**Submission re: Draft General Comment on Article 6 of the International Covenant on Civil and Political Rights – Right to life**

# **Organization Introduction & Position Statement**

Toujours Vivant-Not Dead Yet (TVNDY) is a nonreligious and nonpartisan organization by and for Canadians with disabilities and our allies. Our goal is to inform, unify and give voice to the disability rights opposition to assisted suicide, euthanasia, and other life-ending practices that discriminate against disabled people.[[1]](#footnote-1) (Throughout this document, the terms “euthanasia” and “assisted suicide” will be used. Euphemisms such as “aid in dying” should be avoided; they are created by promoters of these practices.) Our submission focuses on paragraph 10 of the Draft Comment, which reads as follows:

[While acknowledging the central importance to human dignity of personal autonomy, the Committee considers that States parties should recognize that individuals planning or attempting to commit suicide may be doing so because they are undergoing a momentary crisis which may affect their ability to make irreversible decisions, such as to terminate their life. Therefore,] States should take adequate measures, without violating their other Covenant obligations, to prevent suicides, especially among individuals in particularly vulnerable situations. At the same time, States parties [may allow] [should not prevent] medical professionals to provide medical treatment or the medical means in order to facilitate the termination of life of [catastrophically] afflicted adults, such as the mortally wounded or terminally ill, who experience severe physical or mental pain and suffering and wish to die with dignity. In such cases, States parties must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and, unambiguous decision of their patients, with a view to protecting patients from pressure and abuse.

TVNDY opposes the legalization of assisted suicide and euthanasia (AS/E) because they prove dangerous for, and discriminate against, people with disabilities. Efforts to promote these practices arise from societal devaluation of disabled lives and the misconception that disability is a fate worse than death.

Euthanasia and assisted suicide legislation include eligibility criteria that tend to select disabled people and use government services to end disabled lives; they therefore amount to government approval of killing disabled people. As well, neither procedure can be effectively monitored or restrained once legalized. AS/E is tolerated outside the scope of the laws, and the laws are expanded to make more people eligible.

All major disability rights organizations that have taken a position on assisted suicide have opposed it. Studies have shown that the only safeguard that can offer sufficient protection is prohibition.[[2]](#footnote-2), [[3]](#footnote-3) Recognizing the privilege of a few to control details of their death creates a danger of coerced death for many more.

# **“Disability” Definition**

The United Nations Convention on the Rights of Persons with Disabilities defines a disability as “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [a person’s] full and effective participation in society on an equal basis with others.”[[4]](#footnote-4) Under this definition, every person who asks for assisted death has a disability – including people with a terminal illness. (It should be noted that eligibility for assisted suicide eventually expands beyond the terminal illness for which legislation is usually intended.)

People with disabilities already face life-or-death situations on a regular basis. In addition to health concerns directly linked to a disability, life-threatening secondary complications can be caused by[[5]](#footnote-5):

* inadequate access to health care
* misdiagnosis or mistreatment due to assumptions about disability, and

barriers causing delays or denial of treatment.

Our objections to assisted suicide are divided into four broad categories. Assisted suicide is unnecessary, discriminatory, a false “choice,” and the “safeguards” designed to prevent its abuse are not effective.

# **Assisted suicide is unnecessary.**

Whether assisted suicide is legal or not, a person remains free to commit suicide. Any disabled person can kill themselves unaided, even if only by refusing food and drink. Disabled people must make do with the same messy, violent, potentially ineffective suicide methods everyone else uses. Suicide is not supposed to be easy or pleasant, which is in part why we have a public policy to prevent suicides. States parties are under no obligation to create a program of government-sponsored killing in order to provide “access” to death. States parties *are* obligated to do their best to end suffering, not the people who suffer.

Disabled people also have the right to refuse unwanted medical treatment, either to prevent the inception of treatment or to have treatment withdrawn. Canadian cases in the 1990s established the legal principle that any unwanted medical treatment is equivalent to battery.[[6]](#footnote-6) People likewise have the right to palliative care, even to the point of sedation, to relieve pain and other symptoms associated with dying. Unlike AS/E, withholding or withdrawal of medical treatment makes life or death dependent on the person’s underlying condition. No affirmative, proactive measure is taken to end the person’s life.

