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ISSN 0041-9915 (print) 1942-8405 (online) • DOI 10.5195/lawreview.2017.473
<http://lawreview.law.pitt.edu>



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BUILDING BRIDGES BETWEEN THE CIVIL RIGHTS MOVEMENTS OF PEOPLE WITH DISABILITIES AND THOSE WITH TERMINAL ILLNESS

Kathryn L. Tucker*

INTRODUCTION

The movement for disability rights in the United States is grounded on a bedrock commitment to empowering the individual with autonomy and independence. Despite this foundation, a sharp line has been drawn by much of the disability advocacy community when it comes to the autonomy of a mentally competent terminally ill patient to choose a more peaceful death through aid in dying. This exercise of autonomy has largely been opposed by the disability advocacy community. This Article proposes that given the common principles shared by these two social justice movements and evidence from two decades of open practice in the United States that shows that no risk arises for people with disabilities when aid in dying is available, it is time for the disability advocacy community to reexamine and evolve its position on aid in dying. This evolution has the potential to benefit both advocacy communities.

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Part I discusses the principles common to the movements for disability rights and end-of-life liberty, demonstrating how they are virtually identical.¹ Part II reviews arguments advanced by proponents of end-of-life liberty in favor of empowering terminally ill patients with more options, specifically including aid in dying,² and those advanced by disability rights advocates against this position. In Part III, the data from nearly twenty years of openly practiced aid in dying in the United States is reviewed. Particular focus is given to how data regarding this practice relates to persons with disabilities. Finally, Part IV suggests that it is timely and strategic for the disability advocacy community to reconsider its opposition to aid in dying, and it sets forth indicators that such reconsideration is emerging.

I. COMMON PRINCIPLES UNDERLIE THE MOVEMENTS FOR DISABILITY RIGHTS AND END-OF-LIFE LIBERTY

A. *Brief Background and Evolution of the Disability Rights Movement in the United States*

The modern disability rights movement in the United States is grounded in respect for the individual and a concomitant commitment to empowering people with disabilities with information, autonomy, and control over their own bodies, lives, and medical treatment.³ Before the disability rights movement began in earnest half a century ago, people with disabilities were not commonly empowered as autonomous decision-makers over their own lives.⁴ This disposition was in part because the policy lenses applied to disability were the medical model and the economic model.⁵ Both

¹ This has been recognized by others, including those whose advocacy for disability rights leads them to oppose end of life liberty. See, e.g., Katharina Heyer, *Rejecting Rights: The Disability Critique of Physician Assisted Suicide*, in SPECIAL ISSUE: SOCIAL MOVEMENTS/LEGAL POSSIBILITIES STUDIES IN LAW, POLITICS, AND SOCIETY 78 (Austin Sarat ed., 2011) (“Both movements share a concern over paternalism in the medical care of patients and emphasize the importance of autonomy in decision making.”).

² Aid in dying refers to the practice of a physician providing a mentally competent terminally ill patient with a prescription for medication the patient can ingest to achieve a peaceful death, https://en.wikipedia.org/wiki/Medical_aid_in_dying; see also Kathryn L. Tucker & Fred B. Steele, *Patient Choice at the End of Life: Getting the Language Right*, 28 J. LEGAL MED. 305 (2007) (discussing the battle over language in this social change movement).

³ See, e.g., JOSEPH SHAPIRO, NO PITY, PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1st ed. 1993).

⁴ See SHAPIRO, *supra* note 3.

⁵ *Id.*

of these models focused on the limitations of disabled people and paid scant attention to external factors, which created barriers to integration into society.⁶

Through the medical model lens, disability was seen as something unfortunate that befell a person and prevented a fulfilling life.⁷ Under this view, many people with a wide range of disabilities were housed in institutional settings, often against their wishes.⁸ They were not empowered to make basic choices about where they lived, for how long, or with whom they lived.⁹ Family members and health care providers were often the decision-makers in the lives of people with disabilities, despite the fact that living with chronic disability necessarily makes those people experts about their bodies and best-equipped to make informed decisions about their lives and health care.¹⁰

