



Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Systems and Individual Advocacy for vulnerable People with Disability

17th April, 2019

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee,
PARLIAMENT HOUSE QLD 4000

Via email: careinquiry@parliament.qld.gov.au

Dear Committee Members,

We thank you for the opportunity to provide our submission to the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. We are grateful to the Committee for granting us the extension of time until today.

This inquiry is indeed a matter of deep concern to Queenslanders with disability and their families and supporters and we welcome this opportunity to raise our concerns and offer our contribution to the Committee so that any decisions may be based on all the relevant information, ethical dilemmas and human rights.

We attach our submission for your consideration.

Yours sincerely,

Michelle O'Flynn

Director

Ph: (07) 3844 4200 or 1300 130 582 Fax: (07) 3844 4220 Email: qai@qai.org.au Website: www.qai.org.au

2nd Floor, South Central, 43 Peel Street, STH BRISBANE QLD 4101

QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC



SUBMISSION TO

**THE HEALTH, COMMUNITIES, DISABILITY SERVICES AND DOMESTIC
AND FAMILY VIOLENCE PREVENTION COMMITTEE**

**Inquiry into aged care, end-of-life and
palliative care and voluntary assisted dying**

“You gave me the support to die before you gave me the support to live.
And so I died.”

“They killed me because their ideas about ‘dignity’ were not like ours.
They killed me because they had watched a parent die in pain.
They killed me because it was easier to fight for dying than for disability support.
They killed me because it was easier to fight for dying than for palliative care.
They killed me because I cost too much money to support.
They killed me because I had never had a job and I wasn’t ‘productive’.
They killed me because I was disabled.
And so I died.”

“The Greens Killed Me”

written by People with Disability

*‘I sit on a man's back, choking him and making him carry me and yet assure myself and others that I am
very sorry for him and wish to ease his lot by any means possible - except getting off his back’*

Leo Tolstoy



About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (**QAI**) is an independent, community-based systems and individual advocacy organisation and a community legal service for people with disability. Our mission is to promote, protect and defend, through systems and individual advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Queensland Advocacy Inc. (QAI) is an Association of persons with concern for the needs of people with disabilities with a constitutionally designated committee comprising a majority of people with disability; their wisdom and lived experience of disability is our foundation and guide.

QAI was set up progressively from the Steering Committee phase in July 1987 to its incorporation in March 1988 and has operated continuously since.

QAI undertakes systems advocacy aimed at changing policies, laws and attitudes in ways that will benefit groups of people with disability rather than individuals alone.

QAI strives to maintain its complete independence as an organisation and to restrict its function solely to advocacy.

QAI concentrates its advocacy efforts on the people with disability it considers most vulnerable. They are most likely to be denied access to society's benefits, including medical services, on the basis of negative 'quality of life' judgements. These judgments hold that there is a limit to how much finite government resources should be spent on someone with a low 'quality of life'.

QAI has an exemplary track record of effective systems advocacy, with thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law and policy reform and by supporting the development of a range of advocacy initiatives in this state. We have provided, for almost a decade, highly in-demand individual advocacy through our individual advocacy services – the Human Rights Legal Service, the Mental Health Legal Service and the Justice Support Program and more recently the National Disability Insurance Scheme Appeals Support Program and Decision Support Pilot Program.

Values Statement

At QAI, we believe that all human beings are equally important, unique and of intrinsic value. Everyone should be seen and valued as a whole person, first and foremost. The human condition is such that societies tend to devalue those who do not fit within their models of perfection. These groups, including people with disability, are socially marginalised. As an organisation we seek to bring about a common vision where all human beings are equally valued.

The process of interaction between people with and without disability is a social exchange.

The experience of people with disability is that they are often seen as recipients of charity rather than social contributors. A person without a disability gains from the interaction through having an opportunity to engage with another person's experience of disability and, as a result becomes more aware of their own humanity. Both lives can be enriched through this exchange



Every human life is of value, and should be afforded dignity, respect and protection.

People with disability are particularly vulnerable to life threatening interventions. That is why we hold specific positions on some life and death issues. QAI is opposed to assisting another person to suicide or enabling (voluntary or involuntary) euthanasia. QAI is opposed to eugenics, and believe that this can occur on many levels including the scientific, political and legislative. Whilst not taking a position on when human life begins or women's right to choose, because of the particular threats of biotechnology, QAI is opposed to selective abortion and use of prenatal testing for this purpose. When addressing issues of life and death, we recognise that many people in society value a spiritual dimension and hold firm views on social consequences of decisions. QAI does not take a particular spiritual stance but recognises that ignoring the contribution of these views largely abrogates these issues to the realm of science and medicine.”¹

Many disparate views will be posed regarding the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. Given the scope of the Royal Commission into Aged Care, and QAI’s submission to that topic, for this purpose, we will restrict our submission to the aspects of end-of-life, palliative care and “voluntary assisted dying”.

To assist in understanding our position we offer this excerpt from a presentation at a forum “ Exploring Vulnerability and Power: Addressing the Abuse of Vulnerable Adults” co-hosted by The Esther Centre, Applied Ethics at QUT, and the School of Social Work and Social Policy at University of Queensland in 2001.

