COMMONWEALTH OF MASSACHUSETTS
SUPREME JUDICIAL COURT

No. SJC-13194

DR. ROGER M. KLIGLER AND DR. ALAN STEINBACH,

Plaintiffs-Appellants

v.

MAURA T. HEALEY, IN HER OFFICIAL CAPACITY AS THE ATTORNEY GENERAL OF THE COMMONWEALTH OF MASSACHUSETTS, AND MICHAEL O'KEEFE, IN HIS OFFICIAL CAPACITY AS DISTRICT ATTORNEY OF CAPE & ISLANDS DISTRICT,

Defendants-Appellees.

On Appeal from the Suffolk County Superior Court
Civil Action No. 16-3254F

BRIEF OF DISABILITY RIGHTS EDUCATION AND DEFENSE FUND AND EIGHTEEN OTHER ORGANIZATIONS AS AMICI CURIAE IN SUPPORT OF DEFENDANTS-APPELLEES AND URGING AFFIRMANCE

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FULL LIST OF AMICI CURIAE

- Disability Rights Education and Defense Fund
- The Arc of the United States
- The Arc of Massachusetts
- American Association of People with Disabilities
- Association of Programs for Rural Independent Living
- Autistic Self Advocacy Network
- Autistic Women and Nonbinary Network
- Disability Policy Consortium
- Disability Rights Legal Center
- Independence Associates, Inc.
- Metro West Center for Independent Living
- National Council on Independent Living
- Not Dead Yet
- National Organization of Nurses with Disabilities
- Second Thoughts Massachusetts
- Stavros Center for Independent Living, Inc.
- TASH
- United Spinal Association
- World Institute on Disability

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CORPORATE DISCLOSURE STATEMENT

Pursuant to Rule 17(c)(1) of the Massachusetts Rules of Appellate Procedure, undersigned counsel certifies that no Amici has a parent corporation and that no publicly held corporation owns 10 percent or more of any Amici's respective stock.

RULE 17(c)(5) DECLARATION

Pursuant to Rule 17(c)(5) of the Massachusetts Rules of Appellate Procedure, Amici and undersigned counsel declare that they are independent from the parties and have no economic interest in the outcome of this case. Amici and undersigned counsel further declare that none of the conduct described in Appellate Rule 17 (c) (5) has occurred:

a. No party or party's counsel authored this brief in whole or in part;

b. No party or party's counsel contributed money that was intended to fund the preparation or submission of this brief;

c. No person or entity—other than Amici, Amici's members, or Amici's counsel—contributed money that was intended to fund preparing or submitting this brief; and

d. None of the Amici, nor their counsel, represents or have represented one of the parties to the present appeal in another proceeding involving similar issues or was a party or represented a party in a proceeding or legal transaction that is at issue in the present appeal.

IDENTITIES AND INTERESTS OF AMICI CURIAE

Amici curiae are non-profit organizations that represent and advocate for the rights of individuals with disabilities. They are as follows:

Disability Rights Education and Defense Fund: The Disability Rights Education and Defense Fund (DREDF) based in Berkeley, California, is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities. Founded in 1979, DREDF pursues its mission through education, advocacy, and law reform efforts, and is nationally recognized for its expertise in the interpretation of federal disability civil rights laws.

The Arc of the United States: The Arc of the United States (The Arc), founded in 1950, is the Nation's largest community-based organization of and for people with intellectual and developmental disabilities (IDD). Through its legal advocacy and public policy work, The Arc promotes and protects the human and civil rights of people with IDD and actively supports their full inclusion and participation in the community throughout their lifetimes.

The Arc of Massachusetts: The Arc of Massachusetts is the Massachusetts affiliate of The Arc of the United States and –in partnership with its 18 local chapters—serves and advocates for individuals with IDD throughout the state.

American Association of People with Disabilities: The American Association of People with Disabilities (AAPD) works to increase the political and economic power of people with disabilities, and to advance their rights. A national cross-disability organization, AAPD advocates for full recognition of the rights of over 60 million Americans with disabilities.

Association of Programs for Rural Independent Living: The Association of Programs for Rural Independent Living (APRIL) is a national membership organization dedicated to advancing the rights and responsibilities of people with disabilities in rural America. APRIL provides leadership and resources on rural independent living through a national network of rural centers for independent living, programs and individuals concerned with the unique aspect of rural independent living. The goal of APRIL is to work together to find solutions to common problems and to bring rural issues in independent living into focus on the national level.

Autistic Self Advocacy Network: The Autistic Self Advocacy Network ("ASAN") is a national, private, nonprofit organization, run by and for autistic individuals. ASAN provides public education and promotes public policies that benefit autistic individuals and others with developmental or other disabilities. ASAN's advocacy activities include combating stigma, discrimination, and violence against autistic people and others with disabilities; promoting access to health care and long-term supports in integrated community settings; and educating the public about the access needs of autistic people. ASAN takes a strong interest in cases that affect the rights of autistic individuals and others with disabilities to participate fully in community life and enjoy the same rights as others without disabilities.

Autistic Women and Nonbinary Network: The Autistic Women and Nonbinary Network (AWN) is a national nonprofit organization, run by and for autistic people who experience gender-based discrimination, oppression, and violence. AWN focuses on challenging societal ideas about the value of disabled people's lives and participation in society and providing a supportive and affirming community for autistic people experiencing marginalization due to gender, sexual orientation, and race. AWN's advocacy activities include collaboration on research studies on reproductive health care, diagnostic access, and gender-based disparities; publishing resources focused on autism and race, and autism and gender, including autistic transgender people; hosting educational and community-building programs for autistic youth and adults; and raising public consciousness of prejudice, discrimination, oppression, and violence affecting autistic and other disabled people.

Disability Policy Consortium: Disability Policy Consortium (DPC) is a statewide organization of disability rights activists who share a common goal of equal opportunity for all individuals with disabilities. DPC's mission is to promote inclusion, independence, and empowerment by guiding statewide development of policies that ensure that programs and services enable people with disabilities to participate in the political, economic, and social mainstream of the Commonwealth of Massachusetts. The DPC provides a vital link for information to consumers, agencies, organizations, and legislators.

Disability Rights Legal Center: Disability Rights Legal Center (DRLC) is a non-profit legal organization that was founded in 1975 to represent and serve people with disabilities. Individuals with disabilities continue to struggle with ignorance, prejudice, insensitivity, and lack of legal protections in their endeavors to achieve fundamental dignity and respect. DRLC assists people with disabilities in obtaining the benefits, protections, and equal opportunities guaranteed to them under the Rehabilitation Act of 1973, the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Unruh Civil Rights Act, and other state and federal laws. DRLC's mission is to champion the rights of people with disabilities through education, advocacy and litigation. DRLC is generally acknowledged to be a leading disability public interest organization. DRLC also participates in various amici curie efforts in a number of cases affecting the rights of people with disabilities.