Through the economic model lens, functional barriers and a lack of adequate work skills were regarded as obstacles preventing disabled people from achieving independence.¹¹ This lens deemed the physical constraints of disability as the reason that disabled people could not support themselves financially or achieve increased participation in society.¹²

By the late 1960s and early 1970s, following in the footsteps of the civil rights and women's rights movements, disability advocates demanded change.¹³ They created a civil rights model of disability.¹⁴ An oft-heard rallying cry of the movement was: "Nothing about us without us."¹⁵

⁶ See Yongjoo Jeon & Donald P. Haider-Markel, *Tracing Issue Definition and Policy Change: An Analysis of Disability Issue Images and Policy Response*, 29 POL'Y STUD. J. 215, 215–16 (2001).

⁷ See Glen W. White et al., *Moving from Independence to Interdependence: A Conceptual Model for Better Understanding Community Participation of Centers for Independent Living Consumers*, 20 J. DISABILITY POL'Y STUD. 233, 234 (2010).

⁸ *Id.* at 233.

⁹ *Id.*

¹⁰ *Id.* at 234.

¹¹ See Jeon & Haider-Markel, *supra* note 6, at 216.

¹² *Id.*

¹³ *Id.* at 218–19.

¹⁴ *Id.* at 219.

¹⁵ See JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* 3–4 (1998). See also *Nothing About Us Without Us*, WIKIPEDIA, https://en.wikipedia.org/wiki/Nothing_About_Us_Without_Us (last visited Jan. 9, 2017) (discussing how "Nothing About Us

The movement grew out of a reaction to the medical and economic models that identified disability as a personal defect rather than an environmental/societally constructed limitation.¹⁶ A central contention was that marginalization of the disabled was a “failure of a structured social environment to adjust to the needs and aspirations of disabled citizens rather than from the inability of a disabled individual to adapt to the demands of society.”¹⁷ This perspective viewed disability as no different from other bodily attributes that sometimes precipitated discrimination, such as gender and skin color.¹⁸ It shifted emphasis from the individuals’ differences to the failings of the external environment and society to accommodate those differences.¹⁹

B. *The Independent Living Movement*

The Independent Living Movement (“ILM”) launched an empowering, person-centered approach to disability: “The independent living perspective views people with disabilities not as patients or clients but as active and responsible consumers. Independent living proponents reject traditional treatment approaches as offensive and disenfranchising and demand control over their own lives.”²⁰ The first Center for Independent Living (“CIL”) was established in Oakland in 1972. It “emphasized personal independence, consumer sovereignty, and consumer choice; it became a

Without Us!” is a slogan used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy; the term in its English form came into use in disability activism during the 1990s).

¹⁶ See generally White et al., *supra* note 7.

¹⁷ Harlan Hahn, *Toward a Politics of Disability: Definitions, Disciplines, and Policies*, INDEPENDENT LIVING INSTITUTE (1985), <https://www.independentliving.org/docs4/hahn2.html>. This view underlies the fierce criticism expressed by many disability advocates of the California court ruling recognizing the right of Elizabeth Bouvia to direct withdrawal of a feeding tube by the hospital where she was an in-patient. See *Bouvia v. Super. Ct. et al.*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986). Bouvia, age twenty-eight, suffered from cerebral palsy and painful, debilitating arthritis. *Id.* at 299. She was almost entirely immobile. *Id.* at 300. She sought court approval to have the tube removed. *Id.* at 298. The appellate court supported her right to make this decision. *Id.* at 306–07. Disability activists have focused much criticism on the failure of the court to acknowledge factors imposed by insufficient societal support for people with disabilities that may have motivated Bouvia’s decision.

¹⁸ See Hahn, *supra* note 17.