© David Massey
Lecturer in Identity and Applied Ethics
Ethics and Human Rights Program
School of Humanities and Human Services, QUT Carseldine

“Life, for many, is bleak and miserable and the burdens are insurmountable, or nearly so. Is there any likelihood that life could be better: that some good could be accomplished, some joy experienced? I do not propose to answer those questions. Rather, I will conclude with the words of the Japanese poet, Issa, which are pregnant with meaning for me and, I hope, may be for you, too.

A world of grief and pain;
Flowers bloom,
Even then.”

¹ The Values and related statements from Queensland Advocacy Incorporated Policy and Procedure Manual.



From the perspective of people with disability, their families and supporters, there is a secret war but global war being waged against them.

Despite the somewhat meagre advances towards equity in respecting human rights pertaining to people with disability, realising those rights in everyday life for many people is still out of reach, or come with a set of special conditions - thus belying the validity of those rights, or at least, when people actually attempt to activate them.

Governments, local councils and other authorities will deny and respond with defensive commentary about resources, hardships or their need to balance others' rights and to serve the 'silent majority'. This is offensive when one considers the systematic abuse, neglect, violence, marginalisation and demonization that those very authorities have 'served' to people with disability.

Historic discrimination and marginalisation has pervaded the culture and mind-set against people with disability across so many aspects of modern life. This war is conducted almost everywhere in varying degrees of harshness, but it is particularly constructed in wealthy modern western society.

HOW DEVALUATION LEADS TO ABUSE, NEGLECT, TORTURE, DEATHMAKING

"The politics of "lifters and leaners" – "the productive and the burdensome" – lay at the core of Nazi propaganda justifying its involuntary euthanasia program for disabled people – particularly people with intellectually disability – of which babies, children and adults with Down syndrome were a key target.

The "T4 program" – as it came to be known – was effectively a "rehearsal" on disabled people for the broader Holocaust that was to come – by the end of the Second World War approximately 300,000 babies, children and adults with disability from Germany and the countries it occupied would be killed by lethal injection and gassing."²

How is this war strategized? It begins before the actual beginning and as history illustrates, so many threats to the lives and welfare of people with disability originate with the medical profession who are supposed to uphold and prolong life.

Pre-natal Testing

The rise in pre-natal testing for what is termed birth-defects is an indication of societal perceptions about genetics, individualism - perfection.

Yet proponents of pre-natal testing are not necessarily delivering all the information and certainly almost no evidence to prove its effectiveness or the risks associated with some of those tests, nor how those tests are associated with profits for hospitals. Marsden Wagner, M.D., analyzed the existing scientific studies and concluded that routine ultrasound has been shown to be unnecessary, costly, and of no proven benefit: *Ultrasound: More Harm than Good?*³

Protagonists of aborting babies with Down syndrome are convincing vast numbers of parents worldwide by 'worst case' scenarios of health issues and potential quality of life, but motivated by cost to government for health and other care or supports. Are we a nation that determines the value of a human life based on what it may cost to the taxpayer or to the profits of government investments? Iceland ([100% DS abortion rate](#)), Great Britain (90% DS abortion rate) and Denmark (98% DS abortion rate), all have a national healthcare system. France has a 96% DS abortion rate.

²"Usefulness" Is Not A Measure Of Human Worth – It's A Dangerous Ideology" by Catia Malaquias;
<http://www.startingwithjulius.org.au/usefulness-is-a-dangerous-measure-of-human-worth/>

³ <https://midwiferytoday.com/mt-articles/ultrasound-harm-good/>



As a child with DS costs “1 to 2 million Euros,” Belgian pediatrician Patrick Willems says that, “preventing the birth of 50 babies with Down Syndrome will offset the costs of fully implementing the NIPT [a noninvasive, highly accurate prenatal test for DS] into Dutch public healthcare.”

Dutch pediatrician Ko van Wowue treats ending the lives of pre-born DS babies like an investor: “If you put 200% effort in [a child with DS],” he says, “you get 10% in return.”⁴

Yet more and more people with Down syndrome are highly successful and offering insight and expertise with a wide range of talents and contributions all over the world. Not that anyone should have to prove their ‘worth’ in order to live.

“When we tolerate the killing of people simply because of who they are, we lose our own moral standing to exist.”⁵

While we don’t question or judge a woman’s right to determine her own fertility or family planning, it is certainly worth questioning the culture that influences the measure to which people will employ to ‘construct’ their future child.

Professional and lucrative opportunities in the arena of sports entertainment, prestige and national pride of success at formerly amateur competitions like Olympics have driven competitors and their support teams to cheat by the use of illicit substances. This was a whole scale operation in the eastern bloc countries of Europe and the former USSR is indicative of extreme pressure to succeed, and is impelling the genetic determination and creation of supreme beings.

Advances in bio-medicine and fertility has enabled some modern parents to choose not only gender but also hair and eye colour, and here in Australia, our medical professionals are campaigning to eradicate specific characteristics of disability by lobbying for testing to be made available on the Pharmaceutical Benefits Scheme. Australian families would follow the trend in some European countries where there have been no children with Down syndrome born for over 10 years.

