



The Danger of Assisted Suicide Laws

Part of the Bioethics and
Disability Series



National Council on Disability

October 9, 2019

National Council on Disability (NCD)
1331 F Street NW, Suite 850
Washington, DC 20004

The Danger of Assisted Suicide Laws: Part of the Bioethics and Disability Series

National Council on Disability, October 9, 2019

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202-272-2004 Voice

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

October 9, 2019

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit *Assisted Suicide Laws and Their Danger to People with Disabilities*, part of a five-report series on the intersection of disability and bioethics. This report, and the others in the series, focuses on how the historical and continued devaluation of the lives of people with disabilities by the medical community, legislators, researchers, and even health economists, perpetuates unequal access to medical care, including life-saving care.

NCD has long opposed assisted suicide laws. In 1997, after a thorough review of the forms of discrimination people with disabilities experienced in American society, NCD issued *Assisted Suicide: A Disability Perspective*, opposing legalization of assisted suicide, concluding that the evidence indicated that the interests of the few people who would benefit from assisted suicide were “heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities.” Instead, NCD called for a comprehensive, fully-funded, system of assistive living services for people with disabilities.

Eight years later, in 2005, reaffirmed its position opposing the legalization of assisted suicide. The nation had observed the implementation of the Oregon assisted suicide law, and the evolution of cultural attitudes toward so-called “mercy killing,” of both the medical and non-medical variety. Jack Kevorkian was convicted of second-degree murder for committing active euthanasia of a man with ALS, utilitarian euthanasia advocate Professor Peter Singer was hired for a prestigious bioethics chair at Princeton University, two movies favorably depicting euthanasia of people with quadriplegia won Oscars, and numerous courts upheld the right of a guardian to starve and dehydrate a severely brain injured but healthy woman in Florida. The dangers to people with disabilities based on the devaluation of their lives was ever clearer.

Assisted Suicide Laws and their Danger to People with Disabilities reexamines the issue of assisted suicide in light of NCD’s prior reports, brings NCD’s earlier analysis up-to-date, and finds that the dangers and harms that NCD identified in 1997 and 2005 are at least as significant today. The report describes, among other things, a double standard in suicide prevention efforts where people with disabilities are not referred for mental health treatment when seeking assisted suicide, while people without disabilities receive such referrals. The report recommends steps that must be taken at the federal and state levels to ensure that people with disabilities have a system of assisted services and

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supports; that medical providers inform patients seeking assisted suicide of these supports; and that medical providers receive training in disability competency and disability-risk factors for suicide.

NCD stands ready to assist the Administration, Congress and federal agencies to ensure that people with disabilities are not steered toward ending their lives due to a lack of supports and medical providers who are not required to help patients find alternatives.

Respectfully,

A handwritten signature in black ink that reads "Neil Romano". The signature is written in a cursive style with a large, stylized initial "N".

Neil Romano
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Acknowledgments

This report is part of a series of reports on bioethics and people with disabilities which was developed through a cooperative agreement with the Disability Rights Education & Defense Fund (DREDF). The National Council on Disability (NCD) appreciates the work of Marilyn Golden, Senior Policy Analyst, DREDF, who contributed her expertise in the development of this report, and who shepherded the entire report series in cooperation with NCD. We also thank those who participated on the Advisory Panel, in interviews, and in the stakeholder convening, whose knowledge and willingness to share information helped make this series possible.

Executive Summary

Purpose

As 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 1997¹ that the Council later reaffirmed in 2005.² 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.”³ As of this writing, Oregon (1994), Washington State (2008), Vermont (2013), California (2015), Colorado (2016), Washington DC (2016), Hawaii (2018)⁴, 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.⁵

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.⁶ 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,

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?*⁷

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.⁸

Acronym Glossary

ADA	Americans with Disabilities Act
ALS	amyotrophic lateral sclerosis
DREDF	Disability Rights Education & Defense Fund
HCBS	home and community-based services
HHS	Health and Human Services
I/DD	intellectual and developmental disabilities
LTSS	long-term services and supports
NCD	National Council on Disability
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
OCR	Office for Civil Rights
OPHD	Oregon Public Health Division
PCC	Physicians for Compassionate Care
SAMHSA	Substance Abuse and Mental Health Services Administration



“Legalizing assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death to the socially devalued group.”

—Diane Coleman

Chapter 1: Safeguards and Their Limitations

This chapter addresses what safeguards assisted suicide laws provide. Are these safeguards effective, and if not, what are their limitations?

What Are the Safeguards in Assisted Suicide Laws?

US assisted suicide laws and bills contain a number of provisions pointed to by their supporters as tight safeguards. For example, Laurie Wilcox of New Jersey, a nurse “disabled by [a] life-shortening disease,” wrote in an op-ed reprinted on the website of Compassion & Choices, a leading organization promoting assisted suicide in the United States,

In fact, the New Jersey legislation has more than a dozen safeguards to prevent abuse and coercion. For example, two doctors must confirm the terminal prognosis, that the requesting person is mentally capable of making their own medical decisions and is physically able to self-ingest the medication, the person must make two oral requests for the medication, as well as a written request witnessed by two people who can confirm the person is voluntarily making the request.⁹

With the New Jersey legislation passing in 2019, these represent the most current best practices for safeguards for assisted suicide laws in the United States.

Are There Problems with These Safeguards?

There are many ways that provisions of safeguard provisions in US assisted suicide laws are inadequate, can be readily circumvented, or fail to protect patients from pressure to end their lives.

Many experts have contributed important analyses of this key issue. For example, as documented by Drs. Herbert Hendin and Kathleen Foley as early as 2008,

The Oregon law seems to require reasonable safeguards regarding the care of patients near the end of life, which include presenting patients with the option for palliative care; ensuring that patients are competent to make end-of-life decisions for themselves; limiting the procedure to patients who are terminally ill; ensuring the voluntariness of the request; obtaining a second opinion on the case; requiring the request to be persistent, i.e., made a second time after a two week interval; encouraging the involvement of the next

of kin; and requiring physicians to inform OPHD [the Oregon Public Health Division] of all cases in which they have written a prescription for the purpose of assisted suicide.

The evidence strongly suggests that these safeguards are circumvented in ways that are harmful to patients.¹⁰

Following are important ways that asserted safeguards under assisted suicide laws can and have been disregarded and even sidestepped entirely.¹¹

Assisted Suicide Instead of Medical Treatment

The Oregon model assumes that if an eligible patient doesn't want assisted suicide, they can receive medical treatment. But there is evidence that patients, including people with disabilities, are being denied treatment by insurers and offered assisted suicide instead, just as NCD predicted in 1997.¹²

When assisted suicide is legalized in the context of the US healthcare system, it immediately becomes the cheapest treatment. Direct coercion is not necessary. If insurers deny, or even simply delay, approval of expensive life-sustaining treatment, patients can be steered toward hastening their deaths—and sometimes insurers help them to do so. For example, in 2008, Barbara Wagner, a 64-year-old great-grandmother,

was fighting recurring lung cancer. Her physician prescribed Tarceva to extend her life. Studies showed that the drug provided a 30 percent increased survival rate for patients with advanced lung cancer, and patients' 1-year survival rate increased by more than 45 percent. But the Oregon Health Plan (Oregon's Medicaid program) sent Wagner a letter saying the Plan would not

cover the beneficial chemotherapy treatment "but . . . it would cover . . . physician-assisted suicide."¹³

Around the same time, fellow Oregonian Randy Stroup was prescribed Mitoxantrone as chemotherapy for his prostate cancer. His oncologist said the medication's benefit has been shown to be "not huge, but measurable"; while the drug may not extend a patient's life by very long, it helped make the final months of life more bearable by

decreasing pain.¹⁴ Yet Stroup also received a letter saying that the Oregon Health Plan would not cover his treatment, but would pay for the cost of, among other things, his assisted suicide.¹⁵

These treatment denials were based on an Oregon Medicaid rule that denies surgery, radiotherapy, and chemotherapy for patients with less than a 5 percent expectation of 5-year survival. H. Rex Greene, MD, former Medical Director of the Dorothy E. Schneider Cancer Center at Mills Health Center in San Mateo, California and a former member of the AMA

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When assisted suicide is legalized . . . , it immediately becomes the cheapest treatment. Direct coercion is not necessary. If insurers deny, or even simply delay, approval of expensive life-sustaining treatment, patients can be steered toward hastening their deaths . . .

Ethics Council, called this rule “an extreme measure that would exclude most treatments for cancers such as lung, stomach, esophagus, and pancreas. Many important noncurative treatments would fail the 5-percent/5-year [criterion].”¹⁶ These rules also presume that all physician estimates for life expectancy are always correct (see “Mistakes in Diagnosis and Prognosis” below), and that a shortened life span is not worth living.