# **Assisted suicide is discriminatory.**

## **Discriminatory application of suicide prevention measures**

There is a disparity in societal reactions to suicidal behaviour based on a person’s medical status. When a non-disabled person is suicidal, they are directed towards suicide prevention resources. On the other hand, suicide is assumed to be a “rational” choice for a person with a disability – solely because a disability is present.[[7]](#footnote-7) People with disabilities are at a higher risk of suicide,[[8]](#footnote-8) yet they face substantial barriers when trying to access suicide prevention services. Medical professionals overlook typical sources of stress; problems arising from relationship breakdowns, depression, and isolation are wrongly attributed to disability or its associated life aids.[[9]](#footnote-9) Assisted death virtually guarantees a completed suicide, whereas only about 4% of non-assisted suicide attempts result in death.[[10]](#footnote-10) Since such attempts are generally interpreted as a “cry for help,” AS/E denies people with disabilities this option to signal and get help for extreme distress and dissatisfaction with life. Suicide prevention measures should be applied equally to all people.

## **Inexact and discriminatory definitions of “suffering”**

Physical pain is not commonly a factor in requests for euthanasia and assisted suicide. Pain can almost always be managed by effective palliative care. However, most doctors receive little or no training in relieving pain.[[11]](#footnote-11) In annual reports produced by the state of Oregon’s Health Authority, concerns prompting requests for assisted death include “decreasing ability to participate in activities that make life enjoyable (89.5%),” “loss of autonomy (89.5%),” and “loss of dignity (65.4%).”[[12]](#footnote-12) These issues are all associated with disability; the first two are related to physical barriers and public policy, while the last reflects an ableist view of quality of life. Moreover, use of the term “death with dignity” implies that people who live with an illness or disability somehow lack the dignity common to all. Disabled people do not have to die to be dignified.

## **Assisted suicide and other marginalized groups**

The United Nations’ Universal Declaration of Human Rights affirms the right to life in Article 3[[13]](#footnote-13), as well as the right to freedom from discrimination in Article 7.[[14]](#footnote-14) The intersection of these rights – a critical component of the assisted suicide discussion – has received little attention. In its proposal to allow assisted suicide and euthanasia, the United Nations is not taking sufficient notice of the interaction between multiple forms of discrimination affecting the “choice” made by those who renounce the right to life.

The Convention on the Elimination of All Forms of Discrimination Against Women defines its target as “any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women…of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.”[[15]](#footnote-15) This intersection is already recognized by article 6 of the Convention on the Rights of Persons with Disabilities.[[16]](#footnote-16) Problems often correlated with gender, e.g. difficulty getting good medical care generally, poor pain relief, a higher incidence of depression, and a higher rate of poverty, combine with sexist expectations of self-sacrifice, or the literal need to escape an oppressive situation, to increase women’s vulnerability to AS/E.[[17]](#footnote-17) According to one 2008 investigation, women receive less pain medication in an emergency room setting, and must wait longer for the pain relief they do get.[[18]](#footnote-18) Where assisted suicide is practiced, the demographic of its recipients is skewed. A 2014 study found that Swiss women were more inclined to seek assisted suicide from the country’s right-to-die organizations than men.[[19]](#footnote-19) The majority of people euthanized specifically for psychiatric conditions in the Netherlands are women.[[20]](#footnote-20) Women have higher rates of depression and poverty; gendered societal expectations of self-sacrifice only add to these struggles. Also noteworthy is the over-representation of women among the infamous Jack Kevorkian’s patients.[[21]](#footnote-21)

Interaction between multiple forms of discrimination in the realm of health care can have devastating consequences. The Office of the High Commissioner for Human Rights described abuses faced by minority groups in a 2014 statement on sterilization: “(coerced) sterilization of women living with HIV has been linked to inaccurate information about HIV transmission. Assumptions that disabled people are asexual or sexually inactive is also used as justification for involuntary sterilization. In some countries, transgender people are forced to undergo sterilization to obtain identity documents which reflect their gender identity, as well as to access treatments such as hormone therapy or sex reassignment operations.”[[22]](#footnote-22)

