

No. APL-2016-00129

Index No. 151162/15

Court of Appeals

STATE of NEW YORK

SARA MYERS, STEVE GOLDENBERG, ERIC A. SEIFF,
HOWARD GROSSMAN, M.D., SAMUEL C. KLAGSBRUN, M.D.,
TIMOTHY E. QUILL, M.D., JUDITH K. SCHWARZ, PH.D.,
CHARLES A. THORNTON, M.D., and END OF LIFE CHOICES NEW YORK,
Plaintiffs-Appellants,

v.

ERIC SCHNEIDERMAN, in his official capacity
as Attorney General of the State of New York,
Defendant-Respondent.

**CORRECTED EXHIBIT B: AMICUS BRIEF OF DISABILITY RIGHTS
AMICI: NOT DEAD YET, ADAPT, ASSOCIATION OF PROGRAMS FOR
RURAL INDEPENDENT LIVING, AUTISTIC SELF ADVOCACY
NETWORK, CENTER FOR DISABILITY RIGHTS, DISABILITY RIGHTS
CENTER, DISABILITY RIGHTS EDUCATION AND DEFENSE FUND,
NATIONAL COUNCIL ON INDEPENDENT LIVING, NEW YORK
ASSOCIATION ON INDEPENDENT LIVING, REGIONAL CENTER FOR
INDEPENDENT LIVING, AND UNITED SPINAL ASSOCIATION**

Adam Prizio
99 Washington Avenue, Suite 806B
Albany, NY 12210
(518) 320-7100
(518) 320-7122 (facsimile)
aprizio@gmail.com
Attorney Registration No.: 5481882
Attorney for Disability Rights Amici

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CORPORATE DISCLOSURE STATEMENT

Amici Center for Disability Rights and Regional Center for Independent Living are not-for-profit corporations which are affiliated with one another by a common board of directors.

Amicus Center for Disability Rights is also affiliated with not-for-profit corporation All About You, a home health care agency.

Amicus Center for Disability Rights has no owners, subsidiaries, or affiliates other than the two here mentioned.

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All other Amici are independent not-for-profit corporations, having no owners, subsidiaries, or affiliates.

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INTEREST OF DISABILITY RIGHTS AMICI

Not Dead Yet, ADAPT, Association of Programs for Rural Independent Living, Autistic Self Advocacy Network, Center for Disability Rights, Disability Rights Center, Disability Rights Education and Defense Fund, National Council on Independent Living, New York Association on Independent Living, Regional Center for Independent Living and United Spinal Association (collectively the “Disability Rights Amici”), organizations with members in New York, support the ruling of the Supreme Court and the Appellate Division, as well as the Attorney General’s position that Sections 125.15(3) and 120.30 do not violate any New York constitutional provisions.

As noted by both courts below, this case does not concern the settled issue of the individual’s right to refuse treatment, even if it might result in death. *Myers v. Schneiderman*, 140 A.D.3d 51, 59, 31 N.Y.S.3d 45, 51 (N.Y. App. Div. 2016), *Decision*, pages 7, 10-11. This case concerns only whether there is a New York constitutional right to receive active physician assisted suicide or, as appellants rename it, "physician aid in dying".

Were this Court to reverse the decision of the Court below, New York would soon face a number of related questions, including:

- Why should a constitutional right be limited to people who have a disabling condition that is labeled "terminal"? Why not any disabling condition? Why

not a firm decision to commit suicide by any competent person?

- Why should the constitutional right be limited to providing only lethal medications? Why not lethal injections?
- Why should such a right be limited to "aid" only from doctors? What about family members, friends, or advocates?

Whether a constitutional right to physician-assisted suicide exists must be addressed and understood from the perspective of the class of people who will be most adversely impacted were such a right to be found: people with disabilities, whether their conditions are terminal or not.

Although pain and fear of pain are often raised as the primary reason for enacting assisted suicide laws, the top five reported reasons doctors issue lethal prescriptions are disability-related: “loss of autonomy,” “less able to engage in activities,” “loss of dignity,” “loss of control of bodily functions,” and “feelings of being burden.”¹ “[P]atients’ interest in physician-assisted suicide appeared to be more a function of psychological distress and social factors than physical factors.”²

¹ Oregon’s Death With Dignity Act – 2015, page 6, Oregon Public Health Division <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf> (accessed December 29, 2016)

² William Breitbart, MD et al, *Interest In Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients*, Am. J. Psychiatry 153, 238-242 (1996). See also Robert Pear, *A Hard Charging Doctor on Obama’s Team*, N.Y. Times, April 18, 2009, at A14 (noting that pain is “a common stereotype of patients expressing interest in euthanasia. In most cases... the patients were not in excruciating pain. They were depressed and did not want to be a burden to their loved ones”).

Research has shown that:

[t]he desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self [...] Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable for participants: '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.'³

The Disability Rights Amici's members advocate for legal and social change to address these very issues. That these issues may make a person wish to die is not disputed; but Amici know that these feelings are not inevitable, that their causes are and have been successfully addressed and that, most importantly, these emotions do not justify a lethal response from medical providers.

Far from increasing the autonomy of New Yorkers, assisted suicide allows doctors to decide who is eligible – i.e., whose condition is "terminal" and whose desire to commit suicide is "rational." This places disabled persons at great risk of unequal treatment for several reasons. First, although terminal prognoses are often wrong, the seriously terminally ill are a subset of all people with disabilities. Oregon's data shows that virtually all who request assisted suicide are disabled. Second, doctors are generally unaware of how to address and remedy the

³ Block SD & Billings JA, *Patient Requests to Hasten Death. Evaluation and Management in Terminal Care*, Archives of Internal Medicine, 154(18):2039-47 (Sept. 26, 1994).

disability-related concerns of their patients.