Independence Associates, Inc.: Independence Associates, Inc. (IA) promotes the right of people with disabilities in Southeastern Massachusetts to live independently in the community as they choose. IA provides services including advocacy, skills training, peer support, resource coordination and transition services both from youth to adulthood and from nursing homes or other institutionalized settings to the community.

Metro West Center for Independent Living: MetroWest Center for Independent Living provides an array of independent living services that enable people with disabilities to live in the community. The center was created by people with disabilities seeking full integration into society. We empower people with disabilities by teaching the practical skills and confidence to take control over their lives and become active members of the communities in which they live. We promote access and change within society while advocating for programs and services needed by people of all ages with a wide range of disabilities. MWCIL is a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency.

National Council on Independent Living: The National Council on Independent Living (NCIL) is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. NCIL works to advance independent living and the rights of people with disabilities. NCIL's members include individuals with disabilities, Centers for Independent Living, Statewide Independent Living Councils, and other disability rights advocacy organizations.

Not Dead Yet: Not Dead Yet is a national disability rights organization formed in 1996 to articulate and organize the disability rights opposition to legalization of assisted suicide, to oppose public policies that allow the involuntary withholding of life sustaining medical treatment, and to advocate for equal protection of the law in cases of homicides of disabled persons.

National Organization of Nurses with Disabilities: The National Organization of Nurses with Disabilities (NOND) is a 501(c)3 nonprofit organization founded in Chicago, Illinois in 2003, and is an open membership, cross-disability, professional organization that works to promote equity for people with disabilities and chronic health conditions in nursing through education and advocacy by promoting best practices in education and employment; providing resources to individuals, nursing organizations, and educational and healthcare institutions; influencing the provision of culturally responsive nursing practice; and creating systemic improvement and change.

Second Thoughts Massachusetts: Second Thoughts MA is a grassroots group of disability rights advocates from Massachusetts and the region who oppose the legalization of assisted suicide as a deadly form of discrimination against disabled people. We demand social justice against laws, policies, and media messages fueled by a "better dead than disabled" mindset.

Stavros Center for Independent Living, Inc.: Stavros Center for Independent Living, Inc. (Stavros) provides an array of independent living programs and services to persons with disabilities and Deaf people. Stavros' aim is to help individuals develop the tools and skills they need to take charge of their own lives and achieve the life goals that are important to them. Stavros advocates throughout the state of Massachusetts and nationally to bring an end to discrimination in areas including employment, housing, and health care.

TASH: TASH advances equity, opportunity, and inclusion for people with disabilities, with a focus on those with the most significant support needs, in the areas of education, employment and community living through advocacy, research and practice.

United Spinal Association: Founded by paralyzed veterans in 1946, United Spinal Association is a national 501(c) (3) nonprofit membership organization dedicated to empowering people with spinal cord injuries and disorders (SCI/D), such as multiple sclerosis, amyotrophic lateral sclerosis (ALS), and spina bifida, including veterans, and to advancing their independence and quality of life in order to live successful and fulfilling lives. Directed by people with disabilities, United Spinal Association works to overcome the stigma of disability and remove physical barriers from society to include all wheelchair users. Their goal is to actively support people with SCI/D through valuable programs and services that maximize independence and create opportunities to become leaders, advocates, and innovators.

World Institute on Disability: World Institute on Disability is an internationally recognized public policy center organized by and for people with disabilities, which works to strengthen the disability movement through research, training, advocacy, and public education so that people with disabilities throughout the world enjoy increased opportunities to live independently.

Amici are recognized authorities in the field of disability rights who oppose the legalization of assisted suicide. Amici include organizations with members with disabilities in the Commonwealth of Massachusetts and organizations whose members regularly represent the disability community in the investigation and litigation of cases under federal anti-discrimination statutes, and/or engage in other forms of advocacy under such laws. Collectively and individually, Amici have strong interests in preventing discrimination and abuse in the delivery of health care services and ensuring that the lives of disabled people are valued and respected.

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 disabled people have been, or at some point in their lives will be, erroneously labeled with a terminal prognosis by a physician. Many have had medical professionals pressure then to discontinue life-sustaining treatment and/or had to fight to receive the care necessary to keep them alive.

Given Amici's strong interests and lived experiences, Amici are significantly concerned by Appellants' request that the Supreme Judicial Court reverse the January 14, 2020 Order of the Honorable Mary K. Ames and find a right to assisted suicide in the Commonwealth of Massachusetts. As discussed herein, assisted suicide discriminates against people with disabilities, degrades their perceived value and worth, and puts them at higher risk of discrimination and abuse. The only way to avoid such outcomes is to ban the practice without exception.

ISSUES PRESENTED AND STATEMENT OF THE CASE

Amici incorporate by reference the Statement of the Issues, Statement of the Case and Statement of Facts set forth in the Merits Brief for Appellees.

SUMMARY OF ARGUMENT

The question of whether a constitutional right to assisted suicide exists must be addressed and understood from the perspective of the class of people who will be most adversely impacted if such a right is found – people with disabilities, whether terminally ill or not. Amici provide this perspective.

Amici discuss how assisted suicide is part of a long history of discrimination and bias against people with disabilities in medical settings. (pp. 23-33) Legalized assisted suicide discriminates against disabled people by carving them out from the protections of laws against abuse, neglect, and homicide, and by denying them equal access to the benefits of state suicide prevention programs. (pp. 33-34)

Amici also discuss how legalized assisted suicide amplifies ableist beliefs about the quality and value of disabled lives while failing to address the psychological distress and social factors that are the primary causes of suicidal ideations in disabled and terminally ill people. (pp. 34-39) Under the circumstances, assisted suicide cannot be presumed to be a voluntary choice.

Finally, Amici discuss how supposed safeguards are inadequate to protect people with disabilities from the dangers of assisted suicide by examining experiences in Oregon, California, and the Netherlands. (pp. 40-52)

ARGUMENT

I. Assisted Suicide is Part of a Long History of Discrimination and Bias Against People with Disabilities.

A. Disability Discrimination in Medical Settings.

Assisted suicide must be considered against the backdrop of the United States' long and tragic history of state-sanctioned discrimination against people with disabilities.[1] People with disabilities have long faced discrimination in our society, much of it at the hands of medical professionals.