¹⁹ See *id.*

²⁰ Romel W. Mackelprang & Richard O. Salsgiver, *People with Disabilities and Social Work: Historical and Contemporary Issues*, 41 SOC. WORK 7, 10 (1996).

national model for centers for independent living.”²¹ CILs (or “ILCs,” Independent Living Centers) continue to advance these objectives: “A hallmark of CIL service delivery that remains a cornerstone today is the value of personal choice and empowerment in all aspects of service delivery.”²²

The ILM sought to vest autonomy and decision-making power in the disabled. CILs are structured to “maximize the leadership, empowerment, independence, and productivity of individuals with disabilities to integrate these individuals into the mainstream of American society.”²³ Consistent with these goals, CILs were to be run and directed primarily by people with disabilities; board and staff were to be comprised of a majority of people with disabilities.²⁴ Instead of having a caregiver, family member, or physician dictate care and treatment, the person with the disability would retain the autonomy to make decisions about care and treatment and to hire and manage treatment providers.²⁵

Advocacy to eradicate the practice of segregating people with disabilities in institutions, often in substandard conditions and against their will, was pursued. The goal was to facilitate and normalize integrated, community-based living with personal assistance and resources to facilitate independence.²⁶

Recognizing that there are many ways people with disabilities may want or need to interact with others to achieve integration, appreciation of interdependence has emerged.²⁷ This approach continues to emphasize respect for individual autonomy, empowerment, and decision-making.

²¹ White et al., *supra* note 7, at 235.

²² *Id.*

²³ *Id.*

²⁴ *Id.*

²⁵ See Mackelprang & Salsgiver, *supra* note 20, at 12.

²⁶ See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 596 (1999) (discussing the right to be free from undue institutionalization and to live in the community).

²⁷ See White et al., *supra* note 7, at 237.

C. *Landmark Legislation Recognizing Autonomy of People with Disabilities*

The enactment of the federal Americans with Disabilities Act, in 1990,²⁸ “signified a national consensus that people with disabilities are fully capable of, and should be allowed to, exercise control of their lives in the mainstream of our society.”²⁹ States also adopted strong legislation to protect the rights of people with disabilities.³⁰ Some disability activists express the view that these legislative efforts have been insufficient and ineffective.³¹

D. *Court Cases Respecting the Autonomy of Disabled Persons*

Law and policy have evolved in the direction of preserving the autonomy of disabled persons. This can be seen, for example, in the context of conservatorship and guardianship, where courts have been careful to limit the appointment of conservators and guardians for people with disabilities.³² In doing so, courts may observe policy preferences articulated by the legislature: “to encourage the development of maximum self-reliance and independence of a protected

²⁸ The Americans with Disabilities Act reflects a national commitment to equal opportunities for individuals with disabilities, including the right to have access to public streets, public transportation, schools, public services, privately owned places of public accommodation, and places of employment. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12111–12181 (2012). Similarly, the Individuals with Disabilities Education Act reflects the national commitment to appropriate education for students with disabilities. Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400–1450 (2012).

²⁹ Andrew I. Batavia, *Disability Rights in the Third Stage of the Independent Living Movement: Disability Community Consensus, Dissent, and the Future of Disability Policy*, 14 STAN. L. & POL’Y REV. 347, 348 (2003).

³⁰ See, e.g., Unruh Act, CAL. CIVIL CODE § 1801 (West 2009); Unruh Civil Rights Act, WIKIPEDIA, https://en.wikipedia.org/wiki/Unruh_Civil_Rights_Act (last accessed Jan. 9, 2017) (“The Unruh Civil Rights Act is a piece of California legislation that specifically outlaws discrimination based on sex, race, color, religion, ancestry, national origin, age, disability, medical condition, marital status, or sexual orientation.”).

³¹ See, e.g., William Peace, *An Image Problem: the ADA and Business*, BLOGSPOT.COM (Aug. 26, 2010), <http://badcripple.blogspot.com/2010/08/image-problem-ada-and-business.html> (“Discrimination is as rampant today as it was the day the ADA was passed.”).