Racial minorities also encounter bias in the health care system – for instance, when receiving pain management. [[23]](#footnote-23), [[24]](#footnote-24) We are concerned that people of colour are more likely to be disproportionately affected by assisted suicide.[[25]](#footnote-25) In the United States, African-American and Hispanic people are at higher risk of death because of the inferior health care they receive, and their under-representation among physicians.[[26]](#footnote-26) A comparison of children with appendicitis indicated that “black patients with moderate pain were less likely to receive any analgesia than white patients.” Black youth in severe pain “were less likely to receive opioids” than their white counterparts.[[27]](#footnote-27) The likelihood of discrimination does not diminish over time. In the United States, approximately 1000 adult patients per year are “involuntarily discharged” from the dialysis clinics necessary to live with chronic or end-stage kidney disease. A person may be banned from all local facilities besides their own clinic, forcing them to travel long distances or visit hospital emergency departments. The most common “discharged” group is people of colour.[[28]](#footnote-28)

# **The “choice” of assisted suicide is an illusion.**

## **Doctors and governments – not the person – make the decision.**

In order to qualify for AS/E, a person must meet certain eligibility requirements established by legislation. The eligibility determination rests in the hands of two or more medical practitioners, based on the accuracy of their diagnosis and prognosis of the medical condition and interpretation of the criteria set by the government. The individual is also dependent on the availability of funding to pay the medical professionals for their time in making the eligibility determination, as well as administering the drugs, keeping records, and filing reports on the outcome. Contrary to the person’s perception, they must give over control and autonomy in a process they claim to be an expression of those same values. At each step, the person could be prevented from achieving their goal. Publicized complaints from people who were rejected for AS/E often lead to public clamour to expand the eligibility criteria, resulting in ill-considered “mission creep” of the AS/E program.

## **Obstacles to autonomy & choice**

True autonomy is impossible in our society. Everyone is dependent on infrastructure, agriculture, manufacturing, shipping and utilities for their daily survival, yet many people cling to a false notion of independence. People with disabilities often encounter obstacles to individual choice in their daily lives. A bias towards institutional care, lack of affordable, accessible housing, inadequate income supports and lack of home-based personal assistance services[[29]](#footnote-29) all detract from the quality of life of people with disabilities. For example, nearly 30,000 Canadians with disabilities live in residential institutions and group homes, rather than their own homes, due to a shortage of affordable housing and support staff.[[30]](#footnote-30) Canadians who do live in their own homes also obtain less assistance than they need. A 2012 Statistics Canada survey revealed that 461,000 people aged 15 or older needed home care “in the 12 previous months for a chronic health condition, but did not receive it.”[[31]](#footnote-31)

The Convention on the Rights of Persons with Disabilities is designed to improve the quality of life of persons with disabilities; the CRPD’s goals and spirit would be undermined by approving AS/E. Article 19 requires states to ensure “access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.”[[32]](#footnote-32) Article 25 calls on states to “provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons…provide those health services needed by persons with disabilities specifically because of their disabilities…(and) require health professionals to provide care of the same quality to persons with disabilities as to others.”[[33]](#footnote-33) States parties’ failure to meet these requirements means disabled people lack real choice and autonomy in their lives, and one cannot make a free choice to die without also having freedom to choose where and how to live.

Financial and social pressure can cause someone to ask for assisted suicide or euthanasia as well. People with disabilities are more likely than those without to be unemployed or live in poverty;[[34]](#footnote-34) this despite Article 28 of the CRPD that calls for “an adequate standard of living.”[[35]](#footnote-35) In the years leading up to her death, Linda Fleming was divorced, dealt with financial problems, had been unable to work due to a disability, was diagnosed with cancer, and was forced to declare bankruptcy. Yet none of these circumstances were perceived to be warning signs that social and psychological supports were necessary to prevent her suicide. Fleming’s assisted suicide was the first approved under Washington’s law.[[36]](#footnote-36)

Finally, effective palliative care services, including pain relief, counselling to deal with psychological, spiritual, grief and family issues, home-health and personal assistance services, can dramatically improve the quality of the end-of-life experience. However in Canada, only 16% to 30% of people who need them have access to palliative care services.[[37]](#footnote-37)