Torture and Experimentation

The devaluation and historic mistreatment of people with disability has permeated society so deeply that experimentation and torture has been inflicted even within high profile and successful families around the world. The life and death of Rosemary Kennedy has been documented in several publications.⁶ At the age of 23 at George Washington University Hospital, while fully conscious, Rosemary endured the drilling of two holes into her brain, the insertion of a metal spatula and the severing of connections of parts of her brain.

Sterilisation of women, girls and chemical castration of boys and men with disabilities is a continuing but hidden practice. Bodily integrity is a concept which enshrines the individual’s legal right to protection from assault or other bodily interference which occurs without appropriate consent.⁷

There are still many practices and involuntary measures imposed upon people with disability today that are perilously similar ‘experimental’ treatments, especially when diagnoses are inaccurate or conveniently aligned to the treatment.

⁴ “Scandinavia’s War on Babies with Down Syndrome” <https://merionwest.com/2017/08/06/scandinavias-war-on-babies-with-down-syndrome/>

⁵ David F. Forte, Professor of Law, Cleveland State University :The Public Discourse” <https://www.thepublicdiscourse.com/2018/07/21996/>

⁶ “Rosemary: The Hidden Kennedy Daughter” by Kate Clifford Larson and “The Missing Kenned by, Elizabeth Koehler-Pentacoff

⁷ QAI Submission to SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS “The involuntary or coerced sterilisation of people with disabilities in Australia”.



Dehumanisation and Crime

Horrific crimes have been perpetuated against vulnerable people with disability by strangers, paid workers, and strangers. Murder of people with disability is often excused as ‘mercy killings’ and family member perpetrators have been offered sympathy by judges, juries, media and community in general. How we speak about and portray people with disability even unconsciously conveys what is understood and has meaning in community.

One person with disabilities is killed by their carer almost every three months in Australia, but these acts of domestic violence are often excused by the media and judiciary. The focus is too often on the killer.⁸ The misconception or myth about the enjoyment of life by the person with disability is perpetuated over and over again in the media and in public discourse, with the notion that quality of life is poor, or that the burden of care is so overwhelming for the murderer, that they either had no other option or that they performed this ‘merciful act’.

The acts of murder and violence of people with disability is often overlooked, forgotten, disregarded. Some of the most heinous and coldhearted treatment of human beings have been perpetrated by colleagues, schoolmates, friends, and strangers – because of complete devaluation and dehumanization. These are hate crimes and as a society, the offer of deathmaking to people with disability will exacerbate societal views of already devalued and vulnerable people and heighten the risk of coercion, lower esteem and self-worth. The murder of Jennifer Daugherty in the United States is a harrowing story of betrayal and torture and death.⁹ A report into media bias and disregard for people with disability as a source is part of the problem.¹⁰

The lack of responses by police to complaints by people with disability against service providers and or family abuse against people with disability is well known. Police consider people with intellectual or cognitive impairments to be unreliable witnesses and if called to a house will most likely speak to the carer or support worker about the complaint rather than the person themselves or their supporters. The judiciary have little experience or understanding of people with disability and similarly to police officers will often sympathise with the experiences of the perpetrators and their ‘burdens of care’.

Kyla Puhle was 27 years of age when she died of severe dehydration and malnutrition from starvation. Her mother and father had removed her from all services and ‘cared’ for her at home. Angela plead guilty to manslaughter. Honorable Justice Sulan first reduced the non-parole period to 2 years and 6 months and then suspended the sentence. Angela Puhle was placed on a good behavior bond for 3 years.¹¹ Kyla was 27 years old and weighed just 12 kilograms when she died. There were many testaments to the value and contribution of the mother as a teacher and upstanding family member who loved and cared for the daughter she slowly killed. No-one spoke up about the value of the life of Kyla Pyhle.

As ABC Radio National journalist Sarah Dingle discovered during her work on “When Carers Kill” the language in the courts has a very negative and ableist view of disability – often framed by the

⁸ “When Carers Kill” ABC News 2018 <https://www.abc.net.au/news/2018-06-23/when-carers-kill/9894514>

⁹ “The Invisible Hate Crime” https://www.splcenter.org/fighting-hate/intelligence-report/2018/invisible-hate-crime?fbclid=IwAR36HmQi_X83WJVZHKb_QS4yzLWObxqNXqcYXTWLoZf3fyZfx3EOaYQ8Ho

¹⁰ <https://www.pastemagazine.com/articles/2017/03/new-report-discovers-that-the-media-normalizes-the.html?fbclid=IwAR26tWu7MDouEnJTtNiicBU8hptFMkBBV4HRIUOjCqAcoSzc-9MNMbjNNm0>

¹¹ <https://www.abc.net.au/cm/lb/9899454/data/court-documents-from-the-puhle-case-data.pdf>



perpetrators themselves. Lawyer Frankie Sullivan told Sarah “A lot of the judges and judicial officers went to some lengths to outline exactly how much care was or how much assistance was required with what sort of tasks, as if to say that for some reason these needs of the victim contributed to them being killed or murdered”.¹²

The disappearance and death of Krystal Fraser in Victoria (2009) is a cold case mystery that warranted a reward for a mere \$100,000 for information leading to the apprehension and convictions of the perpetrator. Despite an arrest of a man in 2018, he was released ‘pending further inquiries’. Other cold cases have attracted rewards of \$1 million. There has been no plans to increase the reward in the case of Krystal who was heavily pregnant and only days from delivering her baby boy. Neither Krystal, her baby nor her phone have ever been found.¹³