For example, people with disabilities have endured a lengthy history of forced sterilization and other governmental policies to prevent them from creating and maintaining families.[2] In the 1927 case of Buck v. Bell, the Supreme Court

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[1] Although not all disabled people have a terminal prognosis, all patients with a terminal prognosis are disabled: that is, substantially limited in major life activities such as caring for oneself and the operation of the major bodily functions implicated by the medical condition presenting a terminal prognosis. 42 U.S.C. § 12102; 28 C.F.R. § 35.108(c).

[2] See Powell & Stein, Persons with Disabilities and Their Sexual, Reproductive, and Parenting Rights: An International and Comparative Analysis, 11 FRONT. L. CHINA 53, 60–68 (2016) (explaining the ways in which restrictions on sexual, reproductive, and parenting rights for people with disabilities have evolved over time and across jurisdictions).

legitimized early 20th century eugenic sterilization practices.[3] The Virginia statute at issue in Buck was based on the idea that "many defective persons . . . would likely become by the propagation of their kind a menace to society[.]"[4] More than 30 states enacted similar statutes,[5] and over 65,000 Americans, many of whom had disabilities, were sterilized by 1970.[6] Notably, Buck has never been overturned and the forced sterilization of those perceived to be "unfit" is still occurring.[7]

Decades after Buck, the Supreme Court acknowledged that the practice of withholding lifesaving medical assistance from children with severe disabilities demonstrated a "history of unfair and often grotesque mistreatment" arising from

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[3] Buck v. Bell, 274 U.S. 200, 207 (1927).

[4] See Eugenical Sterilization Act, Act of Mar. 20, 1924, ch. 394, 1924 Va. Acts 569 (repealed 1974).

[5] Lombardo, Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom, 13 J. CONTEMP. HEALTH L. & POL'Y 1, 1–2 (1996).

[6] Lombardo, P. A., Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell, 294 app. c (2008).

[7] See finoh, Allegations of Forced Sterilization in ICE Detention Evoke a Long Legacy of Eugenics in the United States, Center for Constitutional Rights, last modified September 18, 2020, https://ccrjustice.org/home/blog/2020/09/18/allegations-forced-sterilization-ice-detention-evoke-long-legacy-eugenics (last visited Feb. 8, 2022); Manin, Immigration Detention and Coerced Sterilization: History Tragically Repeats Itself, ACLU, Sept. 29, 2020, https://www.aclu.org/news/immigrants-rights/immigration-detention-and-coerced-sterilization-history-tragically-repeats-itself/ (last visited Feb. 8, 2022).

this country’s legacy of "prejudice and ignorance."[8] Despite this acknowledgment, some in the bioethics community believe, and contend, that the concepts of dignity and rights do not apply to people with certain disabilities.[9] Peter Singer, tenured professor of bioethics at Princeton University has advocated for actively killing infants with severe disabilities in the belief that they will not lead "good" lives and will burden their parents and society.[10] Singer opines that these “justifications” for death equally “apply to older children or adults whose mental age is ... that of an infant.”[11] Sadly, these are not isolated or antiquated views.

The implementation of health care rationing systems in response to the COVID pandemic provides another example these health inequities. Many states, including Massachusetts, have come under fire for implementing crisis standards

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See also Boyd & Thompson, U.S. Civil Rights Commission Report on Medical Discrimination Against Children with Disabilities, 6 J. CONTEMP. HEALTH L. & POL’Y, 379-410 (1990), https://www.usccr.gov/reports/historical-publications/catalog (last visited Feb. 10, 2022).

[9] See, e.g., Spriggs, Ashley’s Interests Were Not Violated Because She Does Not Have Necessary Interests, 10 AM. J. BIOETHICS, 52-54 (2010) (opining that a young girl with disabilities subjected to involuntary surgery to prevent her growth was “not deprived of anything that she values because she does not have the capacity to value her own existence, let alone to miss anything taken from her.”).

[10] See Singer, Taking Life: Humans, PRACTICAL ETHICS, 175-217 (2d ed. 1993).

[11] Id.

of care that explicitly deprioritize the lives of people with disabilities.[12] An April 2020 investigation by the Center for Public Integrity revealed that in the early months of the pandemic, at least 25 states had crisis standards of care that deprioritized people with disabilities for ventilators and other critical care based on factors such as a patient's expected lifespan; need for assistance with activities of daily living or resources, such as home oxygen; or specific diagnoses, such as dementia or cystic fibrosis.[13]

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[12] See, e.g., Bebinger, After Uproar, Mass. Revises Guidelines on Who Gets an ICU Bed or Ventilator Amid COVID-19 Surge, WBUR, last modified April 22, 2020, https://www.wbur.org/commonhealth/2020/04/20/mass-guidelines-ventilator-covid-coronavirus (last visited Feb. 8, 2022); Not Dead Yet v. Cuomo, No. 20-CV-4819 (GRB), 2021 WL 3577997 (E.D.N.Y. Aug. 13, 2021) (challenging voluntary guidelines promulgated by State of New York which recommended that, in event of public health crisis, ventilators be reassigned to individuals with higher likelihood of survival). Concerns were so severe that the Office for Civil Rights for the U.S. Department of Health and Human Services was driven to issue a warning to states that "persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities." U.S. Department of Health and Human Services, Office of Civil Rights, BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), last updated April 3, 2020, https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf (last visited Feb. 8, 2022).

[13] Whyte, State Policies May Send People With Disabilities to the Back of the Line for Ventilators, Ctr. for Pub. Integrity, Apr. 13, 2020, https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators/ [https://perma.cc/9W64-SZKT] (last visited Feb. 8, 2022).

A second review of publicly available ventilator guidelines, conducted by investigators from Rush University and the University of Chicago, revealed that as of May 10, 2020, withdrawal of mechanical ventilation from one patient to give to another was discussed in 22 of 26 adult guidelines (85%) and 9 of 14 pediatric guidelines (64%). The review also revealed that exclusion criteria for ventilator allocation was recommended in 11 of 26 of adult guidelines (42%) and 10 of 14 pediatric guidelines (71%).[14] Although the use of such criteria has been neutrally characterized as maximizing resources and lives saved, the determination of who is worthy of a ventilator is a subjective decision unavoidably influenced by implicit biases that devalue and disfavor people with disabilities.[15]

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[14] See Piscitello, Kapania, Miller, Rojas, Siegler & Parker, Variation in Ventilator Allocation Guidelines by U.S. State During the Coronavirus Disease 2019 Pandemic: A Systematic Review, JAMA NETW. OPEN, June 2020, https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2767360 (last visited Feb. 8, 2022).

