

End of Life Choice Bill: submission to the Justice Select Committee

March 2018

Dear Chair and members of the Justice Select Committee,

This submission is our reflections on the Bill as members of the Disability Faith Community in Auckland. It has been circulated to our membership and has the support of nine of our members.

We would be interested in giving an oral submission as well as this written submission.

We do not agree with the general intent of the End of Life Choice Bill.

We believe a disabled person's life has as much value as a non-disabled person's life, but this is not a view held by everyone. We are concerned this Bill reinforces the stigmatization of disabled people and their lives.

We oppose this Bill because every time someone takes their own life or another is asked to assist in this process is a mark against our society because life is a gift. Each person is unique and valuable and contributes to society. We believe that EoLC Bill gives yet another way for society to absolve itself from caring for people who deserve our care.

We believe that factors contributing to the desire to end one's life is fundamentally fear of suffering, fear of the unknown, being unable to imagine losing one's independence.

People cannot imagine living life in another way, particularly if it means loss of autonomy and dependency. This can be hard when society prizes individualism over community and those who are dependent tend to be ignored.

Our society perpetuates the myth that our worth depends on us being autonomous and independent. In reality as a society we are all interdependent and need each other to build strong communities where all can flourish.

Often people cannot imagine how they can live a worthwhile life being dependent on others for personal care so they say "I would be better off dead than suffer the indignity of being a burden on others". **Is a person less valuable because they rely on others for personal care?** The indignity comes from not having that assistance with that care provided in a timely and respectful manner. We believe there is a great need for debate around how we as a society provide this care, which allows people to live with dignity.

From discussion with others, when a person wants to end their life because of pain and suffering and is assisted with dealing with these issue; often they actually want to keep living. It is more helpful for professionals and support people to discover what the person is thinking and feeling and do what is possible to help rather than supporting them to end their life.

We believe the End of Life Choice Bill is a result of our society's attitude towards life. We live in a death-denying culture and this contributes to our fear of mortality. As a result, we need to control the way we die.

We disagree with Section 4. *“Meaning of person who is eligible for assisted dying...”* particularly sub sections (c) to (f). What gives the State the right to say to this group of NZ Citizens or residents that they are not valued and their quality of life is not worth investing in making it worth living?

We are concerned about the use of language in this Bill particularly around who is eligible for assisted dying. *“...grievous and irremediable medical condition”, “... state of irreversible decline in capability”, “experiences unbearable suffering... that he or she considers tolerable”*. These terms are emotionally loaded and lack rigorous definition and thus leaving it open to interpretation and abuse.

We are concerned that the use of the words *“mental disability”* is an ambiguous term and does not have any clear definition. It could be interpreted in such a way that it discriminates people who live with mental health conditions and people that live with an intellectual disability. These people are valued members of society and this Bill devalues their lives.

We have concerns about the responsibilities of the medical practitioners as specified in clauses 8 and 9 of the Bill.

Our concerns are that clinicians who would have responsibility for approving patients for physician-assisted dying do not currently have appropriate knowledge or training around disability supports or disability rights perspectives. This means that clinicians may be unreasonably biased and make assumptions about the experience and value of disabled people's lives based on their own prejudice.

We are particularly concerned with sub clause (h) (ii) of Clause 8. Putting the expectation on the medical practitioner *‘to do his or her best to ensure that the person expresses his or her wish free from pressure from any other person’* is being asked to get involved in areas outside of their medical expertise. Should a medical practitioner be an advocate, counsellor and social worker to the person who wishes to end their life - by making judgements about family dynamics.

This Bill creates a double standard in how our society values life. If a person appears fit and healthy we will put resources into preventing them from committing suicide; yet if a person is terminally ill or have a grievous medical condition and wants to die we will assist them.

Some disabled people and others fear this proposed bill will lead to people ending their lives under duress however subtle. The proponents of the bill argue that this debate is all about individual autonomy, without consideration of the wider effect on society. While on the surface assisting an individual, who is sick and dying to take their own life may be seen as a compassionate act, we, as a society, need to take heed of the inherent dangers in such a bill.

Many in the disability community, and others especially those who are elderly, experience a lack of autonomy particularly when ill and decisions are taken out of their hands. Often this is done with the best of intentions, being told it will make it easier for all. Assisted

dying/suicide could so easily be extended to people who are vulnerable because of age, disability and terminal illness because others perceive it as being in their best interests.

It is arrogant to support someone to end their life because they perceive themselves or others to be enduring undue suffering because of the needs for personal care. It is preferable for the state to resource high quality **personal care** options than to encourage people to be assisted in dying just because they need personal care.

It is arrogant to support someone to end their life because they perceive themselves or others to be enduring undue suffering because of the needs for palliative care. It is preferable for the state to resource high quality **end of life care** to encourage people to be assisted in dying just because they have a terminal illness.

Yours sincerely

Reverend Vicki Terrell

On behalf of the Disability Faith Community Auckland.

Included below is an additional submission from one of our members Raewyn Smith. Particularly about her views on the potential impact this bill could have for victims of domestic violence and their perpetrators .

Thoughts on the End of Life Choice Bill by Raewyn Smith

People have never had problems in ending their lives if they wish to and our terrible statistics on suicide in NZ is a testament to that end.

Our suicide rate is an indictment on our society. For the state to want to choose to assist people not to commit suicide in one group and want to choose killing off of another group that they think are less worthy to live is an abomination of human rights.

We don't kill terrorists, murderers, rapists and those that kidnap and torture and abuse their victims. If any group should die these people are the most deserving yet we let them live. Even those that kill and rape over and over.

I would like to raise the question also what does the politicians raising this idea have to gain personally? Does this person or the people supporting him have a chance to gain something from getting rid of someone?

How many people in our community may like to dispose of an aging Aunt or Mother in law or the old man they are responsible now for?

Perhaps it may be a disabled person?

Perhaps it could be the husbands of forced marriages that have become bored with their wives that they have disabled through domestic violence and now they want to be rid of the bother and choose a new fresh victim.

Many women in Indian, Asian or middle eastern marriages are in forced marriages. How easy will it be to just give them a disability then kill them off through this bill. That would be called state approved and enforced murder.

There are many other circumstances that could also occur to legislate murder in this way.

There might be the WINZ case manager that would inherit something through having a person killed or they may have a vulnerable person they don't want to deal with anymore so they can just say wouldn't it be better to not be a burden and choose this option.

The incidents of domestic violence that would result in easy murder would become horrific.

No Doctor or nurse should ever be in a position to end a life they take the hippocratic oath to preserve life.

As for judges having the right to choose any such thing would be a disaster.

NZ judges have no training and refuse training around domestic violence dynamics and are therefore the very last people who should be making any such choices.

In NZ we have had so many innocent people incarcerated and less than 1% of rapists get to prison. This shows horrific incompetency in our already flawed system.

To take this further by giving these incompetent people the right to choose who genuinely wants to die is horrific.

What about the victim who is forced to pretend they want to die so that their abuser does not kill a family member?

What about the person who is seriously and terminally ill who if left to life actually survives and survives well?

No one should ever choose which sick person can die with assistance.

If a person really wants to kill themselves no one can stop them.

This proposed bill is full of holes and opens the doors to abuse and for people to murder others at whim.

These are my thoughts...