasia.org.au/blog/2492-psychiatric-euthanasia-salvos-across-the-atlantic.html>

<sup>9</sup> <https://nlntimes.nl/2015/01/19/clinic-reprimanded-tinnitus-euthanasia/>

<sup>10</sup> <https://nypost.com/2016/10/24/terminally-ill-mom-denied-treatment-coverage-but-gets-suicide-drugs-approved/>



*Euthanasia, disability and healthcare – a choice to die or a chance to live*

People with disability are more likely to suffer from poor health, contract aggressive cancers and consider suicide than other people.

Discussions about euthanasia need to consider the poor supports, barriers, low incomes and additional risk factors faced by people with many kinds of disability that place us in the direct path of the kind of health conditions normally associated with euthanasia.

The discussion of disability within the recent Victorian Bill highlights a number of issues and concerns around the intersection between the denial of access to healthcare and euthanasia

People with disability can be euthanised under the Victorian law. The panel recommends that disability “does not satisfy the eligibility criteria for access to voluntary assisted dying, nor does disability exclude a person from eligibility to access voluntary assisted dying”

The reality is that people like us are not equal and are already excluded – from healthcare and screening which would prevent us getting sick. Assuming a clear definition of terminal illness people with disability are much more likely to be in it, not due to our disabilities, but due to the barriers that we experience in accessing quality health, lifestyle, fitness and other forms of medical care.

When the Victorian Ministerial Advisory Panel was trying to grapple with the issue of where to draw the line for people with disability they used a cameo example which crystallises this lack of meaningful choices in the health system and makes euthanasia such a worrying threat to our lives.

Recommending against excluding people with disability from euthanasia, the panel gave the example of Tina a 43 year woman old with cerebral palsy. "Fully employed as a disability advocate and educator, Tina lives independently and communicates using a communication tool. Six months ago Tina was diagnosed with an aggressive cancer for which she has now exhausted all treatment options".

The panel felt that Tina should be offered euthanasia because her request was "voluntary and enduring".

What's also enduring but decidedly involuntary is the chronic lack of access to our health system for people with a disability like Tina's.

Back in 2003 a community advocacy group, Access for All Alliance, undertook a survey of all general practices around Australia to identify which provided access to adjustable-height examination beds. The survey showed that of the 3,553 response there were just over 14,000 fixed height examination beds and only 719 adjustable-height examination beds. An open letter from the Human Rights Commission found that in many situations patients, particularly women with disability do not get a service at all because of the inaccessibility of fixed height examination beds. One woman *had not had a Pap smear for 10 years* because her doctor could not transfer her onto the fixed height examination bed.

The National People with Disability and Carers Council's Shut Out report in 2010 also gave a sobering account of the exclusion of disabled people from primary and tertiary healthcare including comorbidity arising from a lack of access to yearly checkups and health screenings.

Seven years later the National Disability Strategy reports very little sustained and meaningful improvement in our access to health care including for people with physical disability or

communication issues. While the National Disability Insurance Scheme is starting to make a difference in specialist supports, it won't fix the health system.

Work by the Australian Institute of Health and Welfare has found people with disability experience poor access to a range of health services including dental and GP services. Issues included cost and a lack of support and coordination services <sup>11</sup>

In 2012 1 in 5 (20%) people with disability who saw a GP waited longer than they felt was acceptable for a GP appointment; 17% who needed to see a GP delayed or did not go because of the cost. Nearly one-fifth (18%) of people with disability who saw a medical specialist waited longer than they felt was acceptable to get the appointment. One in 5 (20%) people with disability did not see a medical specialist when they needed to, mainly because of the cost.

Of these, 32% were still waiting for the appointment at the time of the survey. Some 30% of people who needed to see a dentist delayed or did not go. Of these people, 67% delayed or did not go because of the cost.

Of people who saw 3 or more different health professionals for the same health condition, 16% had difficulties caused by a lack of communication or coordination among different health professionals.

About 13% of people with disability who reported a need for ongoing help or supervision with health-care activities (such as taking medication, manipulating or exercising muscles or limbs) had no source of assistance.

AIHW analysis of the health status and risk factors of people with a disability has also found people are more likely to experience other health and wellness issues ranging from diabetes to heart disease to mental illness as well as being more like to attempt suicide.

