



# Report Excerpt: Executive Summary

## The Danger of Assisted Suicide Laws

Part of the Bioethics and  
Disability Series



National Council on Disability

October 9, 2019

# Executive Summary

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## Purpose

**A**s one part of a report series on bioethics, this report presents information on how assisted suicide laws may impact policies and practices related to the delivery of medical interventions and life-saving medical care for people with disabilities.

The purpose of this report is to provide an update to the previous NCD analysis of such laws, to examine whether the NCD predictions about the effect of these laws were correct, and to learn more about the relationship between assisted suicide laws and the provision of life-sustaining medical care and palliative care to people with disabilities. Do misunderstandings about the quality of life and the value of the lives of people with disabilities affect the development and operation of such laws? Are there ways to reduce or eliminate harms, and improve the understanding of policy makers, the medical community, and society in general?

## Background

Promoted as a way to relieve suffering at the end of life, assisted suicide laws, as they have developed in the United States, generally allow physicians to prescribe lethal drugs to patients diagnosed with terminal illness and with a prognosis of 6 months or less to live, if certain

procedural steps are followed. Many national disability organizations have taken positions opposing these laws, due to concerns regarding their impact on people with disabilities.

## Key Findings

### *Safeguards and Their Limitations*

Assisted suicide laws contain provisions intended to safeguard patients from problems or abuse. However, research for this report showed that these provisions are ineffective, and often fail to protect patients in a variety of ways, including:

- Insurers have denied expensive, life-sustaining medical treatment but offered to subsidize lethal drugs, potentially leading patients toward hastening their own deaths.
- Misdiagnoses of terminal disease can also cause frightened patients to hasten their deaths.
- People with the disability of depression are subject to harm where assisted suicide is legal.
- Demoralization in people with disabilities is often based on internalized oppression, such as being conditioned to regard help as undignified and burdensome, or to regard disability as an inherent impediment to

quality of life. Demoralization can also result from the lack of options that people depend on. These problems can lead patients toward hastening their deaths—and doctors who conflate disability with terminal illness or poor quality of life are ready to help them. Moreover, most health professionals lack training and experience in working with people with disabilities, so they don't know how to recognize and intervene in this type of demoralization.

- Financial and emotional pressures can distort patient choice.
- Assisted suicide laws apply the lowest culpability standard possible to doctors, medical staff, and all other involved parties, that of a good-faith belief that the law is being followed, which creates the potential for abuse.

### ***Lack of Data Collection, Oversight, and Investigation of Mistakes and Abuse***

- There is a substantial lack of data about assisted suicide, due not to lack of research, but to unnecessarily strict privacy and confidentiality provisions in assisted suicide laws.
- Where assisted suicide is legal, states have no means of investigating mistakes and abuse, nor even a complaint mechanism or similar way for the public to report suspected problems.
- Nevertheless, a few important conclusions can be gleaned from the minimal available data, including that assisted suicide laws require no evidence of consent when the lethal drugs are administered.

- Trends show that the minimal amount of data collection that was mandated by earlier state laws is decreasing over time as some newer states adopt less restrictive assisted suicide laws.

### ***How Are Assisted Suicide Laws Viewed by Disability Organizations?***

As with many issues and social movements, individuals are not always in complete unison. Many national disability rights organizations oppose the legalization of assisted suicide. All national groups that have taken a position are opposed. NCD respects the rights of individuals to their opinions and acknowledges that some people with disabilities support, or are not opposed to, assisted suicide laws, but NCD, for the reasons described in this report, maintains its position opposing them.

### ***Recent Issues and Events: Bringing the NCD Position Up to Date***

- A Sense of Congress resolution, H.Con.Res.80, was introduced in the 115th Congress to express that assisted suicide puts those most vulnerable at risk of deadly harm. It garnered both Democrat and Republican cosponsors.
- The risks of abuse are significant under assisted suicide laws and safeguards are not effective.
- Loosening of the rules is increasing in various aspects of assisted suicide laws—in eligibility, in who can prescribe lethal drugs, in whether waiting periods are mandatory, and in how people with depression are treated—and in turn, each of these increases the risk of danger.

- Evidence of suicide contagion in states where assisted suicide is legal has been found in several studies.
- Improvement in palliative care in the last decade has the potential to reduce requests for assisted suicide, though palliative care should be more socially oriented and disability informed.
- The criminalization of pain: Due to the opioid crisis, people who depend on opioids to manage pain often find themselves treated like criminals. It may become easier to obtain a prescription to die than one to relieve pain.

## Key Recommendations

### Congress

- Congress should pass a resolution similar to H.Con.Res.80, introduced in the 115th Congress, to express the Sense of the Congress that assisted suicide puts everyone, particularly people with disabilities, at risk of deadly harm.
  - Congress should amend the Social Security Act to remove Medicaid's statutory bias for institutional long-term care rather than long-term services and supports (LTSS) provided for people living in the community.
  - Congress should explore legislative options to provide home and community-based LTSS through the Medicare program.
  - Congress should consider creating a new, public, long-term care insurance program to pay for a broad range of long-term supports and services, such as personal care aides, home modifications, or assisted living costs.
- Congress should consider legislation for a comprehensive LTSS benefit that is not means tested.

### ***The US Department of Health and Human Services (HHS)***

#### **The Substance Abuse and Mental Health Services Administration (SAMHSA)**

SAMHSA should address the mental health challenges of living with a disability and chronic conditions, including challenges to people with a terminal prognosis, in suicide prevention efforts and education.

#### **The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)**

NIDILRR should conduct research on disability-related risk factors in suicide prevention, as well as research on people with disabilities who request assisted suicide and euthanasia.