[15] Reports in the press have highlighted instances in which professionals appear to have rationed care due a perception of the poor quality of life of a person with a pre-existing disability. See Joel Shapiro, As Hospitals Fear being Overwhelmed by COVID-19, Do the Disabled Get the Same Access?, NPR, Dec. 14, 2020, https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc?fbclid=IwAR3ta13WYsUGBFxTHXEvic6cy9CHNH7Aav9xkmio0E9e2b5Y55Pme1p (last visited Feb. 8, 2022).

Legalizing assisted suicide in Massachusetts would add to the above-described history of discrimination and bias against people with disabilities. It would establish a discriminatory double standard for how health care providers, government authorities, and others treat disabled individuals versus others. Only disabled people would be removed from the protections of generally applicable laws on abuse, neglect, and homicide. And only disabled people would face an offer of assisted suicide, as opposed to an offer of services and supports, in response to suicidal ideations.

B. Bias in the Medical Profession is Pervasive and Unavoidable.

Disability status is an important factor affecting decisions about life sustaining health care.[16] Many disabled people are denied necessary treatment because of implicit biases in the medical profession regarding the quality of life and inherent worth of people with disabilities.[17] The pervasiveness of this bias cannot be overstated. Studies have consistently demonstrated that health care

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[16] See, e.g., Okoro, Hollis, Cyrus & Griffin-Blake, Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults—United States, 2016. Volume 67, Issue 32, MORB. MORTAL. WKLY. REP., 882–87 (2018).

[17] See, e.g., Carlson, Smith & Wilker, Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights (2012), http://ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf (last visited Feb. 9, 2022).

providers hold negative views of people with disabilities and fail to fully appreciate the value and quality of life with a disability.

A recent survey found that negative perceptions of patients with disabilities were widespread among physicians — to a degree researchers described as "disturbing."[18] Of over 700 practicing US physicians surveyed, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people.[19] This study affirms prior research demonstrating healthcare providers' implicit beliefs about the low quality of life of persons with significant disabilities.[20]

Consistent with these studies, qualitative research involving interviews with people with disabilities suggests that physicians often make erroneous assumptions about patients' values and preferences, limiting their health care options and

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[18] Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, Donelan, Lagu & Campbell, Physicians' Perceptions of People With Disability And Their Health Care, Volume 40, No. 2, HEALTH AFFAIRS (Project Hope), 297–306 (2021), https://doi.org/10.1377/hlthaff.2020.01452 (last visited Feb. 9, 2022).

[19] Id.

[20] See, e.g., Crossley, Ending-Life Decisions: Some Disability Perspectives, 33 GA. STATE UNIV. L. REV. 893, 900–01 (2017) (reviewing studies); Gerhart, et al., Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers, 23 ANNS. EMERGENCY MED. No. 4, 807–12 (1994).

compromise their quality of care.[21] In 2019, the National Council on Disability released a series of reports exploring how people with disabilities are impacted by bias in critical health care areas including organ transplantation, assisted suicide and determinations of medical futility.[22] The assisted suicide report describes, among other things, a double standard in the provision of suicide prevention efforts where people with disabilities are concerned.[23]

The impact of physician bias is compounded by the lack of knowledge within the medical community of the rights of patients with disabilities under the Americans with Disabilities Act (ADA) and other anti-discrimination statutes. In

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[21] Edwards, Sakellariou & Anstey, Barriers to, and Facilitators of, Access to Cancer Services and Experiences of Cancer Care for Adults with a Physical Disability: A Mixed Methods Systematic Review. Volume 13, Issue 1, DISABILITY AND HEALTH J., 100844 (2020), https://doi.org/10.1016/j.dhjo.2019.100844 (last visited Feb. 9 2022); Varkey, Manwell, Williams, Ibrahim, Brown, Bobula, Horner-Ibler, Schwartz, Konrad, Wiltshire, Linzer & MEMO Investigators, Separate and Unequal: Clinics Where Minority and Nonminority Patients Receive Primary Care, Volume 169, No. 3, ARCHS. INTERNAL MED., 243–250 (2009). https://doi.org/10.1001/archinternmed.2008.559 (last visited Feb 9, 2022).

[22] National Council on Disability, Bioethics and Disability Report Series, (2019) https://ncd.gov/publications/2019/bioethics-report-series (last visited Feb. 9, 2022).

[23] National Council on Disability, The Danger of Assisted Suicide Laws 221 (2019) https://www.ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf (last visited Feb. 9, 2022) (citing Coleman, D., Not Dead Yet, in The Case Against Assisted Suicide—For the Right to End-of-Life Care, ed. Kathleen Foley and Herbert Hendin (Baltimore: The Johns Hopkins University Press, 2002).

the physician study discussed above, 35.8 percent of the physicians surveyed reported knowing little or nothing about their legal responsibilities under the ADA.[24] A majority - 71.2 percent - answered incorrectly when asked who determines a patient's reasonable accommodations, and 20.5 percent did not correctly identify who pays for accommodations.[25] Only 40.7 percent were confident about their ability to provide the same quality of care to patients with disability as they provide others and just 56.5 percent strongly agreed that they welcomed patients with disability into their practices.[26]

Physician bias and lack of knowledge results in barriers to care. Research has shown that disabled patients "experience health care disparities, such as lower rates of screening and more difficulty accessing services, compared to people without disabilities."[27] A 2013 cross-specialty study showed a large segment of the

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[24] Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, Lagu, Pendo & Campbell, U.S. Physicians' Knowledge About the Americans With Disabilities Act And Accommodation Of Patients With Disability, Volume 41, Issue 1, Health Affairs (Project Hope), 96–104 (2022), https://doi.org/10.1377/hlthaff.2021.01136 (last visited Feb. 9, 2022).

[25] Id.

[26] Id. at 297–306.

[27] Iezzoni, Eliminating Health and Health Care Disparities Among the Growing Population of People with Disabilities, Volume 30, No. 10, HEALTH AFF., 1947–54 (2011).

medical community surveyed to be averse to treating patients with disabilities altogether, with a quarter of the doctors studied refusing to even schedule an appointment with potential patients who used wheelchairs.[28]

Legalizing assisted suicide puts people with disabilities at high risk of being killed as the result of the above-described biases, lack of knowledge and the barriers they create. Ample evidence already exists of non-voluntary or involuntary withholding and withdrawal of treatment. For example, in a study published in 2011 in the Journal of Emergency Medicine, over 50% of physician respondents misinterpreted a living will as synonymous with a "do not resuscitate" (DNR) order.[29] About the same percentage of respondents over-interpreted DNR orders as meaning "comfort care" or "end-of-life" care only, while such orders may coexist with the patient receiving aggressive treatments.[30] More clearly involuntary are

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[28] Chen, Disability and Discrimination at the Doctor's Office, N.Y. TIMES, May 23, 2013, https://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/ (citing Lagu, Hannon, Rothberg et al., Access to Subspecialty Care for Patients With Mobility Impairment: A Survey, 158 ANN INTERN. MED. 441–446 (2013), https://doi.org/10.7326/0003-4819-158-6-201303190-00003 (last visited Feb. 9, 2022)).