Recent bills and laws to legalize assisted suicide have included a newer provision to prohibit an insurer from informing a patient in the same communication, such as a letter, about both a denial of treatment and the availability of lethal drugs. For example, the 2015 California law states: “Any [insurance carrier] communication shall not include both the denial of treatment and information as to the availability of aid-in-dying drug coverage.”¹⁷

Shortly after California’s assisted suicide law went into effect in 2016, Stephanie Packer, a mother of four and a cancer patient, was denied her previously approved chemotherapy treatment, but offered low-cost suicide pills by her insurer by phone instead.¹⁸ About a year later, Dr. Brian Callister, associate professor of internal medicine at the University of Nevada, said he tried to transfer two patients to California and Oregon for procedures not performed at his hospital. The patients were not terminal, but “would have become terminal without the procedures.” Representatives from the two patients’ insurance companies denied both transfer requests in separate phone calls. The insurance medical directors told Callister they would cover neither the procedures nor the transfers, but asked if he’d considered assisted suicide for his patients,

though Callister did nothing to prompt such a suggestion.¹⁹

Mistakes in Diagnosis and Prognosis

Assisted suicide laws assume that doctors can estimate whether or not a patient diagnosed as terminally ill will die within 6 months. Actually, it is common for medical prognoses of a short life expectancy to be wrong. “Terminal Uncertainty,” a 2009 article in the *Seattle Weekly*, summarized a number of studies illustrating this problem and the reasons for it.²⁰

The personal experiences of this problem are also noteworthy. For example, Jeanette Hall of Oregon was diagnosed with cancer in 2000 and told she had 6 months to a year to live. She knew about the assisted suicide law, and asked her doctor about it, because she didn’t want to suffer. Her doctor encouraged her not to give up, and she decided to fight the disease. She underwent chemotherapy and radiation. Eleven years later, she wrote, “I am so happy to be alive! If my doctor had believed in assisted suicide, I would be dead. . . . Assisted suicide should not be legal.”²¹ As of this writing in 2019, Jeanette Hall is alive and doing well, 19 years after her terminal diagnosis.²²

In another example, disability rights advocate Anita Cameron, Director of Minority Outreach for Not Dead Yet, testified against an assisted suicide bill in New York, regarding her mother, Alice Bozeman. Cameron stated, “In June 2009, while living in Washington State, my mother was determined to be in the final stages of Chronic Obstructive Pulmonary Disease and placed in hospice. Two months later, I was told that her body had begun the process of dying. My mother wanted to go home to Colorado to die, so the arrangements were made. A funny

thing happened, though. Once she got there, her health began to improve! Almost 8 years later, she is still alive, lives in her own home in the community and is reasonably active.”²³

In a final example, Laurie Hoirup, a California woman with a life-long significant disability of spinal muscular atrophy, survived by decades several terminal prognoses given to her by physicians over the course of her life, including one that she would never reach adulthood. She was a devoted wife, mother, and grandmother, served as director of a center for independent living and as chief deputy director of the State Council on Developmental Disabilities, and was a published author. She was an active disability advocate, including

offering testimony on several occasions against California assisted suicide bills. She was the acting head of the Association of California State Employees with Disabilities. Hoirup finally

died at the age of 60 from accidental causes.²⁴ Her situation is illustrative and not unusual in the disability community.

Faulty prognoses pose considerable danger to people with new or progressive disabilities or diseases, who may often be misdiagnosed as terminally ill, but who, like Laurie Hoirup, could potentially outlive these prognoses by years or even decades. Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in their lives.²⁵ However, adaptation takes considerably longer than the mere 15-day waiting period required by Oregon-model assisted

suicide laws. During an initial period after a new disability, and before one learns that a disability does not preclude a good quality of life, it can be too easy, where assisted suicide is legal, to make an irrevocable choice to die.

A counterexample was Dr. Richard Radtke, a well-known academic oceanographer in Hawaii for many years. Dr. Radtke had a very disabling form of muscular sclerosis for more than 35 years. In the early period after his diagnosis, with an extremely limiting disability, doctors often misclassified him as terminally ill, and he experienced severe depression for 2 years. Had the option for assisted suicide been available at that time, he later acknowledged that he

would have chosen it and died many years earlier. Instead, Radtke went on to a successful academic career, and was a happily married father. After his retirement, he served as president of a charitable

foundation, and was grateful for the length and scope of his life, until he finally died of natural causes in 2012.²⁶

Further, regarding mistakes in diagnosis and prognosis, the definition of “terminal” in Oregon model laws only require two doctors’ estimates that the patient will die within 6 months. There is no requirement that the doctors consider the likely impact of medical treatment, counseling, and other supports on survival. For example, a successful adaptation may necessitate referral to state and community resources, such as social workers, VA benefits, assistive technology, or grants to create an accessible home. Adaptation may also require counseling or antidepressant

Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in their lives.

medication. Yet referrals to services, and to supportive counseling, are not included as safeguards in assisted suicide laws.

Also, while terminal predictions of some conditions, such as some cancers, are fairly well established 1 or 2 months before death, this is far less true 6 months out, as the law provides—and is even less true for other diseases.²⁷

Depression and Demoralization

People with the disability of depression are subject to harm where assisted suicide is legal. Yet the law's supporters frequently suggest that, as a key safeguard, depressed people are ineligible for assisted suicide.²⁸

Michael Freeland of Oregon was a case study of the potential for harm. With his permission, his case was extensively documented by Dr. Gregory Hamilton, a Distinguished Fellow of the American Psychiatric Association. This summary of Michael Freeland's story is excerpted from Hamilton's documentation:²⁹

At age 62, Michael Freeland had a 43-year medical history of significant depression and suicide attempts. After receiving a diagnosis of terminal lung cancer, he requested assisted suicide. Dr. Peter Reagan, an assisted suicide advocate who was associated with the group Compassion in Dying (later renamed Compassion & Choices), a leading pro-assisted suicide organization, prescribed

lethal drugs to Michael Freeland without even a cursory psychological evaluation. Reagan commented that he did not think such a consultation would be "necessary" for Mr. Freeland, according to Freeland's daughter, who accompanied him to an appointment.

Freeland then made a telephone call to Physicians for Compassionate Care (PCC), a medical group dedicated to improving the care of seriously ill people without resorting to assisted suicide. The call was answered by a PCC volunteer who was trained in counseling people with serious illness. With encouragement from a doctor

[T]he definition of "terminal" in Oregon model laws only require two doctors' estimates that the patient will die within 6 months. There is no requirement that the doctors consider the likely impact of medical treatment, counseling, and other supports on survival.

recommended by PCC, Freeland underwent chemotherapy and radiation treatment, which alleviated his cancer symptoms significantly. PCC volunteers arranged for him to receive adequate pain care,

other appropriate medication, and 24-hour attendant services. A PCC volunteer stayed in touch with him to offer encouragement, as did some old friends, who began to visit him daily. He also received assistance to resolve other health and personal problems. With this multifaceted assistance, his suffering abated, as did his wish to take lethal drugs. He was able to fully reconcile with his daughter, who had been estranged from him during certain periods. In the end, he lived 2 years post-diagnosis; he eventually died of natural causes.

What happened to Michael Freeland highlights parts of the complex web of problems for people with depression and demoralization under assisted suicide laws.

First, the work of PCC with Michael Freeland illustrates what Dr. Herbert Hendin, an international expert on suicide intervention, stated in Congressional testimony:

A request for assisted suicide is . . . usually made with as much ambivalence as are most suicide attempts. If the doctor does not recognize that ambivalence as well as the anxiety and depression that underlie the patient's request for death, the patient may become trapped by that request and die in a state of unrecognized terror. . . .

Patients who request euthanasia are usually asking in the strongest way they know for mental and physical relief from suffering. When that request is made to a caring, sensitive, and knowledgeable physician who can address their fear, relieve their suffering, and assure them that he or she will remain with them to the end, most patients no longer want to die and are grateful for the time remaining to them. Advances in our knowledge of palliative care in the past twenty years make clear that humane care for the terminally ill does not require us to legalize assisted suicide and euthanasia. Study has shown that the more physicians know about palliative care, the less apt they are to favor legalizing assisted suicide and

“Study has shown that the more physicians know about palliative care, the less apt they are to favor legalizing assisted suicide and euthanasia.”

euthanasia. Our challenge is to bring that knowledge and that care to all patients who are terminally ill.³⁰

Thus, the challenge for doctors is to find out what is behind the patient's request to hasten death, and address it. Yet, where assisted suicide is legal, such a request begins a legally sanctioned process. The depression remains undiagnosed, and the only treatment consists of a lethal prescription.³¹

Another significant concern is assisted suicide laws' very limited requirement that the attending physician must *inform* the patient of alternative options, including “comfort care, hospice care,

palliative care, and pain control”;³² but no physician or other party is required to actually *provide* the alternative treatments, services, and programs. And nonmedical supports,

such as long-term services and supports (LTSS), including home health care and assistance, as well as counseling, may be even more important—though many doctors do not have knowledge of such services and supports to a degree that allows them to fully inform people requesting lethal drugs.

The 1997 NCD statement addressed the major gap between informing the patient of alternative options and those alternatives actually being available and provided:

. . . In proposals to legalize assisted suicide, proponents are sometimes willing to agree that a decision to choose suicide must be

preceded by a full explanation of the programs, resources, and options available to assist the patient if he or she does not decide to pursue suicide.³³

Many people with disabilities find this to be a very shallow promise when they know that all too often the programs are too few, the resources are too limited, and the options . . . often nonexistent. Society should not be ready to give up on the lives of its citizens with disabilities until it has made real and persistent efforts to give these citizens a fair and equal chance to achieve a meaningful life.³⁴

These unmet support needs impact people with terminal illness as well.