## **Obstacles to “full, free and informed consent”**

The UN Human Rights Council stated in the 2013 Report of the Special Rapporteur on Torture that consent to medical procedures must be “full, free, and informed.” The Council observed that “(structural) inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised.”[[38]](#footnote-38)

Many disabled people remain trapped in long-term care facilities for lack of community-based services. Such facilities are often unsanitary, in poor repair, understaffed and subject to high staff turnover rates. Nursing homes restrict the choices available to residents, and may have policies that amount to inhumane treatment. Meal, wake-up and bed-times are set based on facility schedules, baths may be limited,[[39]](#footnote-39) and toilet paper or adult diapers may be rationed.[[40]](#footnote-40) It is assumed that residents do not know what is best for them, and any aspects of life with which they express dissatisfaction are dismissed as “trivial.”[[41]](#footnote-41) The limitations of institutional life increase the probability of physical, emotional, and financial abuse or neglect.[[42]](#footnote-42) Other sections of this paper describe barriers some patients encounter when accessing proper care and pain relief. Since these situations involve “severe pain or suffering, intent, and involvement of a public official or other person acting in an official capacity,” the terms “torture” and “cruel, inhuman…treatment” apply.[[43]](#footnote-43) If AS/E is perceived as the only way out of unbearable circumstances, consent cannot be “full, free and informed.” AS/E is not an appropriate medical (or humane) response to conditions of torture; nor can the United Nations endorse it as a means of escape.

A variety of additional factors can impede decision-making capacity. Depression has been shown to weaken awareness of positive outcomes while increasing focus on losses in gambling experiment participants.[[44]](#footnote-44) Substance abuse is linked to impulsive behaviour and increased pleasure-seeking.[[45]](#footnote-45) These scenarios make an objective evaluation of one’s current and future state, and thus consent to AS/E, more difficult.

## **Negative messages & societal devaluation**

Someone who becomes disabled later in life is most vulnerable to negative messages about life with a disability and societal devaluation.[[46]](#footnote-46) A period of grief and adjusted self-perception is to be expected. However, tests for psychological competence do not take into account temporary emotional states that may lead to suicidal feelings. The reactions of family, friends, and medical professionals have an enormous impact on how a person adapts to their disability.[[47]](#footnote-47) When these people view disability in a negative light, their judgments interfere with the adjustment process. Given adequate supports and encouragement, most people adjust to their disability and learn to integrate human and technological assistance into their daily routine.[[48]](#footnote-48)

The story of Dan Eley illustrates these points. In 2010, Mr. Eley was on vacation in Colombia when he broke his neck in a diving accident at the age of 32,[[49]](#footnote-49) and became quadriplegic. At first, he wanted to end his life in Switzerland, helped by the non-profit Dignitas. Mr. Eley’s mother, Carolyn, agreed, on the condition that he wait five years before making a final judgment about his quality of life.[[50]](#footnote-50) By 2012, he no longer wished to die. He discovered a new purpose in life after establishing [a non-profit](http://www.daneleyfoundation.org/about/partner-project/) that helps young people in Columbia and the UK access education or employment. Mr. Eley continues to run the organization today.[[51]](#footnote-51)

People with disabilities also face pressure to sign “do-not-resuscitate” orders (DNRs) and other advanced directives that limit life-sustaining treatments.[[52]](#footnote-52), [[53]](#footnote-53), [[54]](#footnote-54) Disability advocate Laura Hershey described the ordeal her friend Ginny experienced when hospitalized for pneumonia. A doctor put a DNR in place without Ginny’s consent, assuming she would rather die than use a respirator if one became necessary to save her life. Life as a wheelchair user was presumed to be too difficult to bear. With help from friends, Ginny was able to clarify her wish to use all available means to save her life.[[55]](#footnote-55)

# **Safeguards don’t work.**

## **Assisted suicide and euthanasia laws are not limited to people who are terminally ill.**

Bill C-14, the Canadian legislation introducing the procedures, stipulates that the recipient’s condition should have reached “an advanced state of irreversible decline” so that death is “reasonably foreseeable.”[[56]](#footnote-56) This safeguard is already being challenged on the grounds that it is unconstitutional.[[57]](#footnote-57) Nothing prevents the definition of “reasonably foreseeable,” nor any other eligibility criteria, from shifting over time.