[29] In fact, a living will sets out the patient's wishes, and may indicate that the patient wishes full care in the event of a code.

[30] Mirarchi, Costello, Puller, Cooney & Kottkamp, TRIAD III: Nationwide Assessment of Living Wills and Do Not Resuscitate Orders, Volume 42, Issue 5, J. EMERGENCY MED., 511-520 (2012), https://www.jem-journal.com/article/S0736-4679(11)00853-5/fulltext (last visited Feb 9, 2022).

futility policies that grant immunity to physicians who deny care that the patient or healthcare surrogate expressly wants.[31]

Because the medical community fails to fully appreciate the value and quality of life with a disability and fails to understand its legal obligation to avoid discrimination in the provision of health care services, the legalizing of assisted suicide will make already troubling matters worse. The more vulnerable members of the disability and aging communities must not be viewed as expendable; assisted suicide must be banned and not merely regulated.

II. Assisted Suicide Violates the Spirit and Letter of the Americans with Disabilities Act by Treating Disabled People Differently and Conveying the Message that Disabled Lives are Less Worthy

A. Assisted Suicide Denies People with Disabilities the Protection of Generally Applicable Abuse, Neglect and Homicide Laws, and the Equal Benefit of State Suicide Prevention Programs.

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). Among other things, the ADA bars the use of disability as a

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[31] Fine & Mayo, Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act, 138 ANN. INTERN. MED. 743-746 (2003).

(dis)qualification for the receipt of services and benefits from the government and medical providers, both public and private, and requires that health care providers provide people with disabilities full and equal access to health care services.[32]

Sanctioning assisted suicide for disabled people, and only disabled people, violates the ADA by treating such persons differently based on explicit disability classifications. Under assisted suicide laws, the presence or absence of disability determines whether an individual is carved out from the protections of abuse, neglect, and homicide laws, and whether expressions of suicidal intent are responded to with intervention and preventative measures or aid in implementing lethal measures. As the mere presence of a disability is the basis for this disparate treatment, assisted suicide laws violate the ADA.

B. Assisted Suicide Promotes Ableist Beliefs that Disabled Lives Are Not Worth Living, and Compounds the Injustice Experienced by Disabled People.

Policies favoring assisted suicide are based on the ableist[33] premise that it is rational for a disabled person to end their own life. Legalizing assisted suicide

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[32] See 42 U.S.C. § 12132; 28 C.F.R. § 35.130(b); 42 U.S.C § 12182; and 28 C.F.R. § 36.202(b) and (c).

[33] On the meaning of “ableist” and “ableism,” see, e.g., Goodley, Dis/Ability Studies: Theorizing Disablism and Ablism 21 (2014) (explaining that ableism “privileges able-bodiedness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias

sends the false and harmful message that the lives of disabled people are intrinsically less valuable and worthwhile than the lives of people without disabilities, and that it is logical for them to want to end their lives. So logical, in fact, that others not only agree with their suicide but actively assist it.

Central to the disability rights movement is the idea that a disabling condition does not inherently diminish one's life and that a life with a disability is not qualitatively worse than life without a disability.[34] To the extent people with disabilities do experience disadvantage, it is the result of pervasive prejudice, stereotypes, and barriers that prevent access to necessary services, supports and social life. Legalizing assisted suicide laws only compounds this injustice, by singling out people with disabilities for different treatment. Under assisted suicide laws only disabled people are removed from the protections of generally applicable

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towards autonomous, independent bodies; and lends support to economic and material dependence on neoliberal and hyper- capitalist forms of production”).

[34] See, e.g., Barnes, E., The Minority Body: A Theory of Disability 71 (2016) (explaining that “there is a vast body of evidence that suggests that non-disabled people are extraordinarily bad at predicting the effects of disability on perceived well-being”); Bagenstos & Schlanger, Hedonic Damages, Hedonic Adaptation, and Disability, 60 VAND. L. REV. 745 (2007) (discussing hedonic damages and noting that “people who experience disabling injuries tend to adapt to their disabilities. To the extent that they experience continuing hedonic loss, it is physical pain and loss of societal opportunities--not anything inherent in the disability--that is the major contributor”).

laws prohibiting abuse, neglect, and homicide. Further, a practice (suicide) that the State would otherwise expend public health resources to prevent as a matter of public health / policy, is instead actively facilitated when a disabled life is at issue.

III. Requests for Assisted Suicide are Intrinsically Intertwined with Social Stigma, Isolation, and Lack of Services, and are Best Addressed by Increasing Access to Supportive Care and Treatment.

A. The Primary Reasons for Requesting Assisted Suicide are the Functions of Psychological and Social Distress.

There are misconceptions about the role pain plays in individuals choosing assisted suicide. Although the desire to avoid pain and fear of pain are often raised as the primary reason for enacting assisted suicide laws, the top five reasons for requesting assisted suicide are disability-related: loss of autonomy; decreasing ability to participate in activities that make life enjoyable; loss of dignity; burden on family, friends/caregivers; and losing control of bodily functions.[35] Studies of patient attitudes toward assisted suicide and euthanasia confirm that patients'

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[35] Based on data from Oregon, the state where assisted suicide has been legal the longest. See Oregon Health Authority, Public Health Division, Oregon Death with Dignity Act - 2020 Data Summary 12 (2021), https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf (last visited Feb. 9, 2022).

interest in physician assisted suicide are more a function of psychological distress and social factors than physical factors.[36] Additionally, 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.'[37]

When people choose to end their lives because of social stigma, isolation, or lack of access to disability-related services, we should not accept this "choice" as voluntary and actively facilitate suicide. Instead, we should respond with supports.

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 pain,

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[36] Breitbart, Rosenfeld & Passik, Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients, AM. J. PSYCHIATRY 153, 238-242 (1996); 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"). See also Hendin & Klerman, Physician-Assisted Suicide: The Dangers of Legalization, 150 AM. J. OF PSYCH. 143 (1993) (Most death requests, even in terminally ill people, are propelled by despair and treatable depression.)