Third, assisted suicide is also dangerous because in many cases it is cheaper than ongoing treatment. Our current healthcare system, with its for-profit insurance and managed care companies, contains pressures both subtle and overt which may coerce patients to use assisted suicide. These are precisely the issues and concerns described in the 1994 report of the New York State Task Force on Life and the Law⁴ and discussed by the U.S. Supreme Court in *Vacco*.

Appellants use the term “dignified death” to justify assisted suicide. When this term is examined, however, the "indignities" nondisabled (and some newly disabled) people invariably describe are the need for assistance in daily activities like bathing, dressing, and other realities of having a disability. Legalizing assisted suicide enshrines in law the prejudice that death is preferable to receiving the assistance that many disabled people rely on.

Amici represent the broad spectrum of people with disabilities, including people with physical, developmental, and/or mental disabilities, and people whose disabilities existed from birth or were acquired during their lifetimes. Many are now, or at some point have been, erroneously labeled "terminal" by a physician. Many have had doctors threaten to remove life sustaining treatment on an

⁴ "When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context", New York State Task Force on Life and the Law, May 1994 available at https://www.health.ny.gov/regulations/task_force/reports_publications/when_death_is_sought/ (accessed December 29, 2016)

involuntary basis, and have had to fight to receive continued care. The legalization of assisted suicide will cause many disabled people and seniors to be killed by coercion, abuse, prejudice, and mistake. For the Disability Rights Amici, the human cost of legalization is too high.

SUMMARY OF ARGUMENT

The Appellate Division and Supreme Court are correct: there is no fundamental right, under the Constitutions of New York or the United States, to receive assistance from a doctor or any other third party in committing suicide. Moreover, compelling State interests exist for prohibiting assisted suicide for all, including people with disabilities, terminal and nonterminal. State-sanctioned assisted suicide degrades the value and worth of people with disabilities and violates the antidiscrimination rights, protections and mandates of the Americans with Disabilities Act, 42 U.S.C. § 12101, *et seq.*

ARGUMENT

I. ASSISTED SUICIDE DISCRIMINATES AGAINST PEOPLE WITH DISABILITIES

A. Assisted Suicide Is Part of the Long and Tragic History of Discrimination Against People with Disabilities

Assisted suicide must be seen in the context of the United States' long and tragic history of state-sanctioned discrimination against disabled people. The U.S. Supreme Court has acknowledged that at least one form of discrimination – the

practice of withholding lifesaving medical assistance by medical professionals from severely disabled children – demonstrates a "history of unfair and often grotesque mistreatment" arising from this country's legacy of "prejudice and ignorance," and continuing well into the 20th century. *City of Cleburne, Texas v. Cleburne Living Center*, 105 S. Ct. 3249, 3262, 3266. (1985)

This history of prejudice, unfortunately, continues into the present. Peter Singer, Tenured Professor of Bioethics at Princeton University,⁵ has advocated for actively killing infants with severe disabilities in the belief that they will not lead a "good" life and will burden their parents and society. Legalization of assisted suicide is another expression of that prejudice.

B. Assisted Suicide Denies People with Disabilities, Including Those With and Without Terminal Conditions, the Benefit of the State's Suicide Prevention Protections

Although not all disabled people have a terminal prognosis, all patients with a terminal prognosis are, or are likely to become, disabled: that is, to require assistance with major life activities such as eating, toileting, dressing, bathing and more. 42 U.S.C. § 12102. Assisted suicide singles out disabled people who have a terminal prognosis for different treatment than other suicidal people receive. A nondisabled person who told their doctor that they wished to kill themselves would be referred to suicide prevention services, while a disabled person with a terminal

⁵ See Peter Singer, *Taking Life: Humans*, in PRACTICAL ETHICS, 175-217 (2d ed. 1993)

prognosis will be assisted to commit suicide. Thus, assisted suicide is a lethal form of discrimination against disabled people because the presence of disability is used to justify the double standard of providing suicide assistance only to suicidal people with disabilities, including those labeled “terminal,” but suicide prevention to the rest of society.

The appellants’ wish to immunize physicians for assisting the suicides of persons with "terminal" disabilities or conditions; this reverses the general presumption that suicide is irrational and is a "cry for help." Appellants seek to invalidate longstanding protections of old, ill and disabled people in order to permit doctors to facilitate suicide, an act that would be a crime but for the person's disability and a label of “terminal.” This denies persons with severe health impairments the benefit of New York's suicide prevention laws and programs. Indeed, the appellants’ proposal guarantees that their suicide attempts will result in death – unlike those of the majority of other persons with suicidal ideation who attempt suicide. A practice that the State expends resources to prevent will instead be actively facilitated based on a "terminal" diagnosis, no matter how unreliable that diagnosis may be, how effectively the person’s underlying concerns can be addressed by other measures, nor how great the risk of non-consensual death through mistake, coercion and abuse.

States throughout the country actively discourage suicide through laws and

prevention programs. *See Washington v. Glucksberg*, 521 U.S. 702, 711 (1997). By asserting that it is irrational for a non-disabled person to end his or her life, but rational for a disabled person to do so, appellants argue that the disabled person's life is intrinsically less worthy of state protection than a nondisabled person's life.