Even when more precise limits exist, such as restricting eligibility to people with six months to live, they are ineffective. Prognoses of terminal illness are often incorrect. In a 1998 study of medical interns making patient prognoses published by the Annals of Internal Medicine, 17 percent of patients outlived the timeline they were given.[[58]](#footnote-58) Another study in the Journal of the American Medical Association examined patients with three chronic conditions – pulmonary disease, heart failure, and severe liver disease. Researchers found that 70 percent of the 900 patients eligible for hospice care lived longer than six months.[[59]](#footnote-59)

## **Disabled people face a high risk of abuse.**

People with disabilities – including elders – are more likely than non-disabled people to be financially, emotionally and physically abused. A review conducted by the World Health Organization’s Department of Violence and Injury Prevention and Disability concluded that the presence of a mental illness, or physical, intellectual, sensory disability, made such abuses 1.5 times more likely.[[60]](#footnote-60) A study published in Lancet Global Health this year showed that, across 28 countries, approximately 16% of people aged 60 years or older are abused. This mistreatment can take many forms: psychological (11.6%), financial (6.8%), neglect (4.2%), physical (2.6%) or sexual (0.9%).[[61]](#footnote-61)

The introduction of assisted suicide can make an abusive situation lethal. For example, 85-year-old Kate Cheney requested assisted suicide while in the early stages of dementia. After her own physician denied the prescription, a second doctor’s input was sought. The new doctor ordered a psychological evaluation. Ms. Cheney was reported not to have “the very high level of capacity required to weigh options about assisted suicide.” Cheney’s daughter – who was present during the appointment – became “angry” at this result. Ms. Cheney received a second evaluation, which she attended alone. She was deemed to be competent and received the prescription, even though the psychologist believed her “choices may be influenced by her family's wishes and her daughter…may be somewhat coercive.” After a week spent in a nursing home to give her family respite, Ms. Cheney took the lethal prescription and died.[[62]](#footnote-62)

## **Problems in assisted suicide/euthanasia programs**

In jurisdictions where assisted suicide is legal, problems may go undetected for a variety of reasons:

* Doctors sometimes don’t file the required reports. Between June and November 2007, approximately half of all euthanasia deaths (549 of 1040) were reported to the Netherlands review committee.[[63]](#footnote-63) Throughout 2010, 77% of all euthanasia or physician-assisted suicide deaths (3136 of 4050) were reported to the same committee.[[64]](#footnote-64)
* Deaths that violate regulations are often not reported.
  + Once the prescription that will cause death is written, there is no follow-up.[[65]](#footnote-65)
  + Where the cause of death is listed as the person’s medical condition, information is insufficient to indicate the circumstances of death.[[66]](#footnote-66)
  + Data are destroyed, preventing long-range study. When a new annual report is published in Oregon, the data from the previous year is made unavailable.[[67]](#footnote-67)
  + Someone may be euthanized without making an explicit request; this was the case for 431 people in the Netherlands in 2015.[[68]](#footnote-68) In 2013, 1.7% of euthanasia deaths in Flanders, Belgium (105 of 6,188) also occurred without a request.[[69]](#footnote-69)

# **Conclusion**

The United Nations’ proposes allowing assisted suicide and euthanasia as an answer to “severe physical or mental pain and suffering.” We strongly oppose this initiative. AS/E is ultimately rooted in anti-disability discrimination. Disability bias causes disparities in responses to suicidal behaviour. Policies that favour institutionalization over independent living limit the free choice in where and how disabled people live, and therefore their freedom to choose to die. Minority groups contend with multiple forms of discrimination in the health care field that would only become lethal with the introduction of assisted suicide. Furthermore, the often-cited benefit of “autonomy” is not as real as it appears. Access to AS/E is dictated by legal eligibility criteria and judgments of doctors as to whether the person’s condition and ability to consent meet those requirements. An individual still has the option to end his or her life, regardless of assisted suicide legality. Finally, abuses frequently go undetected and safeguards are insufficient to protect people at risk. Taking a strong position against legalizing assisted suicide is the safest course of action, the one most consistent with existing UN policy, and most consonant with support for disability rights.

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