[37] Block & Billings, Patient Requests to Hasten Death: Evaluation and Management in Terminal Care, ARCHIVES of INTERNAL MEDICINE, 154(18):2039-47 (1994).

suffering, and perceived burdens on family members, and restore independence, control, and choice. Access to quality mental health care is particularly relevant to lessening the desire to commit suicide.[38] "[T]hose who attempt suicide – terminally ill or not – often suffer from depression or other mental disorders."[39] "Research indicates ... that many people who request physician-assisted suicide withdraw that request if their depression and pain are treated."[40]

B. For People in Pain, Alternatives to Assisted Suicide Exist.

The movement for the legalization of assisted suicide is driven by anecdotes of people who suffer greatly in the period before they die. But the overwhelming majority of these anecdotes describe situations for which legal alternatives exist.

It is legal in every U.S. state for an individual to create an advance directive that requires the withdrawal of treatment under any conditions the person wishes

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[38] By "quality mental health care" Amici mean voluntary mental health treatment and services that are comprehensive, community-based, recovery-oriented, and culturally and linguistically competent. Nothing in this brief should be construed as recommending or supporting involuntary treatment of any kind.

[39] Washington v. Glucksberg, 521 U.S. 701, 703 (1997).
Physician-Assisted Suicide: Considering the Evidence, Existential Distress, and an Emerging Role for Psychiatry, 43 J. Am. Acad. Psychiatry Law, 183–90 (2015) http://jaapl.org/content/jaapl/43/2/183.full.pdf (last visited Feb. 11, 2022).

[40] Id. See also Bannink, van Gool, van der Heide, van der Haas, (2000) Psychiatric Consultation and Quality of Decision Making in Euthanasia, Volume 356 Issue 9247 LANCET 2067-68 (when psychological issues are explored, the request for assisted suicide may be withdrawn).

and for a patient to refuse any treatment or to require any treatment to be withdrawn. It is also legal to receive sufficient painkillers to be comfortable, and research has shown this will not hasten death.[41] And perhaps least understood, for anyone who is dying in discomfort, it is currently legal in any U.S. state to receive palliative sedation, wherein the dying person is sedated so discomfort is relieved during the dying process. Thus, there is already a legal recourse for painful deaths. These alternatives do not raise the serious difficulties of legalizing assisted suicide.

Assisted suicide is not about choice when people with disabilities lack access to appropriate medical care. The COVID-19 pandemic has revealed long standing disparities in our health care delivery system as we witnessed disproportionate rates of infection and mortality among Black and Latinx Americans, and throughout our senior and disability communities. Amici support making health care options other than physician-assisted suicide – such as rehabilitative, therapeutic, palliative and hospice care – available to all. Now more than ever we should be focused on addressing inequities in our health care delivery system, not expanding access to assisted suicide.

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[41] See Hendin & Foley, Physician-Assisted Suicide in Oregon: A Medical Perspective, 106 MICH. L. REV. 1613 (2008), https://repository.law.umich.edu/mlr/vol106/iss8/7 (last visited Feb. 2, 2022).

IV. Purported Safeguards for Assisted Suicide are Inadequate.

A. The Experience in Oregon Illustrates the Dangers of Assisted Suicide.

Proponents of assisted suicide frequently claim that the dangers of the practice have been disproven by the experience in Oregon.[42] There are multiple problems with this claim, discussed below.

First, nothing in the provisions of Oregon's statute[43] prohibits an heir or caregiver from suggesting assisted suicide to an ill person, or from taking an ill person to the doctor to make such a request. If the ill person has a speech impairment, 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."[44] This could allow an interested party to request assisted suicide on behalf of a person with a communication disability, inviting abuse.

The statute also allows 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

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[42] Oregon's law, passed in 1997, is the oldest in the country.

[43] OR. REV. STAT. §§ 127.800 to 127.897.

[44] OR. REV. STAT. § 127.800 § 1.01(3).

witnesses' certification that the patient is not being coerced is seriously lacking in foundation and persuasive value.

Second, physicians' ability to detect coercion is in doubt. The median duration of the physician-patient relationship in Oregon is reported as 12 weeks.[45] Moreover, the majority of doctors who prescribe under the Oregon law have been referrals by Compassion and Choices, the leading lobby group for these laws.[46]

Third, once the prescription for lethal drugs is issued, there are no further witness requirements. There is no requirement that a witness be present at the time of ingestion and death to attest to consent or intentional self-administration. This includes the prescribing doctor. Data from Oregon on whether the prescribing doctor or other health care provider was present when the lethal dose was ingested or at the death shows that in about half the cases, no such person was present.[47]

Fourth, Oregon's assisted suicide law does not require that alternatives to suicide be offered.[48] As discussed above, the top five reasons that prescribing

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[45] Oregon Death with Dignity Act - 2020 Data Summary, supra note 35 at 12.

[46] See authorities discussed in 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 (last visited Feb. 9, 2022).

[47] Oregon Death with Dignity Act - 2020 Data Summary, supra note 35 at 12.

[48] Ganzini, et al., Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists, 157 AM. J. PSYCHIATRY 595 (Apr. 2000);

physicians report for assisted suicide requests are psycho-social reactions to disability. Two of them are loss of autonomy (91%) and feelings of being a burden on others (47%).[49] Nevertheless, the Oregon law does not require disclosures about consumer-directed home care options that could alleviate these feelings, nor does it ensure that such care will be provided if desired. Amici's experience is that most doctors know little or nothing about home and community based long-term care.

Related, the supposed safeguard of psychiatric referral does not effectively ensure that people with disabilities who state a wish to die have access to appropriate mental health care. The misleadingly labeled "counseling" referral is not defined as providing mental health care or alleviating psychological suffering, but only screening for decisional capacity.[50]

Ganzini, et al., Attitudes of Oregon Psychiatrists Towards Assisted Suicide, 153 AM. J. PSYCH, 1469 – 75 (1996).

[49] Oregon Death with Dignity Act - 2020 Data Summary, supra note 35 at 12.

[50] Moreover, in the large majority of cases, no psychiatric referral is made. In the most recent reporting year, 2020, Oregon physicians referred only 1.2% of persons who requested assisted suicide for a consultation to determine whether their judgment was impaired. Only 3.6% have been referred over all reported years. See Oregon Death with Dignity Act - 2020 Data Summary, supra note 35 at 11. This data suggests that the "safeguards" written into the Oregon law are being circumvented; a previously identified concern. See Hendin & Foley, supra note 41 (documenting the failure to ensure that palliative care alternatives were made available to patients, and the inadequacy of the safeguards ostensibly designed to ensure a patient's psychiatric health and voluntariness of the decision).