³² See, e.g., *In re Conservatorship of Bittner*, 879 N.W.2d 269, 274 (Ct. App. Mich. 2015) (striking down a probate court order that appointed a conservator for seventy-four-year-old Shirley Bittner, pursuant to a state statute permitting appointment of a conservator if, among other things, “[t]he individual is unable to manage property and business affairs effectively for reasons such as mental illness, mental deficiency, physical illness or disability . . .”).

individual.”³³ They may thus feel bound to “consider whether arrangements less intrusive than a conservatorship will adequately protect an individual’s property as well as her autonomy.”³⁴

Similarly, courts have denied petitions for appointment of a guardian for persons with disabilities. For example, such a petition was denied in a case involving an adult with Down Syndrome.³⁵ The court rejected the usurpation of autonomy that guardianship would have imposed.³⁶ Instead, less draconian measures and supports were to be preferred, including reliance on a support network of family and friends, to preserve as much as possible the autonomy of the disabled person.³⁷ Less restrictive measures were to be favored because “[t]hese alternative resources enable individuals with disabilities to maintain as much control over their own life decisions as they are capable to make in the least restrictive setting.”³⁸

Even in situations where the disability entails severe mental illness, courts have been careful to preserve autonomy to the maximum extent possible, protecting “the right to participate meaningfully in the course of their treatment, to be free from unnecessary or unwanted medication, and to have their rights to personal autonomy and bodily integrity respected by agents of the state.”³⁹

The right of people with disabilities to make personal decisions such as whether to remain in bed instead of a wheelchair, and to choose their clothing, has been

³³ MICH. COMP. LAWS ANN. § 700.5407 (West 2012).

³⁴ *Bittner*, 879 N.W.2d at 277.

³⁵ *In re D.D.*, 19 N.Y.S.3d 867, 874 (N.Y. Sur. Ct. 2015) (denying the petition of a mother and son to be appointed the co-legal guardians of D.D., her twenty-nine-year-old son/his brother, under New York’s Surrogate’s Court Procedure Act, finding the disabled individual was “able to work, to travel independently, to exercise self care and management, and to make decisions about his own affairs, albeit at times with assistance and supervision from his family and supportive programs”).

³⁶ *Id.* at 876 (quoting *In re Mark C.H.*, 906 N.Y.S.2d 419, 427 (N.Y. Sur. Ct. 2010)) (recognizing that although the family may have honorable intentions in wanting to protect D.D. via the guardianship, there was insufficient evidence to justify such severe legal recourse which “vests in the guardian ‘virtually complete power over such individual’”).

³⁷ *Id.* at 870, 875–76. *See also In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848, 854 (N.Y. Sur. Ct. 2012) (The availability of such a support network precludes a guardianship, as “proof that a person with an intellectual disability needs a guardian must exclude the possibility of that person’s ability to live safely in the community supported by family, friends[,] and mental health professionals.”).

³⁸ *In re D.D.*, 19 N.Y.S.3d at 875.

³⁹ *Disability Rights N.J., Inc. v. Velez*, 974 F. Supp. 2d 705, 709 (D.N.J. 2013), *aff’d in part, rev’d in part sub nom.* *Disability Rights N.J., Inc. v. Comm’r, N.J. Dep’t of Human Servs.*, 796 F.3d 293 (3d Cir. 2015).

recognized.⁴⁰ And the *Bouvia* case, discussed above, exemplifies that courts recognize the right of a severely disabled person to make her own informed decision about treatment, even when respecting her decision could precipitate her death.⁴¹

Thus, it is plain that the evolution of the disability rights movement in the United States has, at its core, the goal of engendering respect for the autonomy of people with disabilities and empowering them with the ability to make informed decisions regarding their lives and how they will live them. These very same principles underlie and animate the movement for end-of-life liberty, which supports a broad variety of end-of-life options, including aid in dying.

E. Background and Evolution of the Movement for End-of-Life Liberty in the United States

Modern medicine can draw out the dying process so long that a patient dying of a terminal illness may feel trapped in a torturous, lingering decline.⁴² Sometimes the process of dying takes too long: suffering becomes unbearable, and some patients will want a swifter, more peaceful end.⁴³

In response to this, advocacy to empower patients with the option of aid in dying began to emerge in the United States. Washington was the first state to put a measure related to aid in dying before its voters, and in 1991 it was nearly adopted.⁴⁴ The following year California voters considered a ballot initiative on this issue,

⁴⁰ *Whittington v. Office of Prof'l Regulation*, 87 A.3d 489 (Vt. 2013) (nursing home administrator sanctioned by licensing board for forcing a resident to change into a dress despite her wishes to wear a hospital gown, and to be seated despite the individual's desire to stay in bed, overrode patient autonomy in violation of Vermont's Nursing Home Residents' Bill of Rights) (citing VT. STAT. ANN. tit. 33, § 7301 (West 2016)).