Perhaps no belief strikes closer to the heart of the disability civil rights movement. Central to the civil rights of people with disabilities is the idea that a disabling condition does not inherently diminish one's life; rather, stereotypes, prejudices, and barriers preventing assistance with activities of daily living do so. In contrast, assisted suicide gives legal force to the idea that life with a disabling condition is not worth living.

The State's interest [in prohibiting assisted suicide] goes beyond protecting the vulnerable from coercion; it extends to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and "societal indifference ... " The State's assisted-suicide ban reflects and reinforces its policy that the lives of terminally ill, disabled and elderly people must be no less valued than the lives of the young and healthy, and that a seriously disabled person's suicidal impulses should be interpreted and treated the same as everyone else's.

Glucksberg, 521 U.S. at 732.

Appellants attempt to justify this double standard by the false belief that people with disabilities who have a terminal prognosis are going to die soon anyway. This argument fails for several reasons.

First, terminal predictions by doctors are uncertain and unreliable.⁶ Amici include many people with disabilities who have outlived an incorrect terminal prognosis. This medical uncertainty, and the potential for an unduly grim prognosis, is of particular concern in cases of people with severe new injuries or severe medical declines such as a stroke, major heart attack, or ALS. In such cases, knowledgeable and genuine suicide prevention is essential.

Second, the Oregon State Health Division's assisted suicide data (the "Oregon Reports") show that non-terminal people with disabilities are receiving lethal prescriptions, presumably based on incorrect prognoses. The state reports reveal that some people outlived their six-month prognosis every year, based on the time lapse between the person's request for assisted suicide and their death,

⁶ E.B. Lamont et al., "Some elements of prognosis in terminal cancer," *Oncology (Huntington)*, Vol. 9, August 13, 1999, pp. 1165-70; M. Maltoni, et al., "Clinical prediction of survival is more accurate than the Karnofsky performance status in estimating lifespan of terminally-ill cancer patients," *European Journal of Cancer*, Vol. 30A, Num. 6, 1994, pp. 764-6; N.A. Christakis and T.J. Iwashyna, "Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists," *Archives of Internal Medicine*, Vol. 158, Num. 21 November 23, 1998, pp. 2389-95; J. Lynn et al., "Prognoses of seriously ill hospitalized patients on the days before death: implications for patient care and public policy," *New Horizons*, Vol. 5, Num. 1, February 1997, pp. 56-61. Also: "17 percent of patients [outlived their prognosis] in the Christakis study. This roughly coincides with data collected by the National Hospice and Palliative Care Organization, which in 2007 showed that 13 percent of hospice patients around the country outlived their six-month prognoses. ... When a group of researchers looked specifically at patients with three chronic conditions—pulmonary disease, heart failure, and severe liver disease—they found that many more people outlived their prognosis than in the Christakis study. Fully 70 percent of the 900 patients eligible for hospice care lived longer than six months, according to a 1999 paper published in the *Journal of the American Medical Association*." See Nina Shapiro, "Terminal Uncertainty," *Seattle Weekly*, January 14, 2009.

with a reported time lapse of up to 1009 days.⁷

Third, the Oregon state reports reveal that virtually all of the people who receive lethal prescriptions have disabilities, based on their reported reasons for requesting assisted suicide. The top five reported reasons are disability related, and ninety-two percent reportedly made their request due to “loss of autonomy,”⁸ which indicates physical dependence on others for activities previously undertaken without assistance. The Amici have direct knowledge and experience in addressing these issues, which would be the crux of meaningful suicide prevention.

Suicide prevention professionals also view these issues as treatable. A wealth of literature addresses elder suicide prevention.⁹ The U.S. Administration on Aging and Substance Abuse and Mental Health Services Administration state in an issue brief entitled “Preventing Suicide in Older Adults”:

There are several important risk factors for suicide in older adults. These include, among others: • Depression, • Prior suicide attempts, • Marked feelings of hopelessness, • Co-morbid general medical conditions that significantly limit functioning or life expectancy, • Pain and declining role function (e.g., loss of independence or sense of purpose), • Social isolation, • Family discord or losses (e.g., recent death of a loved one), • Inflexible personality or marked difficulty adapting to change . . .¹⁰

⁷ Oregon’s Death With Dignity Act – 2015, *supra*, page 7

⁸ *Id.*, page 6.

⁹ See Older Adult Suicide Prevention Resources, available at <http://www.sprc.org/populations/older-adults> (accessed December 29, 2016);

¹⁰ OLDER AMERICANS BEHAVIORAL HEALTH Issue Brief 4: Preventing Suicide in Older

In the State of Connecticut’s Suicide Prevention Plan 2020, risk factors for people with chronic conditions and disabilities¹¹ are identified as follows:

Living with chronic or terminal physical conditions can place significant stress on individuals and families. As with all challenges, individual responses will vary. Cancer, degenerative diseases of the nervous system, traumatic injuries of the central nervous system, epilepsy, HIV/AIDS, chronic kidney disease, arthritis and asthma are known to elevate the risk of mental illness, particularly depression and anxiety disorders.

In these situations, integrated medical and behavioral approaches are critical for regularly assessing for suicidality. Disability-specific risk factors include: a new disability or change in existing disability; difficulties navigating social and financial services; stress of chronic stigma and discrimination; loss or threat of loss of independent living; and institutionalization or hospitalization.