As mentioned above, additional factors complicate the situation of depression in the context of assisted suicide. Though assisted suicide requests from people with terminal illness, like most suicide requests, are usually based on fear and depression,³⁵ Oregon's statistics show that, for example, in 2017, only 3.5 percent of those who reportedly died under the Oregon law were referred by the prescribing doctor for a psychological evaluation before a prescription

for lethal drugs was written.³⁶ In 2018, it was 1.8 percent.³⁷ Some other states refer even fewer people. In Colorado, only 1 out of the reported 69 people (1.4 percent) was so referred.³⁸

Moreover, only 6 percent of Oregon psychiatrists were confident they could diagnose

depression after one visit, according to one study.³⁹ Yet the definition in the Oregon assisted suicide law of psychiatric "counseling" permits only one visit. And another study showed that primary care

physicians are generally not experts in diagnosing depression at all.⁴⁰

Another key factor, poorly understood, is that people with depression can, in fact, receive lethal drugs under assisted suicide laws, because

such patients are still technically eligible as long as they are deemed *legally* competent; that is, "competent and not suffering from a psychiatric or psychological disorder or depression *causing impaired judgment.*"⁴¹

[Emphasis added.] Thus,

patients with depression may be considered legally competent to decide to end their lives merely because the depression doesn't impair their *legal* competency. As Hendin and Foley pointed out, "Reducing the psychiatric consultation to the issue of competency ignores all the other psychological factors that go into the

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request for assisted suicide.”⁴² And these factors can impair decision-making judgment, even if that impairment of judgment does not quite meet the threshold for legal incompetence.

A study in the *British Medical Journal* further documented that people with depression are receiving lethal drugs under assisted suicide laws. As Dr. William Toffler wrote in the *Wall Street Journal Online* in 2015,⁴³

A . . . *British Medical Journal* [study] examined 58 Oregonians who sought information on assisted suicide. Of them, 26% met the criteria for depressive disorder, and 22% for anxiety disorder. Three of the depressed individuals received and ingested the lethal drugs, dying within two months of being interviewed. The study’s authors concluded that Oregon’s law “may not adequately protect all patients [with a mental illness].”⁴⁴

And further, is the depression clinically diagnosable, or subclinical? Recent research and clinical work suggest that affective states such as demoralization also pressure people toward wanting to die, yet these states are even less likely than clinical depression to be addressed. Demoralization may be an unrecognized and unaddressed precipitant of requests to die.⁴⁵

Lastly, given the history of forced treatment and institutionalization that psychiatric survivors have experienced, it is important to be clear that, when discussing the serious matter of

depression in the context of assisted suicide laws, the goal is not to force any treatment on people who may have depression and/or who may wish to hasten their deaths, including but not limited to medication, institutionalization, or hospitalization.⁴⁶ Rather, what’s needed is a variety of available medical treatment options as well as home and community-based service options, ideally self-directed, from which the individual genuinely benefits—similar to the range of services that Dr. Greg Hamilton and his staff assisted Michael Freeland to find.

Demoralization and Internalized Oppression of People with Disabilities

[I]nternalized oppression; in other words, being conditioned by dominant cultural values to believe that needing help is undignified, less than fully human, and again, burdensome to others.

Dr. Carol Gill, Ph.D., Professor Emerita in the Department of Disability and Human Development at the University of Illinois at Chicago, has discussed how, for some people with disabilities, demoralization, similar

in some ways to depression, is one of the most powerful, yet difficult, risk factors regarding assisted suicide. Dr. Gill’s works discuss internalized oppression; in other words, being conditioned by dominant cultural values to believe that needing help is undignified, less than fully human, and again, burdensome to others. She has asked, “How can one provide safeguards for that?”⁴⁷

For some people with disabilities, demoralization or depression may be caused by the long-term struggle against socially constructed obstacles to one’s life goals, social devaluation of disability, social isolation, financial concerns, and lack of support to make life

meaningful. Further, feeling like a burden is a potent risk factor for demoralization. According to Dr. Gill, unfortunately, the tendency to equate disability with burdensomeness is pervasive in our society, placing people with disabilities and seriously ill people at substantial risk of demoralization.⁴⁸

This appears to be borne out in studies. For example, an article on patient requests to hasten death from the *Archive of Internal Medicine* stated,

Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable . . . : “I’m inconveniencing, I’m still inconveniencing other people who look after me and stuff like that. I don’t want to be like that. I wouldn’t enjoy it, I wouldn’t. I wouldn’t. No. I’d rather die.”⁴⁹

A related factor is the absence of alternatives for control in the face of an advanced or terminal condition.

If an individual’s only alternatives to assisted suicide are nursing home placement, burned-out family care, or suffering in isolation, assisted suicide may seem preferable. As the example of Michael Freeland illustrated, no current assisted suicide law requires that resources be made available for real alternatives, including advocacy to help individuals understand that they deserve, and can have, better options than death.

Doctor Shopping

US assisted suicide laws allow physicians to prescribe lethal drugs to patients who meet certain legal criteria relating to terminal illness and with the agreement of a second doctor. If the first doctor believes legal criteria have not been met and denies a patient’s request for lethal drugs, patients may continue to seek additional

physicians until they find one who will obtain a colleague’s concurrence and prescribe a lethal dose.

And if heirs, family members, or caregivers are pushing people with

disabilities, terminal illness, or chronic illness toward assisted suicide, but the patients’ primary care physician refuses the request, they, too, can seek additional physicians until they find one who will grant it. “Shopping” for doctors is part of the

US healthcare system, and an important right, though in the context of assisted suicide, it creates an opportunity for sidestepping safeguards in the law.

One example is Kate Cheney, who was age 85

and experiencing early dementia when she died by assisted suicide under Oregon’s law. Her own physician had declined to provide a lethal prescription. But her managed care provider then found a second physician who ordered a psychiatric evaluation, which found that Cheney lacked “the very high level of capacity required to weigh options about assisted suicide.” Cheney’s request was again denied, and her daughter

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“became angry.” Another evaluation took place, this time with a psychologist who insisted on meeting Cheney alone. The psychologist deemed Cheney competent while noting that her “choices may be influenced by her family’s wishes and her daughter . . . may be somewhat coercive.” Cheney soon took the lethal drugs and died.⁵⁰ The documented concerns about Cheney’s dementia and a “somewhat coercive” adult daughter were not sufficient to stop the assisted suicide process, though either should have been disqualifying.

There is evidence suggesting that a key role is played by organizations that support assisted suicide, which have helped patients and their families through the assisted suicide process, and which can refer interested parties to doctors who will tend to approve such requests. Compassion & Choices (formerly known as the Hemlock Society⁵¹) was

involved in 75 percent to 90 percent of Oregon’s reported assisted suicides, according to their own data, until they stopped releasing such information to the public after 2008.⁵²

Family and Economic Pressures

Oregon and Washington State statistics, minimal though they are, show a high rate of patients’ concern about being a burden on others.⁵³ Yet, assisted suicide laws have no protections for patients when financial or emotional pressures, sometimes from family, distort patient choice. Examples of economic pressures and abuse include Linda Fleming and Thomas Middleton.

Linda Fleming, diagnosed with stage four pancreatic cancer, was the first person to use the Washington State assisted suicide law. Despite the fact that she had financial problems, had been unable to work due to a disability, and was forced to declare bankruptcy, the Director of Compassion & Choices of Washington said that her situation presented “none of the red flags” that might have given his group pause in supporting her request for death.⁵⁴

Thomas Middleton was diagnosed with amyotrophic lateral sclerosis (ALS),⁵⁵ moved into the home of Tami Sawyer in July 2008, and died by assisted suicide later that same month.

Middleton had named Sawyer his estate trustee and put his home in the trust. Two days after he died, Sawyer listed the property for sale, sold it, and deposited the \$90,000 proceeds into her own personal account, not Thomas Middleton’s trust

account.⁵⁶ A federal investigation into real estate fraud exposed this abuse. Sawyer was indicted for first-degree criminal mistreatment and first-degree aggravated theft, partly over criminal mistreatment of Thomas Middleton.

Of those in Oregon who reportedly died from ingesting a lethal dose of medication in 2018, more than 9 out of 168 (7.3 percent) mentioned “financial implications of treatment” as a consideration.⁵⁷

As Dr. Carol Gill explains, not all of the family-related pressures are malicious or even explicit. As one example, supportive family members can find it difficult to accept functional

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impairment in a loved one. The desire to end the perceived suffering of a family member can seem altruistic, but nonetheless, can have the effect of pressuring the ill person to hasten their death. Also, a worried family may be supportive, but can still lead an ill family member to feel pressure toward an early exit from life simply to avoid high medical bills from depleting scarce financial resources. And further, disability is associated with suffering, even by many loving family members. Consequently, while family members may not express the idea in such explicit terms, the notion that people with disabilities are “better off dead” is a common view that may further erode safeguards.⁵⁸

Good Faith

The Oregon law lists procedural steps for the patient, doctors, and other participants, and then provides broad immunity for everyone involved:

No person shall be subject to civil or criminal liability or professional disciplinary action for participating in good faith compliance with ORS 127.800 to 127.897. This includes being present when a qualified patient takes the prescribed medication to end his or her life in a humane and dignified manner.⁵⁹

Thus, the Oregon model protects anyone, including physicians, from all criminal and civil

liability if they provide lethal drugs based on a “good faith” belief that statutory criteria are met. Every other US assisted suicide law and proposal includes a similar provision. As the NCD 2005 statement pointed out, this is the lowest

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culpability standard possible, even below that of negligence, which is the minimum standard governing all other physician duties.⁶⁰ This same protection from liability is also provided to family members,

caregivers, and other associates of the patient, regardless of their actions.