⁴¹ See Hahn, *supra* note 17.

⁴² See, e.g., Atul Gawande, *Letting Go: What should medicine do when it can't save your life?*, THE NEW YORKER (Aug. 2, 2010) ("For all but our most recent history, dying was typically a brief process These days, swift catastrophic illness is the exception; for most people, death comes only after long medical struggle with an incurable condition.").

⁴³ See, e.g., Kathryn L. Tucker, *When Dying Takes Too Long: Activism for Social Change to Protect and Expand Choice at the End of Life*, 33 WHITTIER L. REV. 109 (2011).

⁴⁴ Ellis E. Conklin, *Support for Initiative 119 Slipped Away in Final Hours*, SEATTLE POST-INTELLIGENCER, Nov. 7, 1991, at A9. This effort was the beginning of the modern movement to expand end-of-life choice. Prior to the 1990s, there were a number of advocacy groups focused on expanding end of life choice, including the Euthanasia Educational Council, formed in 1967, renamed Concern For Dying in 1978, and the Hemlock Society, formed in 1980.

which also failed to pass by a small margin.⁴⁵ Oregon learned from these campaigns across its borders and tailored its measure to address the concerns of voters that arose in the Washington and California initiative efforts;⁴⁶ Oregon enacted the nation's first "Death with Dignity Act" in 1994 ("Dignity Act")⁴⁷ by a margin of 51% to 49%.⁴⁸ Oregon's Dignity Act established tightly controlled procedures under which competent, terminally ill adults may obtain a prescription for medication that they ingest to bring about a peaceful death.⁴⁹ In order for a patient to be eligible, the attending physician must, among other things, determine that the patient is an Oregon resident, is mentally competent, and confirm the patient's diagnosis and prognosis.⁵⁰ To qualify as having a "terminal disease," a person must have "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months."⁵¹

The attending physician must inform the patient of his or her diagnosis and prognosis, the risks and probable results of taking the medication, and alternatives to aid in dying, including hospice care and pain relief.⁵² A second "consulting" physician must confirm the attending physician's medical opinion.⁵³ Once a request from a qualifying patient has been properly documented and witnessed, and all waiting periods have expired, the attending physician may prescribe, but not administer, medication that the patient may ingest to bring about a peaceful death.⁵⁴

⁴⁵ Jane Glenn Haas, *Proposition 161 Right-to-die Measure Loses in OC and State*, ORANGE COUNTY REG., Nov. 4, 1992, at A07.

⁴⁶ Oregon achieved this by piling on "safeguards," multiple restrictions on practice and procedure, to survive the political process, a necessity at the time. OR. REV. STAT. § 127.800 *et seq.*

⁴⁷ Carol A. Pratt, *Efforts to Legalize Physician-Assisted Suicide in New York, Washington and Oregon: A Contrast Between Judicial and Initiative Approaches—Who Should Decide?*, 77 OR. L. REV. 1027, 1080–82 (1998).

⁴⁸ OR. LEGIS. COMM. SERVS., BACKGROUND BRIEF: DEATH WITH DIGNITY ACT 1–2 (Sept. 2012), https://www.oregonlegislature.gov/citizen_engagement/Reports/DeathwithDignityAct.pdf.

⁴⁹ Oregon Death with Dignity Act, OR. REV. STAT. § 127.805 (2.01) (2016).

⁵⁰ § 127.815 (3.01).

⁵¹ § 127.800 (1.01) (12).

⁵² § 127.815 (3.01).

⁵³ § 127.820 (3.02); *see also* § 127.800 (1.01).

⁵⁴ §§ 127.840 (3.06)–127.850 (3.08). The Act requires a fifteen-day waiting period between the patient's initial oral request and the writing of the prescription, and a forty-eight hour waiting period between the patient's written request and the writing of the prescription. § 127.850 (3.08).