Parents of students with disability live in fear of the bullying that is routinely dished out to their children. The desire to have their children included in mainstream school is alive and well, yet when so many are left without support or redress when their children have been abused, beaten, and pushed to suicide because of bullying, some are beginning to choose home schooling or other specialized settings. However, students with disability also experience violence, abuse and bullying in these settings as well.¹⁴

People with disability and their families and advocates have fought for a Royal Commission into abuse, neglect and violence for decades and therefore this inquiry into end-of-life, palliative care and ‘voluntary assisted dying’ could not be more timely.¹⁵

Offer to Kill by Intentional Neglect

Deathmaking before life even begins is a construction, but even once a child is born the death offering continues. The withholding of life-giving surgery or medication, or transplants because of the devaluation of a persons with disability is still underpinning societal views worldwide.¹⁶

National Right to Life NEWS (25/03/97) reported that a three year old Dutch boy with spina bifida "in fair general condition" was killed by doctors at his parent's request even though a nurse had offered to adopt him. The parents, on being asked why they were requesting euthanasia said their son "did not feel well for a couple of days".

In Australia the Transplantation Society of Australia and New Zealand sets out the Clinical Guidelines for Organ Transplantation from Deceased Donors (Version 1.0 – April 2016). While there are specific recipient inclusion and exclusion criteria for each organ, there are general conditions that apply across all organs. These are:

1. *Age: with the increasing success of transplantation, the age range considered suitable for transplantation has steadily increased. Age is not by itself an exclusion criterion for most organs. However, the presence of multiple comorbidities in patients over 70 years of age is likely to exclude the majority of such patients from eligibility for transplantation.*

¹² <https://www.abc.net.au/news/2018-06-23/when-carers-kill/9894514>

¹³ " Abducted: The pregnant murder victim Victorians forgot" Jamie Duncan, Herald Sun June 16, 2017

¹⁴ https://www.msn.com/en-au/news/australia/horrifying-moment-an-autistic-boy-is-pulled-off-his-bike-kicked-in-the-head-and-beaten-with-a-wrench-in-a-vile-bullying-attack/ar-AAx0SMz?fbclid=IwAR2var6UChq_vZbdbjHSYy9j0OIk-1XGHHvBIBN9MY-ZWKLmP6KZV6YQ8Ug

¹⁵ <https://www.abc.net.au/news/2016-06-22/concerns-raised-about-culture-of-cover-ups-in-group-homes/7509676>

¹⁶ "Death for Alfie" <https://www.facebook.com/theblaze/videos/1828322090538456/?v=1828322090538456>



2. *Comorbidities: exclusion criteria generally include conditions or combinations of conditions that would result in an unacceptably high risk of mortality or morbidity during or after transplantation (e.g. active malignancy, severe cardiac disease, or chronic infection).*

3. *Behavioural risk factors: the fact that an individual may require a transplant due to lifestyle choices they have made in the past is ethically irrelevant. However, ongoing substance abuse—including excessive alcohol consumption, cigarette smoking and illicit drug use—are generally considered contraindications to transplantation. These lifestyle factors increase the risk of poor transplant outcomes.*

4. ***Inability to adhere with complex medical therapy: for example chronic cognitive or neuropsychiatric deficits in the absence of a carer capable of facilitating adherence to therapy.***

Sometimes this may be offered if a child or an adult presents in hospital for a routine procedure.

QAI holds concerns that despite reasonable guidelines in decision making around allocation of organs, it is the life experience of many people with disability that these decisions are all too often clouded by personal prejudices and devaluation.

It is not uncommon for parents of children and or adults with disability, to be offered deathmaking as if it were an 'opportunity'. Doctors and nurses have told parents and other care-givers of ways and means that the medical profession can alleviate the 'burden of care' of loved ones by removal of feeding tubes and other life-sustaining measures while their family member is undergoing routine medical procedures.

MEDICAL MODEL - THE POWER IMBALANCE OF DISCOURSE CREATES THE THREAT IN PUBLIC PERCEPTIONS

As mentioned previously QAI does not refute a woman's right to determine their own fertility, family planning or bodily integrity. However, there are significant points in medical development that individually appear to be great progress, but cannot be isolated from the discussion when considering the deliberate and planned killing of another human being.

Australian bioethicist and animal rights activist Peter Singer is a proponent of selective infanticide. Indeed his entire view of people with disability and their place in humanity sends tremors of fear to parents and supporters and no doubt countless people with disability. Others are entirely brave in the face of his and Kevorkian's persuasive advocacy for killing. In "Taking Life: Humans Excerpted from Practical Ethics, 2nd edition, Cambridge, 1993, pp. 175-217 Singer writes: "I do not deny that if one accepts abortion on the grounds provided in Chapter 6, the case for killing other human beings, in certain circumstances, is strong."

Singer argues the case for selective infanticide and in doing so equates the killing of humans with the euthanasia of animals. We are not dogs, cats, or other domestic animals that are routinely destroyed to end pain and suffering. He refers to the assumption that a child must endure multiple surgeries then their lives are so miserable as to be not worth living. However, Singer rightly points to the modern concept of that foetuses are 'replaceable'. Certainly with IVF and modern fertility medicine, embryos are created outside the body, stored, implanted, and unwanted embryos destroyed.