A NSW study also found that compared with the general population, people with intellectual disability experience very poor mental and physical health status and substantial barriers to accessing quality health services, with tragic consequences including higher death rates and avoidable deaths<sup>12</sup>.

On the ground, we hear from people who can't even be examined by their GP because they don't have a height adjustable exam table. Clinics, primary care, dentists, holistic health and the tertiary health system still have significant barriers to access, especially in regional Australia.

If Tina has aggressive cancer there is a very good chance that she couldn't even get a proper medical exam or the kinds of screening recommended for women her age. She probably couldn't even find a clinician with the time and capacity to communicate with her.

In the real world someone like Tina is also very unlikely to have a job and to be able to afford private health insurance or find the informal supports that other people could call on following a life changing health diagnosis. Euthanasia will be the default for us.

It's valid to ask why Parliaments are granting us the 'choice' to die when they never fixed the barriers that gave us equal access to preventative health and a chance to live.

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<sup>11</sup> Access to health services by Australians with disability – AIHW 29 • June 2015

<sup>12</sup> Julian Trollor, Preeyaporn Srasuebku, Han Xu, Sophie Howlett, Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data 22 November 2017

### *Euthanasia in a toxic climate*

The Terms of Reference of this inquiry invite us to look at ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

We would contend that the *communities views* about the desirability of disabled lives need to be called into discussion.

We do not suggest that supporters of euthanasia somehow hate disabled people. We acknowledge their deeply held convictions and motives to end suffering and pain, often from personal witness.

However their needs to be a realistic and honest conversation about current and future attitudes by the community, by the medical profession and by those likely to be in positions of influence should euthanasia be legalised.

Introducing state sanctioned euthanasia programs in a toxic climate where disabled lives are regarded as dispensable and people are routinely described as burdens on the state is dangerous.

From where we sit decisions about euthanasia will be made in a context where disabled lives are increasingly devalued in dangerous ways by politicians, the medical profession, relatives, the media and prominent public figures. For instance:

- Australia does not want disabled people as citizens and deports people with disability. Disabled people are not able to migrate to Australia because they are presumed to be burdens by the Federal Government and a cost to Australia (we are actually assigned an actuarial cost by legislation). People are deported for being disabled<sup>13</sup>. What's to stop a future utilitarian government making the same actuarial assessment on the costs of providing disability and health care weighed against the costs of encouraging euthanasia?
- The immediate past Minister for Social Services called disability a \$17 billion national burden<sup>14</sup>.
- A national newspaper headline called disabled people a burden and compared their worth to veterans<sup>15</sup>. Contrasting the value of disabled lives to soldiers in war was a potent argument in Germany along the road to Action T4. The American author and psychiatrist Robert Lifton noted that: "The argument went that the best young men died in war, causing a loss to the Volk of the best available genes. The genes of those who did not fight (the worst genes) then proliferated freely, accelerating biological and cultural degeneration". The government, the eugenicists argued, must intervene to prevent this<sup>16</sup>.

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<sup>13</sup> <https://www.sbs.com.au/news/the-feed/it-s-completely-inappropriate-australian-immigration-deporting-people-with-disabilities>

<sup>14</sup> <http://www.abc.net.au/news/2015-11-04/jericho-disability-support-pension/6910316>

<sup>15</sup> <http://www.abc.net.au/pm/content/2014/s4010134.htm>

<sup>16</sup> [https://ipfs.io/ipfs/QmXoypijzjW3WknFiJnKLwHCnL72vedxjQkDDP1mXWo6uco/wiki/Aktion\\_T4.html](https://ipfs.io/ipfs/QmXoypijzjW3WknFiJnKLwHCnL72vedxjQkDDP1mXWo6uco/wiki/Aktion_T4.html)