Dr. Herbert Hendin, CEO and Medical Director of Suicide Prevention Initiatives based in New York City, has discussed “the inadequacy of safeguards ostensibly designed to ensure a patient’s psychiatric health and the voluntariness of the decision” in assisted suicide as implemented in Oregon.¹²

Adults, available at:

https://aoa.acl.gov/AoA_Programs/HPW/Behavioral/docs2/Issue%20Brief%204%20Preventing%20Suicide.pdf (accessed December 29, 2016)

¹¹ State of Connecticut, Suicide Prevention Plan 2020, page 44, <http://www.preventsuicidect.org/files/2015/04/Suicide-Prevention-Plan-2010.pdf> (accessed December 29, 2016)

¹² Letter by Dr. Herbert Hendin, MD, <http://noassistedsuicideny.org/wp-content/uploads/2015/03/SPI-memo-2015-16-session.pdf> (accessed December 29, 2016)

Finally, lobby groups that support a public policy of assisted suicide, including some appellants, have openly advocated expanding eligibility for assisted suicide beyond those with a six-month terminal prognosis. From the 1996 Harvard Model Act¹³, to repeated introductions of bills in New Hampshire with expansive definitions of “terminal”,¹⁴ to writings by appellant Quill,¹⁵ it is clear that broad assisted suicide eligibility for people with non-terminal disabilities is the goal of this movement. Their sometimes admitted incremental strategy¹⁶ is “Politics 101,” despite any claims to the contrary in the context of this case.

C. Assisted Suicide Denies People with Disabilities the Benefit of State Suicide Prevention Laws and the Enforcement of Homicide Laws, in Violation of the ADA

¹³ Charles H. Baron, Clyde Bergstresser, Dan W. Brock, Garrick F. Cole, Nancy S. Dorfman, Judith A. Johnson, Lowell E. Schnipper, James Vorenberg, and Sidney H. Wanzer. "A Model State Act to Authorize and Regulate Physician-Assisted Suicide." *Harvard Journal on Legislation* 33, (1996): 1-34.
(<http://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=1013&context=lsfp> accessed December 29, 2016)

¹⁴ New Hampshire Death With Dignity Act, HB 1325, Section 137 L2 XIII, providing that “Terminal condition” means an incurable and irreversible condition, for the end stage for which there is no known treatment which will alter its course to death, and which, in the opinion of the attending physician and consulting physician competent in that disease category, will result in premature death.” <http://www.gencourt.state.nh.us/legislation/2014/HB1325.pdf> (accessed December 29, 2016)

¹⁵ Franklin G. Miller, Ph.D., Timothy E. Quill, M.D., Howard Brody, M.D., Ph.D., John C. Fletcher, Ph.D., Lawrence O. Gostin, J.D., and Diane E. Meier, M.D., "Regulating Physician-Assisted Death," *N Engl J Med* 1994; 331:119-123 (July 14, 1994)
(<http://www.nejm.org/doi/pdf/10.1056/NEJM199407143310211>) (accessed December 29, 2016)

¹⁶ Gunderson, Martin and Mayo, David J., "Restricting Physician-Assisted Death to the Terminally Ill" (PDF) *Hastings Center Report*, November-December 2002. (pp. 17-23)

In 1990, responding to the history of discrimination against people with disabilities, Congress enacted the Americans With Disabilities Act (“ADA”), 42 U.S.C. § 12101 *et seq.* To address and remedy the “serious and pervasive social problem” of discrimination against individuals with disabilities, 42 U.S.C. § 12101(a)(2), Congress required that "no qualified individual with a disability shall ... be excluded from participation in or be denied the benefits of the services, programs, or activities of any public entity" 42 U.S.C. § 12132; *See* 28 C.F.R. § 35.130(b) (discrimination includes denying or not affording an opportunity for people with disabilities to benefit from services either equal to or as effective as those afforded nondisabled persons).

Sanctioning assisted suicide only for people with disabilities, and denying them suicide prevention services based on a doctor's prediction of terminal status or other factors violates the ADA because the presence or absence of disability determines whether or not New York:

- Enforces its laws requiring health professionals to protect individuals who pose a danger to themselves;
- Responds to expressions of suicidal intent in people with disabilities with the application of lethal measures that are never applied to people without disabilities; and
- Investigates and enforces its abuse and neglect and homicide statutes in

cases reported as assisted suicides.

A doctor's determination of someone's eligibility for assisted suicide confers virtually absolute legal immunity on the doctor and other participants in the death of that person. All State suicide-prevention procedures are set aside. The mere presence of a disability will be the basis for this disparate treatment.

II. Assisted Suicide Poses Serious, Unavoidable Threats to People with Disabilities That New York Has a Significant State Interest in Preventing

Assisted suicide is contrary to well-established medical ethics. *See Glucksberg*, 521 U.S. at 731 (quoting American Medical Association, Code of Ethics section 2.211 (1994)); *see also Vacco v. Quill*, 521 U.S. 793, 801 n.6 (1997) (discussing medical profession's distinction between withholding treatment, which is grounded in the law of preventing battery or unwanted touching, and assisted suicide). This prohibition is firmly grounded in the potential harm that appellants' proposed public policy poses to the lives of people with disabilities.

A. The State Has a Critical Interest in Ensuring that Assisted Suicide Decisions Are Not Coerced or Made by Others

Some persons killed under assisted suicide laws may "choose" suicide under pressure from others. New York has a significant State interest in preventing that pressure from driving people to end their lives. There is no way to ensure that persons are not unduly pressured by family members for financial, emotional, or other reasons.