Physicians are required to file reports with the state documenting provision of aid in dying, and the state issues annual reports revealing a wealth of information about who chooses aid in dying and why.⁵⁵ The Oregon Health Division's Department of Human Services has issued such reports every year since implementation began in 1998.⁵⁶ A number of other states have since enacted statutory permissions for aid in dying, including Washington in 2008, Vermont in 2013, California in 2015, and Colorado in 2016, each with similar reporting provisions, adding to the data about the practice.⁵⁷ Montana began an open practice of aid in dying in 2010, in the wake of a state supreme court decision issued at the end of 2009;⁵⁸ collection and reporting of data is not required in Montana.⁵⁹ Many articles published in medical and legal journals discuss the data and its implications.⁶⁰ As discussed below, some disability advocates have taken a careful look at the data and been vocal in recognizing that no evidence of harm to people with disabilities can be seen when aid in dying becomes an openly available option.

On a parallel track to the efforts in the political sphere to establish access to aid in dying, advocates sought relief in court: patients and physicians challenged laws

⁵⁵ § 127.865 (3.11).

⁵⁶ See Or. Dep't of Human Servs, *Death with Dignity Act Annual Reports*, OR. HEALTH AUTH. (1999–2011), <http://public.health.oregon.gov/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx>.

⁵⁷ The District of Columbia approved an aid in dying measure in 2016. See Kathryn Tucker, *End of Life Liberty in DC*, JURIST (Dec. 15, 2016), <http://www.jurist.org/hotline/2016/12/end-of-life-liberty-in-dc.php>.

⁵⁸ See *Baxter v. State*, 224 P.3d 1211 (Mont. 2009).

⁵⁹ See *id.*

⁶⁰ See, e.g., Andrew I. Batavia, *So Far So Good: Observations on the First Year of Oregon's Death with Dignity Act*, 6 PSYCH. PUB. POL'Y & L. 291, 293 (2000); Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups*, 33 J. MED. ETHICS 591, 593–95 (2007); Arthur E. Chin et al., *Legalized Physician-Assisted Suicide in Oregon—The First Year's Experience*, 340 NEW ENG. J. MED. 577, 578 (1999); David Orentlicher, *The Implementation of Oregon's Death with Dignity Act: Reassuring, but More Data Are Needed*, 6 PSYCH. PUB. POL'Y & L. 489, 491, 497–98 (2000) (reporting that implementation of Oregon law has so far been limited to terminally ill patients with a clear, persistent, and voluntary request for hastened death); Christine K. Cassel & Timothy E. Quill, *Professional Organizations' Position Statements on Physician-Assisted Suicide: A Case for Studied Neutrality*, 138 ANNALS INTERNAL MED. 208, 209 (2003); Joseph B. Straton, *Physician Assistance with Dying: Reframing the Debate; Restricting Access*, 15 TEMP. POL. & C.R. L. REV. 475, 479 (2006); Amy D. Sullivan et al., *Legalized Physician-Assisted Suicide in Oregon—The Second Year*, 342 NEW ENG. J. MED. 598, 598–99 (2000).

prohibiting assisted suicide on federal constitutional grounds in the cases of *Vacco v. Quill*, in New York, and *Washington v. Glucksberg*, in Washington.⁶¹

These cases asserted that liberty and equality guaranteed by the Fourteenth Amendment of the U.S. Constitution protected the right of a competent terminally ill individual to choose aid in dying.⁶² Two federal courts of appeals, the Second Circuit and the Ninth Circuit, sitting en banc, agreed that statutes construed to prevent patients from exercising this option were unconstitutional.⁶³ Although the Supreme Court reversed these decisions, it left the door open to both future legislative reform and a future successful federal constitutional claim.⁶⁴ The core of the plaintiffs' argument in these cases, and in similar cases subsequently litigated in state courts under state constitutions,⁶⁵ was that the choice of a dying patient about how much suffering to endure in the final throes of terminal illness was a profoundly personal decision, which would be informed by the individual's most deeply held values and beliefs, and thus was deserving of protection from control by the government.⁶⁶ The patient, it was argued, should have the autonomy to make his or her own informed decision about this profound matter.⁶⁷