It is virtually impossible to disprove a claim of good faith, making all other safeguards effectively unenforceable. For example, the individual may be depressed, or may be responding to coercion from other people. But if everyone involved claims they acted in a good faith belief that all circumstances complied with the law, they have no liability, since it is virtually impossible to

disprove a stated claim of good faith, which is merely a personal belief. If the liability standard for physicians under assisted suicide laws were negligence, as it is for all

other medical practices, then physicians might be found negligent in these situations.

Physicians Hold Disproportionate Power

Doctors are respected authority figures for most people and can influence a patient just by bringing up assisted suicide as a potential

treatment, implicitly suggesting that it could be appropriate for them.

As stated in the *Journal of the American Medical Association*,

Physicians can influence patients, even in ways they may not consciously appreciate. Patients seeking physician-assisted suicide may seek validation to end their lives. Indeed, studies have shown that socially isolated vulnerable individuals seek social support and contact through visits with their physicians. [And] physicians can influence patients based on the physician's own potential fears of death and disability.⁶¹

The NCD 1997 position statement addressed prejudice by healthcare professionals in detail:

People with disabilities' lives are frequently viewed as valueless by others, including members of the medical profession. People with disabilities are often harassed and coerced to end their lives when faced with life-threatening conditions, even if the conditions are imminently treatable; others have had their lives involuntarily terminated by medical personnel. These practices manifest blatant prejudice and are a virulent form of the discrimination that the Americans with Disabilities Act and other laws condemn. Legal and medical authorities should denounce and

prohibit any attempt to pressure, harass, or coerce any individual to shorten her or his life; they should certainly proscribe any action to terminate an individual's life taken without that person's full, voluntary, and informed consent, whether it be called "suicide," "mercy killing," "letting nature take its course," or some other euphemistic term. And certainly there should be official condemnation and cessation of practices by which people with disabilities are pressured to sign "Do Not Resuscitate" consent forms, or such forms are hidden within a stack of admission and consent

papers in the hope that [patients] will sign them without paying attention to what is being signed.⁶²

As mentioned above, health professionals, in general, receive little training about life with a disability, or disability resources. Most know

little more than the general public about daily life with a disability and options for supports. Thus, they don't know how to recognize and intervene when patients experience disability-related demoralization as described above.⁶³

Even with benign intentions, physicians generally dispense only medical facts: diagnosis, prognosis, and medical treatment options. Very rarely can they address nonmedical, quality-of-life interventions that are often much more important for managing an advanced chronic or terminal condition and making continued life desirable. For example, John Bach's research showed

[R]esearch showed that health professionals who had negative assessments of quality of life for people with disabilities were less likely to offer, or even know much about, options to extend and enhance life with a disability, such as noninvasive ventilation.

that health professionals who had negative assessments of quality of life for people with disabilities were less likely to offer, or even know much about, options to extend and enhance life with a disability, such as noninvasive ventilation.⁶⁴

Further, “incurable” is often assumed to mean unbearable or hopeless. Because most disabilities are not curable, and disability is equated with suffering, the public and many health professionals conclude that life with disability is hopeless.⁶⁵ Thus, a patient with a pre-existing physical or sensory disability might be perceived differently than someone who is not already disabled, but is diagnosed with a terminal disease such as cancer, in that physicians might allow the disability to be a reason to more easily accept that the patient’s request for death is

valid, due to their a perception that living with a disability is not worthwhile.

All of this can contribute to further erosion of the supposed safeguards in the operation of assisted suicide, once it is legalized.

Safeguards Are Gradually Diminishing

Assisted suicide proposals tend to promise strict safeguards that will, in theory, avoid any dangers or problems. But once passed, the restrictions tend to be ineffective or inadequate, as shown in this chapter. Chapter 2 will discuss how requirements for data collection have been decreased in recent statutes. And Chapter 4 will show how rules governing assisted suicide are being loosened, and how new proposals may reduce them further.

Chapter 2: Lack of Data Collection, Oversight, and Investigation of Mistakes and Abuse

This chapter addresses how assisted suicide laws and proposals in the United States address data collection and analysis. Do they provide adequate oversight? Do they establish a way to investigate mistakes and abuse? Do their data reveal anything useful? And what else is needed?

Minimal Data and Scant Oversight

Many key questions about assisted suicide laws cannot be answered because of the substantial lack of data, including both quantitative and qualitative data, on the medical and demographic profiles of people who have sought and used assisted suicide. This is not due merely to the lack of research, but because of the very strict privacy and confidentiality requirements that are structured into every assisted suicide law to date.

As a *Michigan Law Review* article stated under the heading “Excessive Secrecy;”

OPHD has focused more on patient-doctor confidentiality than on monitoring compliance or abuse. The agency has

developed confidentiality measures unique to physician-assisted suicide which appear to be unnecessarily secretive and limit the potential for thorough research into the dimensions and context of this practice as it unfolds. . . . Medical standards require openness about facts, research data, and records to assess the appropriateness of treatment. The anonymity and secrecy

Medical standards require openness about facts, research data, and records to assess the appropriateness of treatment. The anonymity and secrecy about physician practice of assisted suicide makes such an assessment impossible.

about physician practice of assisted suicide makes such an assessment impossible. If physician-assisted suicide is to be part of the medical treatment for terminal illness, why are existing patient-doctor confidentiality rules

not sufficient . . . ? Restricting access to information about the indications for assisted suicide, patient data, radiologic documentation, and specific drug therapy limits the opportunity to establish an objective standard of care, provides excessive protection to the physician and, in the name of confidentiality, leaves the patient vulnerable.⁶⁶

Consequently, it is difficult to understand the personal, financial, medical, and psychological circumstances of people who request and use assisted suicide. If it were available, this information would enable all parties to better interpret why and how assisted suicide is carried out and what interventions or information might improve the options of doctors, patients, and their families. It would enable the public to better understand if there have been any medical complications during administration of assisted suicide drugs, as well as other problems associated with this practice.

As the NCD 2005 statement pointed out, and as the annual brief statistical reports from Oregon make clear, the state has not, and in fact, cannot assess the extent of nonreporting or noncompliance with the law's purported safeguards. The Oregon Health Authority reports are based on forms filed with the state by the physicians who prescribe lethal doses and the pharmacies that dispense the drugs. As the early reports admitted:

Underreporting and noncompliance is . . . difficult to assess because of possible repercussions for noncompliant physicians reporting to the division.⁶⁷

This odd justification seems to be stating that doctors are unlikely to report their own lack

of compliance with the law. It also implies that physicians may circumvent safeguards or not follow procedures, including mandated reports, because authorities refrain from providing any oversight or follow-up. Given that physicians are already protected by the law and cannot be held negligent, this is especially remarkable.

Similarly, the state has no way for the public, family members, or other healthcare professionals to report suspected problems, nor even a means of investigating mistakes and abuse. As the Oregon Department of Health and Human Services stated:

We are not given the resources to investigate [assisted suicide cases] and not only do we not have the resources to do it, but we do not have any legal authority to insert ourselves.⁶⁸

One consequence, which applies to all assisted suicide laws to date, is that important questions go unasked, such as why some doctors refuse to assist

patients in suicide. Doctors who said "no" may have concluded that a patient did not meet legal requirements—essential information to evaluate a law's outcomes. Further, none of these states interview family members or friends to learn about the physical and emotional status of those who died, nor do they interview or collect any information from patients prior to their deaths.⁶⁹

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Another significant problem with data collection is the secrecy created by a common provision in assisted suicide laws for the last decade concerning death certificates, and the ability of physicians to falsify them so they do not show assisted suicide as the actual cause of death. This provision in Connecticut bills in 2015 and 2019 prompted that State's Division of Criminal Justice to enter the debate. While not taking a position on the overall bill both times, the Division asked the legislature for deletion of this provision:

Section 9(b) effectively mandates the falsification of death certificates under certain circumstances. It states: "The person signing the qualified patient's death certificate shall list the underlying terminal illness as the cause of death." This is simply not the case; the actual cause of death would be the medication taken by or given to the patient. This language contradicts the death certificate form itself, which states for the person making the certification: "On the basis of examination, and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner stated." . . . The practical problem for the criminal justice system and the courts will be confronting a potential Murder prosecution where the cause of death is not accurately reported on the death certificate.⁷⁰

As the Oregon Department of Health and Human Services stated: "We are not given the resources to investigate [assisted suicide cases] and not only do we not have the resources to do it, but we do not have any legal authority to insert ourselves."

Daniel Callahan, Senior Research Scholar and President Emeritus of the Hastings Center, has written:

In the case of Oregon, we have been assured that all is well, that no abuses are occurring. . . . If you know, just know, there are no abuses, why bother? Regulations of that kind, protected from public scrutiny, but with the ring of authority and oversight, are a Potemkin village form of regulatory obfuscation. They look good, sound good, feel good, but have nothing behind them.⁷¹

As Maryland state Senator Bob Cassilly wrote in the *Baltimore Sun* in 2019:

The [Maryland] doctor assisted suicide bill . . . gives undue influence to the health care industry and prevents even close

family members from uncovering the facts or taking any action to protect a loved one's interests.