- In Australia people have been killed for 200 years for being disabled. This is documented in the report of the senate inquiry on abuse of people with disability and the White Flower Memorial project. The communities calls for a Royal Commission into disability abuse have been rejected meaning that this issue and its underlying causes remains to be addressed. In the absence of action on abuse it is conceivable that the people making end of life decisions about people with disability will be the same people that have been abusers across a persons life. Allowing people with disabilities to be euthanised perpetuates this violence and opens up a whole new context for the homicide, suicide and death by neglect.
- Debates about euthanasia often emphasise choice and the wishes of families but the reality is that disabled people are far more likely to be in danger from their own families than other people.
  - Disabled children are more likely to be abused and/or killed by their parents than are nondisabled children<sup>17</sup>. And when parents do kill disabled children, the media almost always presents one of two narratives: the harried-but-saintly parent who couldn't bear the terrible burden and (understandably) snapped one day, or the saintly parent who killed out of the tenderest of mercies. Murders of children with disabilities often lead to minimal sentencing in the courts.
  - These incidents aren't infrequent and often the coroners are our only biographers. (You can read about some of the disabled people who have been killed in Australia at the White Flower Memorial page and the stories of the Uncounted<sup>18</sup>. The White Flower Memorial serves to remember those with disabilities who have died in institutional care, in detention and in domestic care situations<sup>19</sup>.)
- Hate crime and hate speech is on the rise.
  - Our nearest ally the US elected a President who mocked disabled people at an election rally.
  - Two years ago 19 people were killed and 26 others were injured, 13 severely, at a care home for people with intellectual disabilities in Japan. The killer Uematsu insisted that "mentally disabled" people should be euthanized for the good of their families and other guardians<sup>20</sup>.

In this climate, where murder is minimised and disabled lives are devalued, we do *not* have faith in families or doctors making positive decisions about the lives of disabled people; we have grave concerns that vulnerable people will be leveraged into taking their own lives and we do not trust governments and underfunded health systems not to compromise on the care and value assigned to disabled lives once euthanasia is legalised.

We don't believe we will get a choice. And we have due cause.

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<sup>17</sup> <http://autisticadvocacy.org/projects/community/mourning/anti-filicide/>

<sup>18</sup> <https://bolshydivas.weebly.com/the-uncounted.html>

<sup>19</sup> [https://whiteflowermemorial.wordpress.com/2015\\_speeches/](https://whiteflowermemorial.wordpress.com/2015_speeches/)

<sup>20</sup> <https://www.japantimes.co.jp/news/2017/07/16/national/crime-legal/sagamihara-massacre-suspect-says-inspired-trump/>

### *Conclusion*

Lives Worth Living rejects any legalised euthanasia program which includes disabled people while we are subjected to poor health care, rights violations, economic disadvantage, a lack of supports and public vilification which place us in the path of euthanasia.

We don't believe that euthanasia will be an end of life "choice" for people with disability. There is likelihood that we will be levered and co-erced into suicide and there is reason to be concerned that legalising euthanasia will reinforce an authorising climate for suicides and homicides of people with disability.

Wherever euthanasia has been introduced it has grown to encompass disabled people, to negate the value of our lives and to put money and expedience before human rights.

As people with disabilities we ask you to recognise that euthanasia programs hold a horror in our memory. They are responsible for the murder of between 275,000 and 300,000 disabled people within living memory as part of the Aktion T4 euthanasia program. A program started on the pretext of mercy killing and based in a prejudice that labelled people with disability as a burden and a waste of state resources. This door should not be reopened lightly.

As a human rights jurisdiction the ACT should reject the killing of disabled people as inimical to human rights especially article 10 of UNCRPD.

We strongly oppose the Victorian model. People with disability can now be euthanised in Victoria and we are concerned about a host of perverse outcomes as people with disability come into the path of the bill.

LWL also believes that there is a need for more considered national work on a range of issues at the health/disability interface and to harmonise these to avoid the risk of different human rights outcomes based on where people live.

This work should include the adoption of a National Position on Eugenics and Biotechnology by all Australian First Ministers covering issues which act on Article 10 of the UN Convention including: Assisted Suicide on the grounds of disability, Genetic Screening, Involuntary sterilisation and certain surgical procedures.

The ACT should keep to a high path and continue to address the chronic dysfunction in the health and disability support systems that make some people's lives seem unbearable and end our lives early.

In the words of the late Stella Young:

"Before we can talk about death with dignity, we need to ensure that all people, regardless of age or disability, can live with dignity. We're not there yet".

Thank you for considering this submission. We would be happy to speak to the inquiry in more detail.

Regards

Craig Wallace  
 Convenor  
*Lives Worth Living*  
 19 March 2018