In 2001 The European Society of Human Reproduction and Embryology Task Force on Ethics and Law wrote "This embryo is owed respect as a symbol of future human life." Yet the IVF production of 'saviour siblings' or 'spare parts' for existing children with conditions requiring organ transplants or anaemia, indicates that there is a sympathetic view of the replaceability of human foetuses.

Singer poses the unfairness of the birth of children with disabilities - "At present parents can choose to keep or destroy their disabled offspring only if the disability happens to be detected during pregnancy. There is no logical basis for restricting parents' choice to these particular disabilities. If disabled newborn infants were not regarded as having a right to life until, say, a week or a month after birth it would allow parents, in consultation with their doctors, to choose on the basis of far greater knowledge of the infant's condition than is possible before birth."¹⁷

His argument that replacing (by killing) a newborn or young child with disability can make way for an improved version. "When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if killing the haemophiliac infant has no adverse effect on others, it would, according to the total view, be right to kill him."¹⁸

THE HEALTHCARE SYSTEM – AVOIDABLE DEATHS

Avoidable Deaths is how it is termed. Negligence is another word for it. Many people with disability who reside in care, and particularly for those with alternative communication methods (deemed non-verbal) often have their healthcare needs overlooked or ignored, or at best – misunderstood.

Deidentified quotes from families in regard to healthcare of family members living in institutionalised settings:-

The doctor usually comes in, questions the registered nurse, sometimes standing at a distance – at least 6 feet – and makes a comment. Something like "Oh, she's doing well, no problems, but there never is with this one."

I recall one incident when Sam came home, with an incorrectly labeled medicine bottle. If I had followed that instruction my son would surely have died of an overdose. I immediately rang the Centre to be told that I was mistaken, or that the Hospital had made the mistake.

You have the right to say anything, but no one takes any notice of you. It is a case of – we provide the mechanism but we don't have to do anything about it.

Issues discovered relating to neglect of health care range from untreated broken and fractured bones, malnutrition, dehydration due to poor diet, chronic constipation, errors in administering medication, and poor attention to dental hygiene.

This story in the United Kingdom of a man with Down syndrome died following a procedure and where hospital staff failed to ensure he received adequate nutrition via a percutaneous endoscopic

¹⁷ "Taking Life: Humans" Excerpted from Practical Ethics, Peter Singer 2nd editions Cambridge 1993

¹⁸ Ibid



gastrostomy, where a tube is inserted into the patient's stomach through the abdominal wall. He had not received food for 10 days.¹⁹

Most of the issues relating to health care can be attributed to poor understanding of the diversity of support needs and communication methods. While people with disability require understanding, it is not appropriate that they be treated only according to their 'diagnosis type' and individual person-centred responses are highly important.

"Health professionals face challenges communicating with people with intellectual disability, distinguishing health problems from the disability, and diagnosing complex health conditions. They generally have minimal training in intellectual disability health care (an average of 2.6 hours in medical degrees and no content in the majority of nursing degrees).²⁰

Poor Prescribing practices in people with ID may drive adverse health outcomes.

- After accounting for elevated prevalence of mental illness (19), psychotropic medication prescription and polypharmacy remain disproportionately high amongst people with ID (20-22).
- Antipsychotics are the most commonly prescribed psychotropic medication (23), and are often given for challenging behaviour, a practice unsupported by evidence (24) and out of keeping with sector expectations.
- Psychotropic medication use in the general population has been associated with an elevated risk of cardiometabolic morbidity and mortality (25, 26), and may thus drive some of the poor health outcomes experienced by people with ID.²¹

Recent news stories of the treatment of people with mental health issues and the lack of care to their support needs have raged across newspapers and online in the past few years. The impervious and callous disregard for vulnerable people is at the heart of the risk to them by the passing of euthanasia laws.²²

What Is 'Voluntary' About Deathmaking If You Have No Power?

In Final Exit, Hemlock Society founder Derek Humphrey writes: "What can those of us who sympathize with a justified suicide by a handicapped person do to help? . . . When we have statutes on the books permitting lawful physician aid-in-dying for the terminally ill, I believe that along with this reform there will come a more tolerant attitude to the other exceptional cases." Kevorkian has openly admitted that he designed his suicide device as an answer for quadriplegics. He has said that he perceives physical disability as a cause of extreme human suffering that can be addressed by "medicide." He also argued, as did the Nazis, that society will benefit from the deaths of incurably

¹⁹ https://metro.co.uk/2019/03/25/man-with-downs-syndrome-died-after-hospital-didnt-feed-him-for-10-days-9014691/?fbclid=IwAR0otJnI0I4t6FMKVWVrAuZ1bGraqViLXSW9QWfAMKaE4jDjFCovi_xPt7ww

²⁰ The Health Of People With Intellectual Disability Budget and Federal election 2019 Commitments sought from Australian political parties, Inclusion Australia (NCID) and Council for Intellectual Disability

²¹ Health Inequality And People with Intellectual Disability –Department of Developmental Disability Neuropsychiatry (3DN) School of Psychiatry Faculty of Medicine, UNSW 2017 Research Summary