Consider a possible scenario of a brother, George, who wants to find out why his sister, June, recently diagnosed with cancer, was unexpectedly found dead on her kitchen floor only days after her diagnosis. June's death certificate would simply indicate that she died of her illness many months earlier than doctors had first advised, making no mention of the poison she ingested. George would have no access

to any records of the conversations June had with the doctor provided by June's insurance company.⁷² George would never know that June's doctor told her that she could elect expensive treatment, paid in part by her insurer, to extend June's life but that in doing so June would likely become a considerable burden on her family and friends. George would never know that in June's distraught mental state her doctor advised that she could avoid becoming a burden by taking . . . very inexpensive pill[s], paid for by her insurance company, to end her life. George would never know that, despite June's considerable mental anguish over the decision to take her own life, she was never provided access to a mental health counselor nor did any outside doctor review the terminal diagnosis. George would also never know that all of those who influenced June's decision to end her life were employed by the same health care provider who stood to gain financially from June's quick death: the advising doctor, the doctor tasked to prescribe the poison, and two hospital staff who witnessed June sign the written consent. If George was sufficiently alarmed and tried to file a lawsuit, he would find that he could not obtain any of the relevant medical records and that the hospital and doctors are immune from suit so long as George cannot prove they acted in bad faith, an impossible burden given that all of the facts rest with June and the records George cannot obtain.⁷³

Proponents of assisted suicide frequently state that no abuses, problems, or even medical complications have ever occurred under these

laws. For example, current and former governors of Hawai'i stated:

With more than 30 years combined of practice in the authorized states, there has not been a single instance of documented abuse of medical aid in dying. Two decades of rigorously observed and documented experience in Oregon shows us the law has worked as intended, with none of the problems opponents had predicted.⁷⁴

Given the lack of data collection and the absence of transparency, one cannot turn to official records to document such problems. In fact, quite a few problems, complications, and even abuses have been documented, by either the media, patients and their families, or other concerned watchdogs; some of these are described throughout this report. The Disability Rights Education & Defense Fund (DREDF) compiled approximately 16 examples in various categories, including "Doctor Shopping Gets Around Any 'Safeguards,'" "Depression," "Economic Pressures and Coercion," "Self-Administration," "Deadly Mix Between Our Broken Healthcare System and Assisted Suicide," "Breakdown in Rules Attendant to Changing the Law," "Medical Complications," and "Impacts by Doctors and Their Quality of Care."⁷⁵

Rather than correcting any of these fundamental problems, OPHD responded to pressure from pro-assisted suicide advocates to stop using the term "assisted suicide." OPHD had originally employed this term, commonly used in the legal and medical literature, for 7 years on its website and in its annual reports. But Compassion & Choices, in the wake of polling data that public support for assisted

suicide decreases if the word “suicide” appears, successfully pressured OPHD in 2006 to switch to more nebulous terms such as “persons who use the Oregon Death with Dignity Act.” The war over terminology for assisted suicide, which persists to this day, traces back to these events.⁷⁶

Conclusions Regarding the Data That Is Available

Even the minimal data provided by Oregon demonstrates several important points. For one, it shows that, except for the first year, people whose illnesses did not result in death within 6 months have received lethal prescriptions in all 20 years the assisted suicide law has been in effect.⁷⁷ Washington State reports comparable results,⁷⁸ and no other states to date have made this data public.

Further, reasons for requesting assisted suicide that sound like a cry for help with disability-related

concerns appear to be ignored. The top five reasons doctors give for their patients’ assisted suicide requests are not pain or fear of future pain—that alone is noteworthy—but psychological issues that are all-too-familiar to the disability community: “loss of autonomy” (95.5 percent), “less able to engage in activities” (94.6 percent), “loss of dignity” (87.4 percent), “losing control of bodily functions” (56.5 percent), and “burden on others” (51.9 percent).⁷⁹

It should be noted that the “reasons” are not directly gathered from the individuals themselves but are gathered from proxies (their physicians) after assisted suicides have already occurred. This is a concerning source of potential error, without any way to validate the reports. Moreover, the fact

that the reporting forms include these particular check boxes to indicate patients’ reasons means that these reasons were viewed as acceptable from the beginning of the laws’ implementation. Yet they are based on an uninformed analysis of how to address disability-related issues.⁸⁰

And perhaps most importantly, the Oregon data reveal that there is no required evidence of consent or self-administration of lethal drugs. In about half the reported cases, the Oregon Health Authority reports state that no healthcare provider was present at the time of ingestion of the lethal drugs or at the time of death.⁸¹ This means there is no way for authorities to know whether the lethal dose was self-administered and consensual. Therefore, although self-administration is touted as one of

the key “safeguards,”⁸² in about half the cases, there is no evidence of consent. If the drugs were, in some cases, administered by others

without consent, no one would know. See more about this key issue in Chapter 4.

Trends in Data Collection Show Decrease over Time

Possibly due to public discussion and debate over what has been gleaned from the minimal data under the Oregon law, the trend over time is to collect and/or report even less data.

For example, certain data in states that legalized assisted suicide more recently is collected but not reported to the public. In Oregon and Washington State, the first states to legalize assisted suicide (Oregon in 1994 and Washington State in 2008), some general, minimal data about a patient’s reason(s) for

[T]here is no way for authorities to know whether the lethal dose was self-administered and consensual.

requesting lethal drugs is collected and reported annually. Washington State's 2017 Annual Report, for example, stated that leading reasons for requesting assisted suicide were losing autonomy, being less able to engage in activities that make life enjoyable, loss of dignity, and being a burden on family, friends, and caregivers. More than 50 percent of patients cited were concerned about being a burden on others.⁸³ But in California, which legalized assisted suicide in 2015, while this data is collected, it is not required to be publicly reported—and the state has not reported this information voluntarily, so it remains unknown.

Another California example concerns a provision in the law characterized by Rita Marker, Executive Director of the Patients Rights Council, as “extremely dangerous.”

“443.19. (a) The State Department of Public Health shall collect and review the information submitted . . . The information collected shall be confidential and shall be collected in a manner that protects the privacy of the patient, the patient's family, and any medical provider or pharmacist involved with the patient under the provisions of this part. **The information shall not be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding.**” [Emphasis added.]

The first sentence . . . would protect the privacy of patients and individuals participating in doctor-prescribed suicide. However, the second sentence (highlighted in bold) is new. [It] could protect any person who causes a vulnerable patient's death, even if the person's actions were in violation of [California's] End of Life Option Act.

For example, if a family member finds out that someone coerced a loved one into signing the written assisted-suicide request and then forced the loved one to take the lethal drugs after [they] were mailed to the patient's home, [this] provision would actually prohibit any investigation into the loved one's death.

This new wording sets the stage for massive patient abuse and complete protection for those engaged in criminal activity that culminates in a patient's death. Absolutely no information related to the patient's death could be disclosed to law enforcement or any other investigating body.

Nothing in any other state proposal [until this point in time] has ever contained this type of language.⁸⁴

The later Hawaii law (2018) contains a similar provision.⁸⁵

Chapter 3: How Are Assisted Suicide Laws Viewed by Disability Organizations?

The disability community is highly diverse, and not every disability group is actively speaking out about assisted suicide laws, or even working on the issue. However, every prominent national disability organization that takes any position on assisted suicide laws is in opposition. Many of these well-established organizations are predominantly managed and directed by people with disabilities, widely respected for their advocacy, and reflect diverse disability leadership. Included are the National Council on Independent Living, The Arc of the United States, the American Association of People with Disabilities, United Spinal Association, Not Dead Yet, ADAPT, the Association of Programs for Rural Independent

Living, and the DREDF. (See a complete list of national organizations that oppose assisted suicide laws.⁸⁶) Research has not revealed any examples of national disability organizations—whether or not they are led by people with disabilities—that are in favor of such laws. However, there is also a wide range of disability organizations that do not take any position on assisted suicide laws, particularly if it is not a priority for their work.

As with many issues and social movements, various individuals are not always in complete unison. Some people with disabilities do support these laws in whole or in part, but their views have not been echoed by established national disability rights organizations.

Chapter 4: Recent Issues and Events: Bringing the NCD Position Up to Date

Over the last 25 years, there has been a vigorous policy debate in state after state over proposed assisted suicide laws. In many states, multiconstituency coalitions have come together to oppose assisted suicide laws that include disability advocates, physicians, faith-based organizations, and other groups.

Far more state proposals are rejected than passed, often due to education and advocacy efforts about the dangers and harms of assisted suicide laws by the coalitions described above.

According to the Patients Rights Council,

[S]ince Oregon legalized assisted suicide in 1994, many states have rejected assisted-suicide measures,

some multiple times. Since January 1994 [until] the end of January 2019, there have been 269 legislative proposals in more than 39 states . . . Yet, over and over again, bills were either defeated, tabled for the session, withdrawn by sponsors, or languished with no action taken.⁸⁷

For example, in 2018, assisted suicide proposals in 19 states were defeated, while only Hawaii's passed. In 2017, proposals in 27 states

were defeated; none passed. A complete listing of US assisted suicide proposals is maintained by the Patients Rights Council.⁸⁸

Several key evolving issues in the assisted suicide debate were raised in a 2015 California court decision (brought before assisted suicide was legalized there). The judge held that "Most states make it a crime to assist suicide. . . . They are long standing expressions of the States' commitment to the protection and preservation of all human life." (Glucksberg, at p. 710.) The

decision continued,

Far more state proposals are rejected than passed, often due to education and advocacy efforts about the dangers and harms of assisted suicide laws by the coalitions described above.