Similarly, given that the cost of assisted suicide is significantly lower than the cost of ongoing treatment, there is no way to ensure that health providers, whether insurance companies, health maintenance organizations, or others, are not limiting care and thereby pressuring a person to request "aid in dying" for financial reasons.

B. It is Dangerous and Discriminatory to Assume that the Suicide of a Disabled Person, Whether Terminal or Nonterminal, is "Rational"

"[T]hose who attempt suicide – terminally ill or not – often suffer from depression or other mental disorders." *Glucksberg*, 521 U.S. at 730. "Research indicates ... that many people who request physician-assisted suicide withdraw that request if their depression and pain are treated." *Id.* A study of cancer patients showed that those with depression were four times more likely to want to die.¹⁷ Pain is rarely the reason people consider assisted suicide. Many people do so because they fear they will be a burden on their families. The Oregon Reports indicate that 41% of assisted suicide requests involved this fear.¹⁸

In the most recent reporting year, 2015, Oregon physicians referred only 3.8% of persons who requested assisted suicide for a consultation to determine whether their judgment was impaired, and only 5.3% were referred over all the

¹⁷ See William Breitbart et al., *Depression, Hopelessness and Desire for Hastened Death in Terminally Ill Patients with Cancer*, 284 JAMA 2907, 2909 (Dec. 13, 2000).

¹⁸ Oregon's Death With Dignity Act – 2015, *supra*, page 6

reported years.¹⁹ More than half of psychiatrists were "not at all confident" they could assess whether a psychiatric condition impaired a person's judgment in a single consultation; only six percent were "very confident" that they could.²⁰ This is because such assessments are inherently subjective and unreliable. As one research analysis concluded:

There is a marked lack of clarity about the goals of mandatory psychiatric assessment in all patients requesting [physician-assisted suicide]... There are no clinical criteria to guide such an assessment - just as there are no criteria to assess the rationality of any person's decision to commit suicide.²¹

The supposed "safeguard" of psychiatric referral is insufficient to ensure that suicidal people with disabilities are acting voluntarily.

C. The Uncertainty of "Terminal Prognosis" Means that Disabled People Who Are Not Terminal Will Receive the Lethal Prescription of Assisted Suicide

As noted above, the diagnosis and prognosis of a "terminal condition" is inherently uncertain. Because terminal conditions are often misdiagnosed, assisted suicide will be available for many people with disabilities who are not "terminally ill" within any predictable time frame. The risks to recently disabled people, such

¹⁹ *Id* at page 6.

²⁰ Linda Ganzini et al., *Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists*, 157 AM. J. PSYCHIATRY, 595 (Apr. 2000).

²¹ Brendan D. Kelly et al., *Euthanasia, Assisted Suicide and Psychiatry: A Pandora's Box*, 181 British J. Psychiatry 278, 279 (2002).

as those with significant spinal cord injuries and strokes, are particularly great. Perhaps unlike the general public, "people with disabilities are aware of enough instances of dramatic mistakes that many of them have a healthy skepticism of medical predictions, particularly as it relates to future life quality."²² Evan Kemp, former Director of the Equal Employment Opportunity Commission, wrote:

As a disabled person, I am especially sensitive to the "quality of life" rationale that is frequently introduced in the debate [over assisted suicide]. For the past 47 years I have lived with a progressive neuromuscular disease that first began to manifest itself when I was 12. My disease, Kugelberg Weylander Syndrome, has no known cure, and I have no hope for "recovery." Upon diagnosis, my parents were informed by the physicians treating me that I would die within two years. Later, another group of physicians was certain that I would live only to the age of 18. Yet here I am at 59, continuing to have an extraordinarily high quality of life.²³

D. Appellants' Position that Disability Inherently Deprives Life of Dignity and Value Is Dangerous and Discriminatory

Many people identified as candidates for assisted suicide could benefit from supportive care or treatment, such as counseling, peer support, pain medication, or in-home consumer-directed personal assistance. These measures lessen their pain and suffering, perceived burden on family members, and restore independence,

²² National Council on Disability, *Assisted Suicide: A Disability Perspective* at 27- 28, available at <http://www.ncd.gov/publications/1997/03241997>.

²³ Evan J. Kemp, *Could You Please Die Now?*, Wash. Post, Jan. 5, 1997, at C1.

control and choice.

The lack of this type of assistance and support, rather than any intrinsic aspect of disability, is the primary motivation for suicide. As a physician at New York's Memorial Sloan-Kettering Cancer Center has stated, assisted suicide "runs the risk of further devaluing the lives of terminally ill patients and may provide the excuse for society to abrogate its responsibility for their care."²⁴ Rather than expanding choice, assisted suicide will reduce access to services by which disabled people can choose to live.

Appellants argue for a simplistic mental "competency" determination for assisted suicide. One study noted that "the focus on competence may distract from adequate attention and resources on the person and their circumstances"²⁵ Another study concluded that competency determinations "do not provide a framework to address social circumstances that contribute to the desire for euthanasia or assisted suicide."²⁶

²⁴ Kathleen M. Foley, *Competent Care for the Dying Instead of Physician-Assisted Suicide*, 336 NEW ENG. J. MED 54 (Jan. 2, 1997).

²⁵ Ganzini et al., *supra* note 7, at 600.

²⁶ James V. Lavery, et al, *Origins of the Desire for Euthanasia and Assisted Suicide in People with HIV-1 or AIDS: A Qualitative Study*. LANCET, 358 (9279), 366 (2001).