²² <https://www.justiceaction.org.au/media-releases/media-release-miriam-merton/miriam-merton-mental-hospital-death-inquiry-9th-november-2017>



disabled people. Chillingly, he wrote: ". . . the voluntary self-elimination of individual and mortally diseased or crippled lives taken collectively can only enhance the preservation of public health and welfare."²³

End of life decisions for people with intellectual impairment living in Dutch institutions was a deliberate intention to hasten their deaths. It transpired that 44% (97 of 222) of their deaths involved such a decision, with only two of the people expressing a wish to die. How this can be interpreted as 'voluntary' is cause for scrutiny and no matter what protections are intended in legislation, there is no guarantee that people with disability and others who are devalued will not be coerced, or misled into seeking or accepting willful deathmaking.

Explained as "non-verbal communications" the act of a person removing a feeding tube was explained as acquiescence to wanting to die. Every death, including three cases of "active euthanasia" without any expression verbal or otherwise of a wish to die, were reported as "natural deaths.

In 1998 Alison Davis spoke at an international conference about her own experiences living with pain, and wanting to die, and then wanting to live and fighting against the progressive will to kill people with disability. "The willingness to kill people like me who are capable of rediscovering (or in my case, perhaps, in many ways discovering for the first time) their human value, the acceptance of the philosophy that people in PVS may be killed, the devaluation of elderly people, the killing of young disabled children, despite protestations of 'compassionate motives' are really based on a deadly mix of emotion, economics and a negative view of human value and worth, where the infinite value of human beings is reduced to a relative value, depending on how closely the person approximates to arbitrary notions of 'normality'." ²⁴

The following story again illustrates the vulnerability of people with disability who are perceived as "suffering", are a "victim" of polio or a "burden of care" or have lives unworthy. In the Netherlands increasing numbers of people with disability are being killed because of their disability including people whose only diagnosis is autism. While childhood abuse and trauma can be mitigating factors leading to a person's consent to die, it doesn't and shouldn't be the first resort when counselling and mental health assistance is the most appropriate solution. In nearly all examples of deathmaking of people with disability there is an alternative to destroying life.

In a study conducted of assisted deaths of people in the Netherlands, two of whom had autism and a common diagnosis of depression, the researcher discovered that the doctors disagreed that the criteria of "unbearable suffering" capacity to consent and futility had been met yet the deathmaking proceeded²⁵. They were dead no matter. In more than a quarter of the cases, patients sought help from a doctor who wasn't a psychiatrist and hadn't been involved with their care. Typically, this was a physician with a mobile clinic funded by a local euthanasia advocacy group."²⁶

Dr Paul Appelbaum from the New York State Psychiatric Institute wrote "Will psychiatrists conclude from the legalization of assisted death that it is acceptable to give up on treating some patients? There is also understandable anxiety about the secondary consequences of an assisted death option for people with mental disorders, including inducing hopelessness among other individuals

²³ "Physician Assisted Suicide a Huge Threat to Disabled" Testimony of Diane Coleman, J.D. and Carol Gill, Ph.D. Exposure draft of the Medical Services (Dying with Dignity) Bill 2014 Sub 04 Attachment1

²⁴ A Disabled Person's Perspective on Euthanasia Given at a Conference Organised Jointly by the Society for the Protection of Unborn Children and International Right to Life on 14th March 1998 Alison Davis.

²⁵ <https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2491354>

²⁶ <https://www.lifenews.com/2016/03/10/in-europe-people-are-being-euthanized-just-because-theyre-autistic/>



with similar conditions and removing pressure for an improvement in psychiatric and social services."²⁷

Indeed, given that loneliness was a common theme, Dr. Appelbaum questions whether assisted death "served as a substitute for effective psychosocial intervention and support."²⁸

History of Coverups and the Implications of the Royal Commission into the Abuse Neglect and Violence Against People with Disability

The westernisation of cultures and civilisations across the globe has imprinted western values including those about productivity, personal worth, instant gratification, beauty and family. Unlike some other cultures, modern western society does not revere or embrace our elderly citizens, with the rapid growth and demand for facilities to warehouse our aging population. With most families with two working parents, our family structures no longer include our extended families. Caring for aging family members is 'out-sourced' to providers and this trend is also an expectation – our grandparents have been and are shamed by our culture into thinking that they might become a burden.

Measures are taken to protect communities, but all too often in the process vulnerable people are shunned and demonised. While people may at times present a risk to themselves or to others, protective actions have habitually translated to incarceration in institutions - highly restrictive and or experimental treatments used upon them - mostly because they are poorly understood by the people charged with their care. These experiences have not been exclusive to adults – they have been also shared by very young children.

Forced co-habitation, with strangers, people that are incompatible, grouped unlike any other people merely because systems deny adequate support is untenable and the source of many brutalities. Access means more than physical or sensory access to some people whose access needs are diverse yet ignored. This creates another source of frustration that is manifested in ways that is blamed upon the person whose access needs are forgone daily. Denial of augmented or alternative communication methods is not a simple frustration, but a cruelty that is violent. QAI has submitted papers attesting to the issues that compound and demean people with disability at all levels of government.