It is one thing to take one's own life, but quite another to allow a third person assisting in that suicide to be immune from

investigation by the coroner or law enforcement agencies.

In such a case, the state has a legitimate competing interest in protecting society against abuses. . . . It is the interest of the state to . . . protect the lives of those who wish to live . . . (Donaldson, at p. 1622)

Since "Aid in Dying" is quicker and less expensive [than other treatment options], there is a much greater potential for its abuse,

e.g., greedy heirs-in-waiting, cost containment strategies, impulse decision-making, etc. . . . Further, “Aid in Dying” creates the possible scenario of someone taking his life based upon an erroneous diagnosis of a terminal illness, which was, in fact, a misdiagnosis . . . After all, doctors are not infallible.

Furthermore, “Aid in Dying” . . . could have the unintended consequence of causing people who are not terminally ill . . . to view suicide as an option in their unhappy life. For example, . . . a bullied transgender child, or a heartsick teenaged girl whose first boyfriend just broke up with her,

questioning whether life is really worth living. These children may be more apt to commit suicide in a society where the terminally ill are routinely opting for it. . . .” (Donaldson, at p. 1623.)⁸⁹

Sense of Congress Resolution

In the US House of Representatives in 2017, Congressman Brad Wenstrup introduced H.R. Con. Res. 80, “Expressing the sense of the Congress that assisted suicide . . . puts everyone, including those most vulnerable, at risk of deadly harm. . . .” It garnered both Democrat and Republican cosponsors in equal numbers.⁹⁰ NCD wrote a letter in support of this resolution.

Other key evolving issues and noteworthy events in the assisted suicide debate include the following examples.

The Risks of Abuse

Disability abuse⁹¹ and elder abuse⁹² are rising problems. NCD has recently released several reports documenting such abuse. Elder law attorney Margaret Dore has written that the Washington State assisted suicide law “invites coercion.” According to her analysis, where assisted suicide is legal, an heir or abusive caregiver can steer someone toward it, witness the request, pick up the lethal dose, and even, in the end, give the drug—because when the lethal agents are administered, no witnesses are required.⁹³

[W]here assisted suicide is legal, an heir or abusive caregiver can steer someone toward it, witness the request, pick up the lethal dose, and even, in the end, give the drug—because when the lethal agents are administered, no witnesses are required.

This surprising fact, a part of every assisted suicide proposal and law, was underscored by the Patients Rights Council in discussing a recent bill:

Patients would have no protection once the prescription is filled. The patient’s health care provider

is not required to be present when the patient takes the lethal drugs. There is no way to know who, if anyone, is present or what actually takes place leading up to the patient’s death. The patient could be tricked or forced into taking the overdose. And no one would ever know. Why aren’t there any protections at the most important part of the process?⁹⁴

As John Kelly, a leading disability rights advocate and writer working against assisted suicide laws, and the Director of Second

Thoughts Massachusetts, pointed out, “For there to be any real safeguard against abuse, officials would need to investigate the home situation.”⁹⁵

However, as discussed in Chapter 2, no assisted suicide laws to date authorize any type of investigation of alleged abuse, nor do they even include a means for the public to report suspected mistreatment.

Loosening of the Rules

Proposals to legalize assisted suicide are gradually growing less and less protective of public safety, and thus, their legalization would pose increased dangers. Loosening of the rules is occurring in a number of different ways. Examples include:

Eligibility Determinations. The definition of “terminal” in most assisted suicide statutes requires that two doctors predict that the person will die within 6 months. Many conditions will or may become terminal if certain medications or routine treatments are discontinued. The list of conditions found eligible for assisted suicide in Oregon, according to annual reports, has grown over the years to include: neurological disease, respiratory disease, heart/circulatory disease, infectious disease, gastrointestinal disease, endocrine/metabolic disease (e.g., diabetes), arthritis, arteritis, sclerosis, stenosis, kidney failure, and musculoskeletal system disorders.⁹⁶ But people with many such conditions would not die if properly treated.

As one advocate explained,

In legislation that we have seen to date, it is far too easy to qualify for assisted suicide. Most set the bar at anyone who, with or without treatment, would have six months to live. Using myself as an example, if I were to stop managing my diabetes, I would easily meet this standard. I am not alone; this expansive definition includes a great many people with disabilities who will happily live for

[N]o assisted suicide laws to date authorize any type of investigation of alleged abuse, nor do they even include a means for the public to report suspected mistreatment.

Conditions Eligible for Assisted Suicide in Oregon

- Neurological disease
- Respiratory disease
- Heart/circulatory disease
- Infectious disease
- Gastrointestinal disease
- Endocrine/metabolic disease (e.g., diabetes)
- Arthritis
- Arteritis
- Sclerosis
- Stenosis
- Kidney failure
- Musculoskeletal system disorders.

Note: People with many such conditions would not die if properly treated.

decades with proper treatment. This is a definition which leaves people [with disabilities] wide open to potential abuse.⁹⁷

A recent Hawaii bill had no requirement for a second doctor, often termed the consulting physician, to confirm the patient's diagnosis or eligibility for assisted suicide. All actions could be carried out by a single attending physician. In the end, this bill failed to pass, though a bill passed the following year that did require a consulting physician's concurrence.⁹⁸ Further, as of this writing in 2019, an Oregon bill to broaden its law, HB 2232, would define *terminal disease* as "a disease that will, within reasonable medical judgment, produce or substantially contribute to a patient's death."⁹⁹

Almost anyone with a chronic condition or disability would be eligible under that definition.

Authority to Prescribe Lethal

Drugs. Some recent assisted suicide proposals would allow nonphysicians to prescribe lethal drugs. For example, a 2019 bill in New Mexico would have allowed a "health care provider,"¹⁰⁰ defined as a physician, an osteopathic physician, a nurse licensed in advanced practice, or a physician

assistant to diagnose a patient's terminal disease and to prescribe the lethal drugs for assisted suicide.¹⁰¹ And the Hawaii law, as originally proposed, would have permitted advanced practice registered nurses, as well as doctors, to be "attending provider[s]" who could diagnose a patient's terminal disease and prescribe lethal drugs.¹⁰²

Waiting Periods.

The Oregon model requires a waiting period of 15 days after lethal drugs are initially requested. This has been touted as a way to allow considerations of alternatives and protect vulnerable

individuals. Yet some recent bills are moving away from this protection. For example, a recent bill in New York State would make it possible for the patient to receive the lethal drugs within a day after the diagnosis of

a terminal illness is confirmed.¹⁰³ As of this writing in 2019, a bill in Oregon would also create exceptions to the waiting period.¹⁰⁴

People with Depression.

As of this writing, an amendment to a Maryland bill¹⁰⁵ would require psychiatric evaluations, geared toward determining if a mental state such as depression is causing impaired judgment. Compassion & Choices issued a press release calling this and other amendments "excessive."¹⁰⁶ In response,

[A]n Oregon bill to broaden its law, HB 2232, would define terminal disease as "a disease that will, within reasonable medical judgment, produce or substantially contribute to a patient's death."

[A] recent bill in New York State would make it possible for the patient to receive the lethal drugs within a day after the diagnosis of a terminal illness is confirmed.

five Maryland state senators from the Democratic Party released a statement saying, "By deeming mental health evaluations as 'excessive,' Compassion and Choices is saying that the success of this flawed proposal is more important than attempts to protect those [people] who have a mental illness. We are asking that if you share OUR commitment to mental health, please [contact] Committee members . . . [to vote] NO on . . . Senate Bill 311."¹⁰⁷ [Emphasis in original.]

Expansion is most overt in the few countries outside the United States that permit assisted suicide and other forms of hastened death, such as active euthanasia (lethal injections by doctors). These countries include the Netherlands, Belgium, and Canada.¹⁰⁸ As Rita Marker pointed out, "The true relevance for the US of developments in other countries is seeing how fast this moves and how it's promoted for those who can't even request it themselves."¹⁰⁹ The countries permitting this include the Netherlands, Belgium, and Canada.¹¹⁰

To illustrate these two consequences of expansion, the Dutch example provides the longest experience with assisted suicide in any country. Although it remained technically illegal until 2002, the Netherlands first began to legally tolerate assisted suicide in the early 70s.¹¹¹ Today, active euthanasia has almost completely replaced assisted suicide.¹¹² Dr. Herbert Hendin

documented how assisted suicide and lethal injections have become not the rare exception but the rule for people with terminal illness in the Netherlands. Hendin was one of only three foreign observers given the opportunity to study these medical practices in the Netherlands in depth. He stated in Congressional testimony:

Over the past . . . decades, the Netherlands has moved from assisted suicide to euthanasia, from euthanasia for the terminally ill to euthanasia for the chronically ill, from euthanasia for physical illness to euthanasia for psychological

distress, and from voluntary euthanasia to nonvoluntary and involuntary euthanasia. Once the Dutch accepted assisted suicide, it was not possible legally or morally to deny . . . active . . . euthanasia [lethal injections] to those who could not

effect their own deaths. Nor could they deny assisted suicide or euthanasia to the chronically ill who have longer to suffer than the terminally ill or to those who have psychological pain not associated with physical disease. To do so would [have been seen as] a form of discrimination.