III. THE CREATION OF A CONSTITUTIONAL RIGHT TO ASSISTED SUICIDE FOR A CLASS OF NEW YORKERS BASED ON THEIR HEALTH AND DISABILITY STATUS IS A LETHAL FORM OF DISCRIMINATION

A. People with Disabilities, Whether Terminal or Nonterminal, Are the Precise Class of People Who Will Be Affected If a Right to Assisted Suicide Is Found

The issue before the Court goes far beyond the 1980's cases in which courts dismissed the state interest in protecting the lives of disabled individuals and found a "right to die" through the withdrawal of routine life-sustaining treatment. See *e.g.*, *Bouvia v. Superior Court*, 179 Ca. App. 3d 1127, 255 Cal. Rptr. 297 (1986), *review denied* (June 5, 1986); *McKay v. Bergstedt*, 801 P.2d 617 (Nev. 1990); *State v. McAfee*, 385 S.E.2d 651 (Ga. 1989). With appropriate treatment and services, many of them would be alive today, as a leading bioethicist has admitted.²⁷ Even in those cases, the courts specifically distinguished active physician-assisted suicide from the right to refuse treatment. Before this Court is the request to obliterate this distinction. Against the backdrop of these and other cases, your Amici request protection from the very real threat to the lives of people with disabilities that will result from a right to assisted suicide through active measures.

²⁷ H Brody, A bioethicist offers an apology, Lansing City News, October 6, 2004 (<http://dredf.org/public-policy/assisted-suicide/a-bioethicist-offers-an-apology/>).

B. There Are No Safeguards Adequate to Protect People with Disabilities from Assisted Suicide

1. Limiting Assisted Suicide to Terminally Ill Persons Will Fail to Protect Nonterminal People with Disabilities

Given the "history of purposeful unequal treatment" to which people with disabilities are subjected, 42 U.S.C. § 12101 (a)(7), assisted-suicide "safeguards" cannot prevent abuse against people with nonterminal disabilities. History demonstrates that assisted suicide has not and will not be limited to terminally ill persons.²⁸ Moreover, terminally ill persons who request assisted suicide are, or fear they will become, disabled, and are a demographic subset of people with disabilities.

At issue is nondisabled peoples' intense fear of becoming disabled. The wish to die is based on the nondisabled view that the primary problem for disabled people is the disability itself and/or dependence on others. Medical professionals, jurists, and the public ignore underlying treatable depression, lack of pain relief, in-home long term care services or other supports, and exhaustion from confronting interpersonal and societal discrimination. When medical professionals and the media use phrases like "imprisoned by her body," "helpless" and "suffering needlessly," they are really expressing fear of severe disability. Appellants translate this fear into a supposedly "rational" policy of assisted suicide. They

²⁸ See H. Hendin and K. Foley, *Physician-Assisted Suicide in Oregon: A Medical Perspective*, 106 MICH. L. REV. 1613 (2008).

argue that the wish to die is "rational" and, therefore, different from suicides resulting from the same emotional disturbance or illogical despair that nondisabled persons face.

The medical profession is not immune to these erroneous assumptions. Doctors frequently assess the "quality of life of chronically ill persons to be poorer than patients themselves hold it to be, and give this conclusion great weight in inferring, incorrectly, that such persons would choose to forgo life-prolonging treatment."²⁹ Research demonstrates that suicidal feelings in terminally ill people are remediable through other means, including pain management, hospice services and counseling.³⁰ As long as physicians believe, however, that a person with a severe illness or disability has a "life unworthy of living," lethal errors and abuses will occur.

Safeguards cannot protect one from family pressures due to financial burdens which may accompany a disability, especially when the health care system may not pay for assistance in daily living activities. Nor can safeguards stop families from doctor-shopping when one doctor says the person is not "terminal" or is not acting "voluntarily," to find another doctor who will prescribe the lethal dose. The majority of Oregon assisted suicides involve assisted suicide "friendly"

²⁹ S. Miles, *Physicians and Their Patients' Suicide*, 271 JAMA 1786 (1994).

³⁰ Most death requests, even in terminally ill people, are propelled by despair and treatable depression. H. Hendin and Gerald Klerman, *Physician-Assisted Suicide: The Dangers of Legalization*, 150 AM. J. OF PSYCH. 143 (Jan.1993).

doctors referred by Compassion and Choices, the leading lobby group for assisted suicide bills.³¹

2. Limiting Assisted Suicide To "Voluntary" Requests Will Fail to Protect People with Disabilities from Abuse

As long as people with disabilities are treated as unwelcome and costly burdens on society, assisted suicide is not voluntary. The Disability Rights Amici are profoundly disturbed by the appellants' advocacy for a constitutional right for assisted suicide in a society which refuses to find a concomitant right to adequate health care to stay alive. The trend to managed health care, with its emphasis on cost containment, further constrains the choices and endangers the lives of people with disabilities. Our society is not committed to providing life supports, including in-home personal assistance services and technology supports. The "choice" disabled people are offered is death but not life.

Without health care, consumer-directed personal care services, and access to competent palliative and hospice care, people with disabilities do not receive what they need to live as independently and with as much autonomy as possible. Without the professional commitment to provide essential services, which is the

³¹ Kenneth R. Stevens, Jr., M.D., *The Proportion of Oregon Assisted Suicides by Compassion & Choices Organization*, Physicians for Compassionate Care Educational Foundation, March 4, 2009, available at <http://www.pccf.org/DOWNLOADS/AssistedSuicidesbyCC2009report.pdf> (accessed December 29, 2016)

core of suicide prevention, people with disabilities, including those whose conditions are terminal, will not receive the support necessary for informed and voluntary decisions.