F. Disability Views of End-of-Life Liberty

Some disability advocates recognize that the principles animating support for disability rights are identical to those which animate support for end-of-life liberty. "How a person faces their own death is a private and intimate decision that should be made by that person and that person alone. Nobody else, particularly the state, should have the power to take away that most private and intimate decision."⁶⁸

⁶¹ *Vacco v. Quill*, 521 U.S. 793, 796–97 (1997); *Washington v. Glucksberg*, 521 U.S. 702, 705–06 (1997). These cases have been the subject of extensive commentary. See, e.g., Leading Case, *Physician-Assisted Suicide*, 111 HARV. L. REV. 237, 237–39 (1997).

⁶² *Compassion in Dying v. Washington*, 79 F.3d 790, 838–39 (9th Cir. 1996), *rev'd sub nom.*; *Washington v. Glucksberg*, 521 U.S. 640 (1997); *Quill v. Vacco*, 80 F.3d 716, 718, 731 (2d Cir. 1996), *rev'd*, 521 U.S. 793 (1997).

⁶³ *Compassion in Dying*, 79 F.3d at 838–39; *Quill*, 80 F.3d at 731.

⁶⁴ *Vacco*, 521 U.S. at 797–99; *Glucksberg*, 521 U.S. at 707–09.

⁶⁵ See, e.g., *Morris v. Brandenburg*, 376 P.3d 836 (N.M. 2016); *Myers v. Schneiderman*, 31 N.Y. S.3d 45 (N.Y. App. Div. 2016).

⁶⁶ See generally *Glucksberg*, 521 U.S. 640; see generally *Quill*, 80 F.3d 716.

⁶⁷ See generally *Glucksberg*, 521 U.S. 640; see generally *Quill*, 80 F.3d 716.

⁶⁸ Amicus Curiae Brief of the ALS Association New Mexico Chapter in Support of Plaintiffs-Petitioners at 5, *Morris v. Brandenburg*, 356 P.3d 564 (N.M. Ct. App. 2015) (No. 33,630).

Accordingly, some disability advocates participate as amici in cases seeking to expand in support of end-of-life liberty, arguing:

[I]nterests in autonomy and self-determination are the cornerstones of the disability rights movement . . . the movement has successfully brought recognition to a broad array of rights for people with disabilities and has established a presumption in our society that disabled individuals should be empowered to make independent decisions about their lives. Amici believe that people with disabilities who are facing imminent death, and who are capable of reasoned and voluntary choice, should be permitted to (choose aid in dying). Emphatically, Amici do not believe that providing this choice to terminally ill, competent adults—including those with disabilities—in any way poses a threat to them or diminishes their significance as valuable members of society.⁶⁹

Disability community advocates recognize that across the spectrum of that large community there will be a range of views on the issue: “People with disabilities do not speak with one voice on whether individuals with terminal illnesses should be permitted to end their own suffering with the assistance [of] their physicians and to choose death with dignity.”⁷⁰ That fact was true nearly twenty years ago when *Glucksberg* was litigated and it remains true today. In 2015, the Canadian Supreme Court noted that while some people with disabilities oppose aid in dying, others “take the opposite view.”⁷¹

Disability advocates supportive of end-of-life liberty assert that their peers who oppose this liberty assume that people with disabilities are not capable of making a rational and voluntary decision about how much suffering to endure prior to death when confronted by death due to the progression of a terminal illness.⁷² Further, they argue that this assumption invites the return of a paternalistic view of disabled persons—an attitude which the disability community has worked long and hard to eradicate: “[It] threatens to set back decades of legislative action and social advocacy

⁶⁹ Brief of Autonomy, Inc. and Cascade Aids Project as Amici Curiae Supporting Respondents at 1, 3, *Gonzales v. Oregon*, 546 U.S. 243 (2006) (No. 04-623).

⁷⁰ Brief for Amici Curiae: Gay Men’s Health Crisis et al. in Support of Respondents, *Washington v. Glucksberg*, 521 U.S. 702 (1997) (No. 96-110), 1996 WL 711205, at *1 [hereinafter Brief for Gay Men’s Health Crisis].