Moreover, even where referral is made, studies have shown that 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.[51] 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.[52]

Finally, under the Oregon statute, the state has no authority (or resources) to investigate abuses.[53] The blanket immunities granted to participants in the death,

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[51] Ganzini et al., Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists, supra note 48. See also Sulmasy, Finlay, Fitzgerald, Foley, Payne & Siegler, Physician-Assisted Suicide: Against Medical Neutrality, 34 J. GEN. INTERNAL MED., 1372, https://doi.org/10.1007/s11606-019-05019-1 (last visited Feb. 10, 2022) (explaining how "[i]t is beyond the ken and expertise of the physician to judge whether such suffering is adequate to fulfill the criteria for the provision of lethal drugs.")

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Box. Volume 181, Issue 4, BRITISH J. PSYCHIATRY, 278–279 (2002), https://doi.org/10.1192/bjp.181.4.278 (last visited Feb. 2, 2022).

[53] See, e.g., Oregon Public Health Division, DHS News Release*: investigate Death with Dignity case, DHS says*, March 4, 2005 ("The state law

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.[54] 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.

B. California's Roll Back of Critical Safeguards Illustrates that Safeguards can be Easily Eliminated

In October 2021, California enacted Senate Bill 380, eliminating critical safeguards for individuals with disabilities considering ending their lives under the state's assisted suicide law.[55] SB 380 decimated protections that the Legislature included in the law only a few years prior, including (1) reducing the mandatory 15-day waiting period between requests for assisted suicide drugs to 48 hours; eliminating the requirement that an individual make a final attestation affirming their choice before the drug is administered. These requirements were critical guardrails against erroneous or coerced requests for assisted suicide; without them,

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authorizing physician-assisted suicide neither requires nor authorizes investigations by DHS").

[54] See Disability Rights Education & Defense Fund, Oregon and Washington State Abuses and Complications (2015), https://dredf.org/wp-content/uploads/2015/04/Revised-OR-WA-Abuses.pdf (last visited Feb. 9. 2022) (compiling cases). See also Hendin & Foley, supra note 41.

[55] SB-380 End of Life (Cal. Stats. 2021, ch. 542, eff. Jan. 1, 2022).

the risks to people with disabilities have increased exponentially. The experience in California demonstrates how assisted suicide laws incrementally evolve with no guaranteed protections.

C. The Diagnosis and Prognosis of a "Terminal Condition" is Inherently Uncertain.

The diagnosis and prognosis of a "terminal condition" is inherently uncertain.[56] Clinicians are frequently wrong in their predictions of the capabilities and life spans of people with disabilities.[57] Estimates can be either overly optimistic or overly pessimistic, with prognostication being far from an exact science. For example, one study found 15 percent of critical care patients thought to be dying survived unexpectedly, even when predicted to die by all medical caretakers.[58] Multiple reviews reporting on the accuracy of clinician estimates for cancer patients suggest that clinicians' predictions about length of survival are

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[56] Shapiro, Terminal Uncertainty, SEATTLE WEEKLY, January 14, 2009, https://www.seattleweekly.com/news/terminal-uncertainty/ (exploring both the clinical and statistical uncertainty in terminal prognoses). See also Quill et al., Sounding Board: Care of the Hopelessly Ill, 327 New Eng. J. Med. 1380, 1381 (1992) ("[W]e acknowledge the inexactness of such prognosis [of imminent death]").

[57] Id.

[58] Meadow, Pohlman, Frain, Ren, Kress, Teuteberg & Hall, (2011) Power and Limitations of Daily Prognostications of Death in the Medical Intensive Care Unit, Volume 39, No. 3, CRITICAL CARE MEDICINE, 474–479, https://doi.org/10.1097/CCM.0b013e318205df9b (last visited Feb. 9, 2022).

inaccurate and unreliable.[59] Clinicians' determinations of prognosis in non-cancer patients may be even more inaccurate.[60]

Data from the state of Oregon confirms the above-described uncertainty. Since 1998, four percent of patients prescribed lethal doses of medication under Oregon's assisted suicide statute outlived their prognosis (i.e., lived more than six months after their prescription), data that does not consider people who might have survived had they not taken the drugs quickly.

Because terminal conditions are so often misdiagnosed, establishing a right to assisted suicide will open the door to death imprecisely and unjustifiably to many people with disabilities who are not terminally ill. The risks to recently disabled people, such as those with significant spinal cord injuries and strokes, are

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[59] See, e.g., White, Reid, Harris, Harries & Stone, A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts?, PLOS ONE (2016), https://doi.org/10.1371/journal.pone.0161407 (last visited Feb. 9, 2022) (accuracy of categorical prognostic estimates ranged widely from 23% to 78%). See also, Glare, Virik, Jones, Hudson, Eychmuller, Simes & Christakis, A Systematic Review of Physicians' Survival Predictions in Terminally Ill Cancer Patients, Volume 327, No. 7408, BMJ (Clinical research ed.), 195–198 (2003), https://doi.org/10.1136/bmj.327.7408.195; Zhou, Holden, Lao, Lam, Zeng, Chow, Accuracy of Clinicians' Prediction of Survival and Prognostic Factors Indicative of Survival: a Systematic Review, Volume 16, No. 3, HONG KONG J. OF RADIOLOGY, 168–82 (2013).

[60] Coventry, Grande, Richards & Todd, Prediction of Appropriate Timing of Palliative Care for Older Adults with Non-Malignant Life-Threatening Disease: A Systematic Review, Volume 34, No. 3, AGE & AGEING, 218–27 (2005).

particularly great.[61] These individuals may be misdiagnosed as terminal but end up outliving these prognoses by years. Moreover, 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.[62]

D. Assisted Suicide Can Easily Expand Beyond the Terminally Ill.

Supporters of assisted suicide claim that the practice will be narrowly limited to people who are terminally ill. However, if enacted, assisted suicide can easily expand beyond those with a terminal label. As the New York State Task Force on Life and the Law wrote,

> Once society authorizes assisted suicide for … terminally ill patients experiencing unrelievable suffering, it will be difficult if not impossible to contain the option to such a limited group. Individuals who are not [able to make the choice for themselves], who are not terminally ill, or who cannot

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[61] See, e.g., Ruder, Refusing to Die: The Chris Dunn Story, (United Spinal Ass'n., Kew Gardens, NY), https://unitedspinal.org/refusing-to-die-the-chris-dunn-story/ (last visited Feb. 10, 2022).