Finally, no system of safeguards can control conduct which results in the death of the primary witness to any wrongdoing or duress. The only "safeguard" that offers some protection against abuse is that assisted suicide remain illegal and socially condemned for all persons equally.

C. Assisted Suicide Prevents People With Disabilities, Whether Terminal or Nonterminal, From Receiving Equal Protection of Laws Pertaining to Suicide Prevention and Homicide

Appellants urge this Court to minimize and ignore the risks of abuse impacting vulnerable people. Ample evidence already exists of non-voluntary and involuntary withholding and withdrawal of treatment. For example, in a study published in 2011 in the Journal of Emergency Medicineⁱ, over 50% of physician respondents misinterpreted a living will as having a "do not resuscitate" (DNR) order. About the same percentage of respondents over-interpreted DNR orders as meaning "comfort care" or "end-of-life" care only.³² The study shows clearly that having a living will and/or a DNR order makes it much more likely that physicians will withhold treatments that a patient actually wants. More clearly involuntary are

³² F Mirarchi, et al., TRIAD III: Nationwide Assessment of Living Wills and Do Not Resuscitate Orders, Journal of Emergency Medicine, Volume 42, Issue 5, pages 511-520 (May 2012) ([http://www.jem-journal.com/article/S0736-4679\(11\)00853-5/abstract?cc=y](http://www.jem-journal.com/article/S0736-4679(11)00853-5/abstract?cc=y)).

futility policies that grant immunity to physicians who deny care that the patient or surrogate expressly wants.³³ Legalizing assisted suicide will make already troubling matters worse by expanding the population of people who are eligible to have their lives ended by medical professionals. Amici have a great deal of experience with incorrect terminal prognoses, and the involuntary denial of care and self-fulfilling prophesy that can result from a “terminal” label. The more vulnerable members of the disability and aging communities must not be viewed as expendable.

Appellants frequently claim that the dangers of assisted suicide have been disproven by the experience in Oregon and Washington. Their claim, however, ignores at least three problems with the practice of assisted suicide in those States: 1) the Oregon and Washington assisted suicide statutes provide a blanket of “good faith” immunity to participants in the death, which shrouds gaping loopholes in patient protection; 2) the common sense factual and legal analyses by numerous courts that have considered the issue; and 3) cases of mistake and abuse which have come to light despite minimal reporting requirements, the lack of

³³ Fine & Mayo, Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act, *Ann Intern Med* 2003; 138: 743-746.
(http://portal.mah.harvard.edu/templatesnew/departments/MTA/MAHEthics/uploaded_documents/Texas%20Advance%20Directive%20Act.pdf (accessed December 29, 2016))

investigation by Oregon state authorities,³⁴ and the impact of strict health care confidentiality laws.

First, nothing in the provisions of the Oregon and Washington assisted suicide statutes³⁵ prohibits an heir or caregiver from suggesting assisted suicide to an ill person, or taking the person to the doctor to make a request. If the person has a speech impairment, such as due to a stroke, or speaks another language, the laws provide that a patient may communicate “through a person who is familiar with the patient’s manner of communicating.” *See, e.g., Oregon DWD Act, 127.800 § 1.01(3).* An interested party can request assisted suicide on behalf of a person with a communication disability.

The statutes allow an heir to be a witness to the assisted suicide request as long as the second witness is not an heir. Alternately, both witnesses can be complete strangers who merely check the patient’s identification. In either case, the witnesses’ certification that the patient is not being coerced is seriously lacking in foundation and persuasive value.

³⁴ Oregon Public Health Division, DHS News Release: *No authority to investigate Death with Dignity case, DHS says*, March 4, 2005

³⁵ Oregon Death With Dignity Act, ORS 127.865, Washington Death With Dignity Act, RCW 70.245

The physicians' ability to detect coercion is similarly in doubt. The median duration of the physician-patient relationship in Oregon is reported as 12 weeks.³⁶ The majority of doctors who prescribe under the Oregon assisted suicide law are referrals by Compassion and Choices, the leading lobby group for these laws.³⁷

In addition, once the prescription for lethal drugs is issued, there are no further witness requirements, including at the time of ingestion of the lethal drugs and death. As Washington elder law attorney Margaret Dore has written:

Without witnesses, the opportunity is created for someone other than the patient to administer the lethal dose to the patient without his consent. Even if he struggled, who would know? The lethal dose request would provide the alibi. . . .³⁸

The Oregon Reports include data on whether the prescribing doctor or other health care provider was present when the lethal dose was ingested or at the death. In about half the cases, no such person was present.³⁹ Assuming *arguendo* that healthcare provider witnesses would report a lack of consent or intentional self-

³⁶ Oregon's Death With Dignity Act – 2015, *supra*, page 6,

³⁷ See footnote 34 and additional authorities discussed in M Golden, Why Assisted Suicide Must Not Be Legalized, Part C.1. Safeguards in Name Only/Doctor Shopping, <http://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/#marker43> (accessed December 29, 2016)

³⁸ Margaret Dore, Esq., “‘Death with Dignity’: A Recipe for Elder Abuse and Homicide (Albeit Not by Name),” 11 Marquette Elder's Advisor 387, 2010, *available at* <http://www.choiceillusion.org/p/the-oregon-washington-assisted-suicide.html> (accessed December 29, 2016)

³⁹ Oregon's Death With Dignity Act – 2015, *supra*, page 6

administration, in the other half of the cases, there is no evidence of consent or intentional self-administration.