The elimination or extinction of a part of humanity is no less than genocide. Concerted pressure by doctors and nurses on parents to have the screening, without complete information about the successes of people with disability, the supports available it is little wonder many parents consent to the abortion.

When people require support to exercise their fundamental rights, and particularly (but not exclusively) when those supports and services are purchased there is a high level of risk of abuse and neglect. QAI has been involved in advocacy for over thirty years where people with disability have been subjected to abuses and even died in institutional care. The Disabled Persons Ward in Maryborough, Ward10B Townsville, Baillie Henderson Hospital in Toowoomba, Halwyn, Basil Stafford, Challinor, Jacana, the Forensic Disability Service, and authorised Mental Health Services are just some of the places where people have suffered abuse, neglect and violence. Many of these institutions were supposed to close – some still operate despite the exposure of abuse and crime.

²⁷ https://www.washingtonpost.com/opinions/where-the-prescription-for-autism-can-be-death/2016/02/24/8a00ec4c-d980-11e5-81ae-7491b9b9e7df_story.html?utm_term=.618e7563b02a

²⁸ <https://health.jotwell.com/physician-aid-in-dying-and-mental-illness/>



In 1990 Queensland government officials were involved in the destruction of significant documents in the investigation of physical and sexual abuse of children at the John Oxley Youth Centre.²⁹ Investigations into such abuse are often superficial due to the conflicts of interests whether they are

private facilities or government run institutions. The Committee Inquiry found “The Committee also concludes that there is evidence of abuse at JOYC which appears not to have been investigated exhaustively by the Forde inquiry or the CJC. Indeed, the investigation of the CJC at least arguably points to a cover-up. Despite the limitations of the Forde inquiry with respect to abuse at JOYC, it did uncover much evidence of abuse at other institutions, both state and privately run.

3.168 Of grave concern to the Committee is the fact that serious abuse in Queensland institutions, and particularly in youth detention centres, appears to be continue unabated – despite the Forde inquiry in 1999. For example, on 17 June 2004, The Courier-Mail newspaper reported allegations of staff brutality, including the beating of children while handcuffed, at the Brisbane Youth Detention Centre. That Centre opened in 2001 as the replacement for JOYC.”³⁰

Culture Change

Deathmaking is not restricted to people with Down syndrome or people with physical disabilities. The higher rates of abortion based purely on disability has been accompanied by more and wider acceptance of assisted suicide. Devalued people are rarely noticed until they become a nuisance or inconvenience. In our western culture, it appears we never learn from our mistakes. Aging people are commonly (and incongruently) warehoused in larger and more whole-sale institutions, just as we attempt to move people out of other long stay health facilities. When international events such as Olympics, or Commonwealth Games or G20 summit (Brisbane 2014) occur, homeless people are undesired and moved elsewhere (but where?) Similarly, people with disability are unnoticed and unheard except when they are inconvenient.

In parts of Europe where assisted suicide is gaining more momentum, the involuntary deathmaking of homeless people, people with mental illness and other devalued people is becoming more commonplace.

Belgium, the Netherlands and other European countries with proactive pre-natal testing have almost eradicated the birth of babies with Down syndrome. Those same countries have adopted liberal laws on euthanasia. Firstly for people with terminally ill conditions, which has since been amended and broadened to include people with mental illness experiencing ‘extreme pain and suffering’³¹

Belgium and the Netherlands are now considering the euthanasia of “emancipated minors”³² The Queensland Council for Civil Liberties is now suggesting that 12 year old Queenslanders who are ‘mature minors’ should exercise their rights to voluntary assisted dying. The language used in the QCCL submission echoes those used in Europe and yet ignores or is unaware of the implied threat to vulnerable people who have not been given the opportunity to experience or appreciate their own worth and contribution that their very existence brings to humanity.

²⁹ http://www.heineraffair.info/site_pages/key_people.html

³⁰ https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=laca/criminthecommunity/report/vol2chapter3.pdf

³¹ <https://www.faithwire.com/2019/01/08/belgium-summoned-to-europes-highest-court-over-euthanasia-of-depressed-woman/>

³² Raus, Kasper (1 June 2016). "The Extension of Belgium's Euthanasia Law to Include Competent Minors". *Journal of Bioethical Inquiry*. 13 (2): 305–315. doi:10.1007/s11673-016-9705-5. ISSN 1176-7529. PMID 26842904.



Bioethicists Alberto Giubilini and Francesca Minerva go further than Joseph Fletcher, euthanasia proponent, arguing that killing a newborn "should be permissible in all the cases where abortion is, including cases where the newborn is not disabled."³³

With voices barely above a whisper, yet their screams have gone unheeded throughout history, the offering of 'voluntary' assisted dying is a misnomer. There will always be others whose voices are louder, with more power, with more control.

Palliative Care

Pain and 'long term suffering' are not diagnoses, nor are they adequate reasoning for the killing of human beings. While QAI understands and holds empathy for people with acute and unbearable pain, the advocacy must be for more and better palliative care.

The respect for and preservation of life while addressing the comfort and pain of the person is the crux of palliative care. Respecting a person's wish to either accept or refuse treatment other than for the purpose of ending life, is crucial to humanity.