Involuntary euthanasia has been justified as necessitated by the need to make decisions for patients not competent to choose for themselves. . . . The Rummelink report [the Dutch government's commissioned study of the problem] revealed that in over

[A]n amendment to a Maryland bill would require psychiatric evaluations, geared toward determining if a mental state such as depression is causing impaired judgment. Compassion & Choices issued a press release calling this and other amendments "excessive."

1,000 cases, of the 130,000 deaths in the Netherlands each year, physicians admitted they actively caused or hastened death without any request from the patient. . . . In [many] of these cases . . . , physicians gave the patient's impaired ability to communicate as their justification for not seeking consent.¹¹³

Further on the subject of loosening the rules, Hendin also testified,

Legal sanction creates a permissive atmosphere that seems to foster not taking the guidelines too seriously. The notion that . . . American doctors . . . would follow guidelines if assisted suicide were legalized is not borne out by the Dutch experience; nor is it likely given the failure of American practitioners of assisted suicide to follow elementary safeguards in cases they have published.¹¹⁴

Double Standard in Suicide Prevention

Diane Coleman, president and founder of Not Dead Yet, a grassroots disability organization opposed to legalizing assisted suicide, developed the important critique that the

public image of severe disability as a fate worse than death . . . become[s] grounds

for carving out a deadly exception to longstanding laws and public policies about suicide [prevention] services. . . . Legalizing assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death to the socially devalued group.¹¹⁵

Evidence of Suicide Contagion

Before Oregon legalized assisted suicide, its suicide rate was similar to the national average. Yet by 2010, Oregon's suicide rate was 41 percent above the national average. In states overall, assisted suicide laws are associated, on average, with a 6 percent increase in a state's total suicide rate.

Studies show an increased rate of general suicide in states where assisted suicide is legal. In Oregon, government reports show a statistical correlation between assisted suicide under the Oregon law and an increase in other suicides. Before Oregon legalized assisted suicide, its suicide rate

was similar to the national average. Yet by 2010, Oregon's suicide rate was 41 percent above the national average.¹¹⁶

In states overall, assisted suicide laws are associated, on average, with a 6 percent increase in a state's total suicide rate.¹¹⁷

Dr. Aaron Kheriaty, associate professor of psychiatry and director of the medical ethics program at the University of California at Irvine School of Medicine, pointed out, "[Such] results should not surprise anyone familiar with the literature on the social contagion effects of

suicidal behavior. You don't discourage suicide by assisting suicide . . . [P]ublicized cases of suicide can produce clusters of copycat cases, often disproportionately affecting young people, who frequently use the same method as the original case."¹¹⁸ This dynamic, known as the Werther Effect, was cited as a danger of assisted suicide by Judge Gregory W. Pollack in his decision in the 2015 California lawsuit quoted at the beginning of this chapter.

Suicide Prevention and Disability

In 2014, the State of Connecticut issued the "Connecticut Strategic Plan for Suicide Prevention (PLAN 2020)" to increase the effectiveness of suicide prevention.¹¹⁹ This was the first known suicide prevention effort to specifically address disability issues. Notably, it singled out disability-specific suicide risk factors including:

- Difficulties navigating social and financial services;
- Stress of chronic stigma and discrimination;
- The loss or threat of loss of independent living, and
- Institutionalization or hospitalization.

Further, Plan 2020 included acknowledgement that:

- The active disability community in Connecticut has been vocal about the need for suicide prevention services, including disability cultural competency;
- There may be unintended consequences of assisted suicide legislation on people with disabilities;

- Many assume disability is a fate worse than death; and
- People with disabilities have a right to responsive suicide prevention services.

Plan 2020 recommendations included:

- Training practitioners to develop expertise in working with people with disabilities who are suicidal; and
- Not assuming that suicide is a rational response to disability.

Consequences for People with Intellectual and Developmental Disabilities

Assisted suicide laws also have consequences for people with intellectual and developmental disabilities (I/DD). There is a major emphasis currently in I/DD services on future planning and end-of-life care.¹²⁰ Families and professionals who endorse assisted suicide may advocate for people with I/DD to have this option with guardian consent. This raises complex issues beyond the scope of this study, such as surrogate versus supportive decision making. There is also a history of institutionalization, as was addressed above for psychiatric survivors, which has been shown, in many cases, to violate the Americans with Disabilities Act (ADA) and the Supreme Court Olmstead decision.¹²¹

People of Color, Healthcare Disparity, and Assisted Suicide Laws

There is concern about the impact of assisted suicide laws on people of color, as has been shown both through research¹²² and statements from legislators and other opinion leaders

(see later in this section). This is true despite data from the Oregon Health Authority consistently showing that mostly white, educated, insured people request assisted suicide.¹²³

The Pew Research Center in 2013 found that 65 percent of people in the African American and Hispanic communities oppose these laws.¹²⁴

Anita Cameron explained that “black, indigenous, and [other] people of color” are at particular risk of being harmed by assisted suicide laws.¹²⁵

In the run-up to passage of the California law, opposition from Latino legislators nearly stopped it. For example, Assemblyman Jimmy Gomez

said the bill had insufficient protections for vulnerable patients. He said he grew up without health insurance and

watched his father delay getting treatment for cancer until it was too late. He worried that

uninsured patients would be more likely to choose assisted death because they felt it was their only

treatment option, while those who do not speak English might not fully understand the choice.

“How do we deal with the fact that the system is fundamentally unfair to people in underserved communities?” he said.¹²⁶

In Washington, DC, with half its population being African American, there was significant resistance to an assisted suicide bill. The *Washington Post* quoted Patricia King, a Georgetown Law School professor who has written about the racial dynamics of assisted death, when she said that “Many in the black community distrust the health-care system and fear that racism in life will translate into discrimination in death. . . . Historically, African

Americans have not had a lot of control over their bodies, and I don’t think offering them assisted suicide is going to make them feel more autonomous.” The *Post* continued, “Some worry that blacks, who tend to have less access to treatment and preventive care, may think that ending their lives early is their best option when given a terminal diagnosis.”¹²⁷ An opinion piece in *The Hill* by Dr. Lydia S. Dugdale also linked assisted suicide to the facts of healthcare disparities affecting African American patients. She wrote,

A study . . . found that black women are more than twice as likely as white women

to die from cervical cancer—a disease which is largely preventable. . . .

Still other studies found that blacks are less likely than non-Hispanic whites to be referred for

cardiac procedures, to receive opiate pain medication in the emergency room, or to be referred for evaluation for kidney transplantation once on dialysis. . . .

Each day doctors strive to care for their patients, regardless of race, ethnicity, or socioeconomic status. Many are cognizant of past abuses . . . and are keen to demonstrate that things have changed. But if physician-assisted suicide bills are passed, particularly in places with predominantly minority and vulnerable populations, we may just be adding to the atrocities committed by society and the health profession toward black and Hispanic patients.¹²⁸

“Historically, African Americans have not had a lot of control over their bodies, and I don’t think offering them assisted suicide is going to make them feel more autonomous.”

Improvements in Palliative Care

Palliative care is comfort care that affords relief, as opposed to curative care. In the last decade, the field of palliative care has developed significantly.

One aspect of palliative care is palliative sedation. In rare cases, when other forms of palliative care cannot relieve significant pain or discomfort, the patient can be sedated to the point where the discomfort is relieved while the dying process takes place, in a way that does not cause or hasten death.¹²⁹ This and other aspects of palliative care today can provide a legal solution to significantly painful or uncomfortable deaths that do not endanger others in the way that assisted suicide laws do.

Ideal approaches to palliative care should encompass social and lifestyle interventions as well as medical supports. There has been an increased emphasis on cultural competence as the context in which palliative care should be understood and practiced. Arguably, living with disability entails many cultural and social factors that should be addressed by professionals working with people with functional limitations (and their families) at the end of life. Improvements in palliative care have the potential to reduce requests for hastening one's death.

The Criminalization of Pain

Disability activist Anita Cameron has written about how "Our country is in the midst of an

opioid crisis which has resulted in what I call the criminalization of pain. . . . Many people who depend on opioids . . . to manage pain . . . [find themselves] subjected by doctors to drug testing and pill counting . . . and feel as if they are being treated like criminals." Cameron points out that emergency rooms treat such patients like addicts and drug seekers. As more people experience poor pain management, she argues, it's easy to see that if assisted suicide is legal, this could drive increased requests for lethal drugs. Cameron commented, "How ironic that it may become easier . . . to get a prescription to die than one to relieve pain. . . . Policymakers should

be working to increase access to . . . palliative care, not enacting laws that allow doctors [to hasten . . . deaths]."¹³⁰

Cameron's concerns are echoed by others' findings. In fact, the news media and the Centers for Disease Control have reported

a rise in suicidal thinking and actual suicides among people with chronic pain who are denied the drugs they need, especially among veterans, people in rural areas with limited healthcare choices, and people of color.¹³¹ Also, writers in the *Journal of Palliative Medicine* and the *Journal of the American Medical Association* have written about how patients often fear the prospect of unrelieved pain. Unfortunately, more physicians withhold pain medication because of ungrounded concerns about patient addiction or that higher doses may accelerate death through respiratory suppression. Appropriate pain relief, however, rarely does either.¹³²

[Palliative sedation] and other aspects of palliative care today can provide a legal solution to significantly painful or uncomfortable deaths that do not endanger others in the way that assisted suicide laws do.