Second, a recent California assisted suicide case provides a comprehensive and persuasive review of previous court rulings, giving realistic weight to the many dangers that legalizing assisted suicide poses, particularly in an aging population in which, according to federal estimates, one in ten elders are abused.⁴⁰

Since "Aid in Dying" is quicker and less expensive, there is a much greater potential for its abuse, e.g., greedy heirs-in-waiting, cost containment strategies, impulse decision-making, etc. Moreover, since it can be employed earlier in the dying process, there is a substantial risk that in many cases it may bring about a patently premature death. For example, consider that a terminally ill patient, not in pain but facing death within the next six months, may opt for "Aid in Dying" instead of working through what might have been just a transitory period of depression. 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 that could have been brought to light by the passage of time. After all, doctors are not infallible.

Furthermore, "Aid in Dying" increases the number and general acceptability of suicide, which could have the unintended consequence of causing people who are not terminally ill (and not, therefore, even eligible for "Aid in Dying") to view suicide as an option in their unhappy life. For example, imagine the scenario of a

⁴⁰ Mark S. Lachs, M.D., M.P.H., and Karl A. Pillemer, Ph.D., "Elder Abuse," *N Engl J Med* 2015; 373:1947-1956, November 12, 2015 (<http://www.nejm.org/doi/full/10.1056/NEJMra1404688>) (accessed December 29, 2016) ; See D. Heitz, "U.S. Official: Elder Abuse is 'Broad and Widespread'," *Healthline News* (Jan. 27, 2014), available at <http://www.healthline.com/health-news/senior-elder-abuse-more-common-than-you-think-012714> (accessed December 29, 2016).

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.

O'Donnell v. Harris, San Diego Superior Court Case No. 37-2015-00016404-CU-CR-CTL, pg 8 (July 24, 2015) (granting demurrer without leave to amend). This analysis is consistent with the issues discussed in the report of the New York Task Force on Life and the Law.⁴¹

The Oregon and Washington assisted suicide laws include no requirement for treatment of depression.⁴² As previously discussed, the top five reasons that prescribing physicians report for assisted suicide requests are psycho-social reactions to disability. Two of them are loss of autonomy (92%) and feelings of being a burden on others (41%).⁴³ Nevertheless, neither the Oregon nor Washington laws require disclosures about consumer directed home care options that could alleviate these feelings, nor do they ensure that such home care will be provided if desired. The Amici's experience is that most doctors know little or nothing about home and community based long-term care.

⁴¹ "When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context", New York State Task Force on Life and the Law, May 1994.

⁴² See L. Ganzini, et al., *Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists*, 157 Am. J. Psych., 595, 598 (April 2000); L. Ganzini, et al., *Attitudes of Oregon Psychiatrists Towards Assisted Suicide*, 153 AM. J. PSYCH, 1469 – 75 (1996).

⁴³ See Oregon's Death With Dignity Act – 2015, *supra*, page 7, *supra*.

Moreover, under the statutes, the state has no authority (or resources) to investigate abuses. The blanket immunities granted to participants in the death, and the impact of patient confidentiality laws, present formidable barriers to uncovering mistakes, coercion and abuse. Despite these obstacles, some cases have come to light.⁴⁴ These cases emphasize the critical importance of applying equal protection principles to protect people with disabilities, whether terminal or not, from the dangers inherent in a public policy of legalized assisted suicide.

CONCLUSION

People with disabilities in New York are seriously threatened by physician-assisted suicide. The Disability Rights Amici request this Court to recognize that, cloaked in the false rhetoric of “death with dignity,” and “aid in dying,” physician-assisted suicide threatens the civil rights, and the lives, of an already oppressed and marginalized minority.

The Disability Rights Amici hope that the time will come when old, ill and disabled people are recognized as a “suspect class” entitled to strict scrutiny protection from discrimination. That is the expansion of constitutional rights that we hope to see. As we have argued above, people with disabilities, whether those disabilities are terminal or nonterminal, deserve equal protection under the laws

⁴⁴ The Disability Rights Education & Defense Fund, an Amicus, has compiled brief descriptions of some of these cases, with citations to source materials, entitled “Oregon and Washington State Abuses and Complications.” Available at <https://dredf.org/wp-content/uploads/2015/04/Revised-OR-WA-Abuses.pdf> accessed December 29, 2016)

and professional standards pertaining to suicide prevention and homicide law enforcement. We urge this Court to protect old, ill and disabled people from the risks of mistake, coercion and abuse inherent in a public policy of assisted suicide, and to uphold the Appellate Division's ruling in this important case.

Respectfully submitted,

ADAM PRIZIO
Attorney at Law

Dated: Albany, NY
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By: _____
Adam Prizio
99 Washington Avenue, Suite 806B
Albany, NY 12210
(518) 320-7100
(518) 320-7122 (facsimile)
aprizio@cdmns.org

Attorney for Disability Rights Amici

NOT DEAD YET, ADAPT,
ASSOCIATION OF PROGRAMS FOR
RURAL INDEPENDENT LIVING,
AUTISTIC SELF ADVOCACY
NETWORK, CENTER FOR DISABILITY
RIGHTS, DISABILITY RIGHTS CENTER,
DISABILITY RIGHTS EDUCATION AND
DEFENSE FUND, NATIONAL COUNCIL
ON INDEPENDENT LIVING, NEW
YORK ASSOCIATION ON
INDEPENDENT LIVING, REGIONAL
CENTER FOR INDEPENDENT LIVING
AND UNITED SPINAL ASSOCIATION