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DEATHS OF INELIGIBLE PEOPLE WITH DISABILITIES ARE NOT “ACCEPTABLE LOSSES”

Several recent events have catapulted questions of access and safety of assisted suicide and euthanasia into the headlines. On January 7, a court began hearing evidence in the legal challenge by Jean Truchon and Nicole Gladu of the eligibility requirement in the Québec and federal laws that the person must be at the end of life or their death must be “reasonably foreseeable.” This week the criminal trial in the killing of Jocelyne Lizotte by her husband Michel Cadotte began as well.

Events in December attracted less media attention, but were no less important. Québec’s Commission on End-of-life care released its third annual report, showing that at least seven ineligible people have been euthanized since the program began in 2015, that procedural safeguards failed in more than 26 cases, and 171 deaths were not reported by doctors. Also in December, McGill University released a Québec study showing that, far from being the last option after palliative care has failed, euthanasia is frequently offered before other options have been tried.

While disability rights leaders like the Council of Canadians with Disabilities and other disability-led groups oppose assisted suicide and euthanasia (AS/E), some individuals and groups representing disability interests support access to "Medical Assistance in Dying." Disability rights activists have worked for 35 years to point out the disproportionate impact of AS/E on disabled people, and the discriminatory beliefs and policies that form the basis of the assisted dying movement. Toujours Vivant-Not Dead Yet is a project of the Council of Canadians with Disabilities to inform, unify and give voice to the disability rights opposition to AS/E.

While not all people with disabilities have a terminal illness, those with terminal illness have disabling conditions that subject them to discrimination and barriers in our society. As well, non-disabled people are excluded from assisted suicide and euthanasia, while many people with non-terminal disabilities are given AS/E, despite end-of-life eligibility requirements.

The disability rights opposition to AS/E is based on a few simple ideas.  First, legalizing AS/E is unnecessary.  Everyone has the right to palliative care, even to the point of sedation. Pain and other unpleasant physical symptoms of disability and terminal illness can be managed with effective palliative care; but that care must be available to everyone who needs it, which is not currently the case.  As well, the reasons most people ask for AS/E are associated with the onset of disability, beliefs about what it means to be disabled, and the public policies that deny adequate in-home supports and shunt people into institutional care, where they are deprived of control over every detail of daily life.  A shift in funding priorities toward consumer-directed in-home personal assistance services, home modifications and accessible communities would go a long way toward easing the existential suffering of people who wish to retain control in their lives.

Disability rights activists also argue that legalizing AS/E creates a discriminatory double standard as it pertains to suicide, and suicide prevention.  Only people with disabilities (whether or not they also have a terminal illness) are deemed eligible for AS/E.  People with disabilities who ask to die are considered to be making a "rational" choice, whereas non-disabled people who express a wish to die are labelled as irrational, in need of suicide prevention intervention, and may even be deprived of their liberty to prevent them from killing themselves.  This double standard is based on the widely-held view that life with a disability is a fate worse than death.

The third principle is that there can be no free "choice" to die as long as people with disabilities do not have a free choice in where and how they live.  As long as discrimination limits our options, choice is an illusion.

And finally, safeguards don't work.  Even the strictest safeguards cannot predict or prevent all eventualities, and none of the statutes currently in effect even comes close to preventing ineligible people from being euthanized, ensuring that doctors report every AS/E, protecting against abuse and exploitation by family members, or any number of hazards associated with allowing the state to establish criteria for who lives and who dies. The failure of safeguards and the deaths of ineligible disabled people should not be counted as “acceptable losses.”

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