[62] Harris, Louis & Associates, The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream (1986); Gerhart et al., supra note 20; Cameron et al., The Life Satisfaction of Nonnormal Persons, 41 J. CONSULTING AND CLINICAL PSYCHOLOGY 207-14 (1973); Ray & West, Social, Sexual and Personal Implications of Paraplegia, 22 PARAPLEGIA, 75–86 (1984); Stensman, Severely Mobility-Disabled People Assess the Quality of Their Lives, 17 SCANDINAVIAN J. REHAB. MED. 87-99 (1985); Whiteneck et al., Rocky Mountain Spinal Cord Injury System Report, NAT'L INST. HANDICAPPED RESEARCH 29-33 (1985); Eisenberg & Saltz, Quality of Life Among Aging Spinal Cord Injured Persons: Long Term Rehabilitation Outcomes, PARAPLEGIA 29 (1991).

> self-administer lethal drugs will also seek the option of assisted suicide, and no principled basis will exist to deny [it][63]

The inevitable expansion of assisted suicide beyond the terminally ill is illustrated by the experiences in the few countries outside the U.S. that permit assisted suicide and other forms of hastened death, including Canada and the Netherlands.[64]

In Canada, people with disabilities who are not terminally ill can already be given a lethal injection to end their lives, and the protections and limitations on the law keep deteriorating. In 2021, the Canadian Government passed a bill that relaxed a number of significant safeguards for getting an assisted death.[65] Under the new law: (1) it is no longer required that death be reasonably foreseeable; (2)

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[63] New York State Task Force on Life and the Law, When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context (1994), https://www.health.ny.gov/regulations/task_force/reports_publications/when_death_is_sought/ (last visited Feb. 9, 2022).

[64] See generally Patients Rights Council, The Netherlands, http://www.patientsrightscouncil.org/site/holland/ (last visited Feb. 10, 2022), Canada, https://www.patientsrightscouncil.org/site/canada/ (last visited Feb. 10, 2022).

[65] Bill C-7 (An Act to amend the Criminal Code (medical assistance in dying)) 2nd Session, 43rd Parliament, 2020-2021. See also, Council of Canadians with Disabilities, CCD Disappointed by House of Commons Yes Vote on Bill C-7 (Medical Aid in Dying), March 12, 2021, http://www.ccdonline.ca/en/humanrights/endoflife/Media-Release-Bill-C7-12March2021

the waiting period has been reduced; (3) the number of witnesses required has been reduced; and (4) the requirement that the individual seeking to die give final consent has been eliminated.[66] The law also expands availability of assisted dying to people with solely mental health disabilities.[67]

The Netherlands provides a twenty-year illustration of the expansion of assisted suicide laws. As the late Dr. Herbert Hendin, one of the world's foremost suicide experts, explained in Congressional testimony:

> Over the past two 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.[68]

Hendin further testified:

> 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.[69]

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[66] Id.

[67] Id.

[68] National Council on Disability, supra note 23 at 45 (quoting Herbert Hendin, MD, *Suicide, Assisted Suicide and Euthanasia: Lessons from the Dutch Experience*, Testimony Summary, US House of Representatives, Subcommittee on the Constitution, April 29, 1996).

[69] Id.

Given the "history of purposeful unequal treatment" to which people with disabilities are subjected,[70] assisted suicide “safeguards” cannot prevent abuse against people with disabilities. The above described history demonstrates that assisted suicide has not and will not be limited to terminally ill persons.[71] Moreover, the fact that doctors frequently assess the "quality of life of chronically ill persons to be poorer than patients themselves hold it to be[72], and give this conclusion great weight in inferring, incorrectly, that such persons would choose to forgo life-prolonging treatment"[73] all but guarantee that assisted suicide will not be limited to terminally ill persons.

E. 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 and lack equal access to the services and supports necessary to live full and equal lives, we cannot presume that requests for assisted suicide are truly voluntary. Amici are profoundly disturbed by the Appellants’ attempts to establish a constitutional right to assisted suicide for people with disabilities in a

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[70] 42 U.S.C. section 12101 (a)(7). See also Section I.A., supra.

[71] See Hendin & Foley, supra note 41.

[72] See Section I.B., supra.

[73] Miles, Physicians and Their Patients’ Suicide, 271 JAMA 1786 (1994).

society that devalues their existence and refuses to find a concomitant right to adequate health care services for people with disabilities. The trend to managed health care, with its emphasis on cost containment, and multiple states' discriminatory response to the COVID pandemic through adoption of crisis care standards that treat elder and disabled lives as disposable,[74] evidence and illustrate how the health care choices of elders and disabled people are unduly and discriminatorily constrained, endangering their lives. Our society is not committed to providing life supports, including in-home personal assistance services and technology supports. The "choice" people with disabilities – and only people with disabilities – are offered is death but not life.

Without adequate and accessible health care services, including 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

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[74] See Section I.A., supra. Further evidencing the lack of respect for and devaluing of disabled lives, consider the recent controversy over comments made by Rochelle Walensky, Director of the Centers for Disease Control and Prevention on January 7, 2022, characterizing the fact that a disproportionate number of deaths due to COVID-19 occurred among "people who were unwell to begin with" as "encouraging news" and failing to acknowledge or address the fact that the disproportionate deaths the disability community has faced are the result of longstanding systemic failures and inequities. See Disability Rights Education and Defense Fund, Letter to Dr. Rochelle Walensky, Director, Centers for Disease Control and Prevention, January 13, 2022, https://dredf.org/wp-content/uploads/2022/01/CDC-Letter-FINAL.pdf (last visited Feb. 9, 2022).

with as much autonomy as possible. Without the professional commitment to provide these essential services, which is the core of suicide prevention, people with disabilities, including those whose conditions are terminal, will not receive the support necessary to make informed and voluntary decisions. There are no safeguards that can protect against these prejudices and realities.

Additionally, no system of safeguards can control conduct which results in the death of the primary witness to any wrongdoing or duress. 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 only "safeguard" that offers effective protection against such abuse is that assisted suicide remain illegal and socially condemned for all persons equally, and that we commit to other policy choices that support the lives of people with disabilities.

CONCLUSION

People with disabilities in the Commonwealth of Massachusetts are seriously threatened by assisted suicide. Amici asks this Court to uphold the order of the Superior Court in this matter, and to recognize that cloaked in the false rhetoric of “death with dignity” and “aid in dying” assisted suicide threatens the civil rights, and the lives, of a profoundly oppressed and marginalized community of people.

Respectfully Submitted,

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