Chapter 5: Recommendations

NCD has considered recommending ways to “improve” assisted suicide proposals and laws by making their provisions more stringent, but has decided against doing so, because the Council does not believe that added safeguards, modified safeguards, or indeed safeguards of any kind, will remove the inherent dangers in assisted suicide laws. Also, such a message can be readily confused with the idea that legalized assisted suicide is acceptable as long as its rules are stronger, which is not true. On the contrary, the basic dangers of legalizing assisted suicide are inherent and cannot be eradicated.

Implementation of assisted suicide laws has demonstrated that even the current “safeguards,” which are modest at best, are easily circumvented. Rather than strengthening safeguards, the tendency has been either to propose looser rules or to simply disregard them, notwithstanding the letter of the law. Examples from other countries have also demonstrated that once assisted suicide seems “safe,” then euthanasia and assisted suicide for nonterminal diseases becomes a reasonable next step. Thus, there is no reason to believe that better laws, training of physicians, data collection or safeguards will provide real protection from harms and abuse in any meaningful way.

Congress

Congress should pass a resolution similar to H.Con.Res.80 from 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. Although the Olmstead decision calling for Medicaid home and community-based services rather than institutionalization for people with disabilities has reduced states’ emphasis on institutionalization, the funding bias remains.

Congress should explore legislative options to provide home and community-based LTSS through the Medicare program. Options could include expanding the limited in-home benefit; building on supplemental services recently made available through Medicare Advantage; and

(continued)

Congress, *continued*

creating a new complex care benefit that would deliver a comprehensive range of healthcare services, including LTSS.

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. Consideration should be given to supporting the program through a modest tax, comparable to recently enacted legislation in Washington State.

Congress should consider legislation for a comprehensive LTSS benefit that is not means tested.

Executive Branch

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.

(continued)

Executive Branch, *continued*

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 requiring 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, whether called by these terms or any other terms. States must, rather, ensure a strong healthcare system that includes LTSS for all, including people with disabilities with or without a terminal prognosis; ensure that people with disabilities are protected from discrimination; and provide services that enable independent living and supported self-determination for people with disabilities.

State Agencies That Deal with Suicide Prevention

All state agencies that deal with suicide prevention should address the specific challenges of people with disabilities and people with chronic conditions, including people with a terminal prognosis.

State agencies that deal with suicide prevention should appropriate funding for research to address the challenges of people with disabilities and people with chronic conditions, including people with a terminal prognosis, on disability-related risk factors in suicide prevention, as well as research on gathering data directly from people who request assisted suicide and euthanasia.

Professional Healthcare Practitioners

Professional healthcare practitioners should always inform patients with disabilities, including those with a terminal prognosis and regardless of the cause of their disability, about the full array of clinical treatment options available to them. Patients should also always be informed about and referred to available LTSS, including palliative care, personal care and assistance, counseling, skilled nursing, and other supports available through government programs, health insurance, and community-based sources.

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 ADA and Section 504 of the Rehabilitation Act, and that are consistent with culturally competent care. Similarly, LTSS programs, particularly those provided in a community location, must also ensure physical accessibility and provide any accommodations clients require to participate fully as required by the ADA and Section 504.

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 and should develop a core set of disability competencies based on the Ohio State cultural competency standards¹³³

(continued)

Medical Schools and Other Healthcare Professional Education and Training Programs, *continued*

to facilitate the integration of disability content into healthcare education and training programs, specifically:

- Training on palliative and other end-of-life care, including palliative sedation in the rare cases when patients are dying in unrelievable pain or other significant discomfort.

Core competencies should also include:

- Contextual and conceptual frameworks on disability,
- Professionalism and patient-centered care,
- Legal obligations and responsibilities for caring for patients with disabilities,
- Teams and systems-based practice,
- Clinical assessment, and
- Clinical care over the life span and during transitions.

Endnotes

- 1 National Council on Disability (NCD), “Assisted Suicide: A Disability Perspective Position Paper,” March 24, 1997, <https://www.ncd.gov/publications/1997/03241997>.
- 2 NCD, “Cover Memorandum upon the Reissuance of the NCD Statement Opposing Legalization of Assisted Suicide,” June 9, 2005, <https://www.ncd.gov/publications/2005/cover-memorandum-upon-reissuance-ncd-statement-opposing-legalization-assisted-suicide>.
- 3 *Washington v. Glucksberg*, 521 US 702 (1997) and *Vacco v. Quill*, 521 US 793 (1997).
- 4 Some of these laws became effective in a later year. For example, the Hawaii statute did not become effective until 2019. Our Care, Our Choice Act, 2018 Haw. Sess. Laws Act 2739, § 12 at 39. https://www.capitol.hawaii.gov/session2018/bills/GM1102_.PDF.
- 5 At the federal level, Section 1553 of the Affordable Care Act prohibits discrimination against individuals or institutional healthcare entities that *do not* provide assisted suicide services.
- 6 Carol Gill, Ph.D., and member, Advisory Panel, NCD Bioethics series, personal communication to the author, April 6, 2019, and Carol J. Gill, Ph.D., “Disability, Constructed Vulnerability, and Socially Conscious Palliative Care,” *Journal of Palliative Care* 22, no. 3 (2006): 186–89.
- 7 S. I. Rosenbaum, “Killing with Kindness: Why the Death with Dignity Act Endangers People with Disabilities,” *The Boston Phoenix*, October 31, 2012, <https://dredf.org/wp-content/uploads/2012/08/Boston-Phoenix-on-Question.pdf>.
- 8 Paul Longmore, “The Resistance: The Disability Rights Movement and Assisted Suicide,” in *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003): 178–95.
- 9 Laurie Wilcox, “My Sister and I Are Nurses Who Are Disabled by Life-Shortening Diseases. Let Us Die Our Own Way,” *New Jersey Star Ledger* Opinion, November 13, 2018, <https://www.nj.com/opinion/2018/11/my-sister-and-i-are-nurses-who-are-disabled-by-lif.html>. This is a summary. For example, regarding the California law, the California Medical Association listed its rules in detail. See <https://www.cmadocs.org/store/info/productcd/3459/t/the-california-end-of-life-option-act>.
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life of her seriously ill mother. See *Nederlandse Jurisprudentie* 1973, no. 183, District Court of Leeuwarden, 21, February 21, 1973; translation in Walter Lagerway, *Issues in Law and Medicine*, 3 (1988): 429, 439–42. Her admission that she had given her mother a lethal injection seemed calculated to force public and legal reconsideration of the laws against assisted suicide (Penal Code of the Netherlands, §294) and euthanasia (Penal Code of the Netherlands, §293). While finding Dr. Postma guilty of the crime of mercy killing that was punishable by imprisonment for a maximum of 12 years, the court imposed a 1-week suspended sentence and a week’s probation. The Dutch court relied heavily on expert testimony by the District’s medical inspector who set forth certain conditions “under which the average physician thought euthanasia should be considered acceptable.” Inclusion of those conditions formed the basis for subsequent acceptance of euthanasia and assisted suicide in the Netherlands. The guidelines required that the patient must be considered incurable and experiencing subjectively unbearable suffering; the request for termination of life should be in writing; and there should be adequate consultation with other physicians before death could be induced. See Carlos Gomez, *Regulating Death: Euthanasia and the Case of the Netherlands* (Old Tappan, NJ: Free Press, 1991), 30. Other cases followed, each widening the boundaries and further liberalizing the conditions under which euthanasia and assisted suicide, although remaining illegal, would not be punished. Among the cases was the Alkmaar case (*Nederlandse Jurisprudentie* 1985, no. 106) in which a woman died after requesting death because “her advancing age and physical condition caused her to be dependent on others, thus leading to psychological suffering.” The case gave rise to the 1986 decision by the Hague Court of Appeals that recognized “psychic suffering” and “potential disfigurement of personality” as grounds for induced death. The courts have also exonerated physicians who assisted in the suicides of a young woman with anorexia nervosa (Amelo, *Tijdschrift voor Gezondheidsrecht*, 1992, No. 19) and a woman who was depressed over the death of her two children and the failure of her marriage (Assen, *Nederlandse Jurisprudentie*, 1994, No. 656). This discussion is drawn from the International Task Force on Euthanasia and Assisted Suicide, *Assisted Suicide & Death with Dignity: Past, Present & Future—Part III, International Perspective*, available at http://www.internationaltaskforce.org/rpt2005_3.htm (accessed July 13, 2009). For additional discussion of these and other cases, see Gomez, *Regulating Death*; I. J. Keown, “The Law and Practice of Euthanasia in the Netherlands,” *Law Quarterly Review* 108 (1992): 51–52; Herbert Hendin, *Seduced by Death: Doctors, Patients, and Assisted Suicide* (New York: Norton, 1997); and Jonathan T. Smies, “The Legalization of Euthanasia in the Netherlands,” *Across Borders International Law Journal*, 7 (2004).

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