In the words of Dr. Brian Pollard "Unrelieved human suffering urgently calls for the removal of the cause before it calls for the removal of the human".³⁴

As Palliative Care points out during the debate to legislate euthanasia in Victoria, there is no research to suggest that voluntary assisted dying has had any decrease in non-assisted suicides. IN fact almost 25% of Victorians die without assistance to palliative care, access to it even when residing in aged care facilities is very low, and that funding is inadequate to meet demand.

Further to this it sends the message to people that their lives indeed are not worth living and as Dr. Michael Gannon (president of the Australian Medical Association) said it is "commonplace" for patients to tell doctors in front of their loved ones that they have no wish to be a burden on families. He went on to say "Once you legislate this you cross the Rubicon. The cause for euthanasia has been made in a very emotional way and this is the latest expression of individual autonomy as an underlying principle. But the sick, the elderly, the disabled, the chronically ill and the dying must never be made to feel they are a burden."

And as former Prime Minister Paul Keating said "Voluntary euthanasia is a threshold moment for Australia, and one we should not cross. What matters is that under Victorian law there will be people whose lives we honour and those we believe are better off dead.

In both practical and moral terms, it is misleading to think allowing people to terminate their life is without consequence for the entire society.... An alarming aspect of the debate is the claim that safeguards can be provided at every step to protect the vulnerable. This claim exposes the bald utopianism of the project – the advocates support a bill to authorise termination of life in the name of compassion, while at the same time claiming they can guarantee protection of the vulnerable, the depressed and the poor.

No law and no process can achieve that objective. This is the point. If there are doctors prepared to bend the rules now, there will be doctors prepared to bend the rules under the new system.³⁵

QAI asserts that doctors have always bent the rules as evidenced by previous inquiries into healthcare provided in institutional settings and particularly where deaths have occurred.

³³ Giubilini, A.; Minerva, F. (2012). "After-birth abortion: Why should the baby live?". *Journal of Medical Ethics*. 39 (5): 261–263. doi:10.1136/medethics-2011-100411. PMID 22361296

³⁴ Euthanasia Dr. Brian Pollard, 1998

³⁵ <https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html>



QAI submitted to the Australian Senate Legal and Constitutional Committee on Euthanasia Laws Bill in 1996:

INDIRECT THREATS - SLIPPERY SLOPES, WEDGES AND FLOOD GATES

The indirect threats to the lives of people with disability from legalizing voluntary euthanasia arise from the changing values which have led to, and which flow from, that legalization process. Often these threats are from non-voluntary and involuntary euthanasia - where the person with disability is threatened by the decisions of others.

The slippery slope, the wedge, the flood gate, the domino effect - these are the metaphors employed to describe the argument that once we legislate for voluntary euthanasia, a whole host of other practices - such as non-voluntary and involuntary euthanasia - will come flooding out which go way beyond what was intended.

But, this interpretation is too simplistic, too linear. In fact, our social actions are being influenced by a broad movement in social values, many of which are operating at the same time and in the same arena. It may be that, in settling for the floodgates, the slippery slope, the wedge, that we have settled for the wrong metaphor. For the legalization of voluntary euthanasia is not a spearhead - it is merely an inevitable reflection of the existence of certain social values in our community. These are the same social values which underlie many other practices of a non-voluntary nature which, according to the floodgates approach, will follow the legalization of voluntary euthanasia. Yet, in terms of legality, non-voluntary euthanasia is probably far more legally advanced, even in this country, than is any form of voluntary euthanasia. In fact, if we want to talk in terms of slopes, we might even argue that the slope has been slipping in the opposite direction. The killing of people with disability without their consent is going on now, and it has gone on for hundreds and thousands of years.

But what legalizing euthanasia does, is grant to its ethical underpinnings greater validity. And it is these underpinnings which also give support to non-voluntary and involuntary euthanasia. It is these which impact most markedly upon the lives of people with disability.

It is deeply concerning that the continued threat against the rights and lives of people with disability is perennial. When one considers the implications of why we are about to embark on a Royal Commission into the abuse violence and neglect of people with disability, that high levels of risk of deathmaking is painfully evident. There are significant failures in the attempts at protections and safeguards even within the new system of the National Disability Insurance Agency and the Quality and Safeguards Commission. Reports of neglect caused by mere delays in decision making has resulted in significant harm and detriment to participants in the Scheme.

Deathmaking offered by those who should 'do no harm' is an unforgiveable betrayal yet is more common than one would believe possible. How frequently these offers are rejected or taken is yet to be discovered.

This submission attempts to convey the will and determination that people with disability want to live. They want to have the same experiences, opportunities and lives that all Australians may have, with the supports and understanding and acceptance to do this. They don't want to die. They don't want to be killed.



It is vital that our society examines ways to change our views and mindsets about people with disability, to be patient, to get to know and understand people better so they may exercise the same rights and responsibilities as us all. It is important for the health of our communities and the people within it that we welcome and respond with genuine respect rather than enabling deathmaking.

So much of what lay at the root of this war is devaluation of people with disability as equal part of our common humanity. Examining our collective values on what it means to be part of this humanity is important to recognise and give acknowledgment to the important contribution that all people with disability offer to ourselves as a species. There can be no exceptions to this value or contribution – to deny that we all bring some wealth to our human nature is to deny the cosmos.