#### **HHS Office for Civil Rights (OCR)**

OCR should issue a regulation specifically requiring nondiscrimination in suicide prevention services, which states that physicians must treat a request for assisted suicide or any other form of hastened death the same, regardless of whether or not the patient has a disability; an individual's expression of wanting to die should not be explored any less rigorously or fully solely because the individual has a disability or a chronic or terminal condition.

As part of this nondiscrimination requirement, OCR should make clear that all HHS suicide prevention grants and services must comply with existing disability rights laws, including the ADA, Sections 504 and 508 of the Rehabilitation

Act, and Section 1557, including the provisions requiring accessible communications, so that all videos, documents, and other products ensure access to persons with disabilities.

OCR should issue a clarifying regulation pursuant to Section 504 and Section 1557 and any other relevant federal laws to require physicians to provide people with disabilities with information on the full array of available clinical treatments and available LTSS and to require that referrals to such treatments and services be given if requested. The regulation should require hospitals to create a disability ombudsperson position who is authorized to facilitate communication between healthcare providers and patients with disabilities or their proxies and advocate on the patient's behalf, when required, to ensure that all clinical and LTSS options and choices are made available.

### ***State Legislatures, and State Referenda and Initiatives***

- States should not legalize any form of assisted suicide or active euthanasia.

### ***Primary Care Practitioners, Specialty Providers, Clinics, Hospitals, Laboratories, Diagnostic and Therapy Centers, and Other Healthcare Services***

- Primary care practitioners, specialty providers, clinics, hospitals, laboratories, diagnostic and therapy centers, and other healthcare services must offer a full range of physical, communication, and programmatic access accommodations for patients with disabilities that are in compliance with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that are consistent with culturally competent care.

### ***Medical Schools and Other Healthcare Professional Education and Training Programs***

- Medical school and other healthcare professional education and training programs, including hospice, should require courses on skills and competencies needed to provide quality interprofessional health care to patients with disabilities.

### **Methodology**

The methodology for this study included a stakeholder convening held at the beginning of the project, a literature review of disability studies, medical and social science articles, and media articles in popular newspapers and magazines. The literature review was supplemented by interviews with stakeholders. Further interviews and technical assistance were provided by scholars with expertise on this subject who served on the project's Advisory Panel, and by two disability organizations that have focused on assisted suicide laws for at least two decades.

### **Introduction and Background**

The National Council on Disability (NCD, also "the Council") was an early opponent of the legalization of assisted suicide, having released a forceful, thorough statement in 1997<sup>1</sup> that the Council later reaffirmed in 2005.<sup>2</sup> The dangers and harms to people with disabilities that NCD identified appear to be as significant today as they were in 1997 and 2005.

NCD's concerns, then and now, stem from the understanding that if assisted suicide is legal, some people's lives, particularly those of people with disabilities, will be ended without their fully informed and free consent, through mistakes, abuse, insufficient knowledge, and the unjust lack

of better options. No safeguards have ever been enacted or proposed that can prevent this outcome.

In 1997, the US Supreme Court left the question of whether to legalize assisted suicide, and “the . . . challenging task of crafting appropriate procedures . . .” to the “‘laboratory’ of the States.”<sup>3</sup> As of this writing, Oregon (1994), Washington State (2008), Vermont (2013), California (2015), Colorado (2016), Washington DC (2016), Hawaii (2018)<sup>4</sup>, New Jersey (2019), and Maine (2019) have legalized assisted suicide. A Montana Supreme Court decision (2009) may provide a

defense against criminal charges for physicians who practice assisted suicide.<sup>5</sup>

Oregon was the first state to legalize assisted suicide. The Oregon “Death with Dignity Act” is the statutory model for all assisted suicide laws and proposed bills in the United States. For this

reason, the Oregon model is a key focus throughout this report.

Most proponents and supporters of assisted suicide, like most of the medical establishment,

still hold a deficit-oriented medical framework of disability instead of sociopolitical models of disability where disability can be neutral, an identity, the basis for a community, or ever-evolving depending on barriers and supports in the environment. Moreover, proponents have been slow to recognize how crucial LTSS can be, with home and community-based services (HCBS) providing many people with options that make longer lives far more appealing, even when they have been diagnosed (or misdiagnosed) as having a terminal illness. And most assisted suicide laws reference “dignity.” The idea that hastened death is a pathway to dignity for people facing physical decline reveals the public’s extreme disparagement of functional limitations and a perception that “dignity” is not possible for people who rely on supports, technology, or caregivers to be independent or alive.<sup>6</sup> Many hold the attitude that a person with a disability may be better off dead than alive. For example, in 2012, an op-ed author in the *Boston Phoenix* reported that, on the night that her boyfriend with a significant disability suddenly became ill and later died in the emergency room, a nurse murmured to her, “Maybe it’s better this way.” She continued,

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*The Oregon “Death with Dignity Act” is the statutory model for all assisted suicide laws and proposed bills in the United States.*

### States Where Assisted Suicide Is Legal

- Oregon (1994)
- Washington (2008)
- Vermont (2013)
- California (2015)
- Colorado (2016)
- District of Columbia (2016)
- Hawaii (2018)
- New Jersey (2019)
- Maine (2019)
- Montana (2009 MT Supreme Court decision may provide a defense against criminal charges for doctors who participate in an assisted suicide)

I'll never forget that moment. We'd been watching a movie together a few hours before. We had plans to go clubbing. *Maybe it's better this way?*<sup>7</sup>

These types of misperceptions and misunderstandings are rooted in disability prejudice, and in the context of assisted suicide

laws and policies, they create a deadly mix that poses multifaceted risks and dangers to people with disabilities as well as people in other vulnerable constituencies. These include people who are aging, are underinsured, have chronic or progressive conditions, and/or lack privilege in other ways.<sup>8</sup>