⁷¹ *Carter v. Canada*, [2015] 1 S.C.R. 331, ¶ 10 (Can.).

⁷² See Brief for Gay Men’s Health Crisis, *supra* note 70.

devoted to the goal of empowering the disabled to take control over every aspect of their lives.”⁷³ Accordingly, these advocates remind us:

For decades, individuals with disabilities have had to defend their right to make choices and maintain control over all aspects of their lives. . . . [T]his right to autonomy and self-determination applies with no less force to the most uniquely personal, moral[,] and religious choice of all—the choice of whether to hasten impending death from a terminal condition.⁷⁴

Societal pressures may operate differently on those with disabilities than on others. However, the solution is not to ban an end-of-life option; some want the freedom to choose for themselves. Instead, the solution respectful of both the disabled and dying patients is to work to minimize and eradicate disparate treatment of people with disabilities, while respecting the right of competent terminally ill patients to choose a more peaceful death through aid in dying.

II. THE DISABILITY COMMUNITY OPPOSITION TO END-OF-LIFE LIBERTY

As the movement for end-of-life liberty emerged, many disability community advocates became vocal opponents of it. A leading disability rights scholar and advocate characterized this opposition as based on the following reasoning:

[S]ociety has devalued and oppressed people with disabilities, and in a health care system designed to cut costs . . . people with terminal illnesses and other disabilities will be coerced into choosing to end their lives. . . . [T]he right to physician assisted suicide cannot be limited to competent individuals in the terminal stage of an illness, and [] it will inevitably be expanded to competent individuals with non-terminal disabilities, to incompetent individuals, and ultimately to euthanizing people with disabilities against their wills.⁷⁵

⁷³ Amicus Brief for Autonomy, Inc. at 11, *Gonzales v. Oregon*, 546 U.S. 243 (2006) (No. 04-623).

⁷⁴ *Id.* at 26.

⁷⁵ Andrew I. Batavia, *Disability Rights in the Third Stage of the Independent Living Movement: Disability Community Consensus, Dissent, and the Future of Disability Policy*, 14 STAN. L. & POL’Y REV. 347, 350 (2003). Professor Batavia, died in 2003 as this article was being prepared. He was a staunch advocate of end-of-life liberty. He was himself disabled with quadriplegia, following high-level spinal cord injury. Educated at Harvard, Stanford and the University of California, he was an attorney, a health policy expert

Disability advocates opposed to aid in dying commonly rely on slippery slope arguments.⁷⁶ Some in the disability community—who retain the ability to make their own informed decisions about their bodies, lives, and medical treatment—nonetheless fear that someone would deny them medical care if the law permitted removal of life sustaining treatment from a patient who has lost the capacity to express their wishes and whose wishes are expressed through a surrogate. This apprehension was clear from the events surrounding the medical treatment provided to Terri Schiavo. Many disability advocates opposed the withdrawal of Schiavo's feeding tube, even though her properly authorized surrogate expressed that her wish would be to have it withdrawn.⁷⁷ The fear, shared by many persons with disabilities, is that they will be coerced into giving up on life because others devalue their lives or that those who devalue their lives will seek to deny or remove treatment and cause them to die. Those who believe in the right to self-determination in end-of-life medical decision-making must address this fear.⁷⁸ One might hope it could be effectively addressed by evidence showing that there is no adverse impact on people with disabilities when aid in dying is openly available. And such evidence is available. The evidence, along with its impact, is discussed below.

III. WHAT CAN BE LEARNED FROM NEARLY TWENTY YEARS OF DATA ABOUT HOW AVAILABILITY OF AID IN DYING IMPACTS PERSONS WITH DISABILITIES?

As noted above, state statutes permitting aid in dying typically require the collection and reporting of a vast amount of data concerning who chooses aid in dying and the motivations for doing so. Close scrutiny has been given to data concerning the practice of aid in dying. Observers have uniformly concluded that

and an internationally known disability rights activist, having served as a Special Assistant to U.S. Attorney General Thornburgh, and as Professor at Florida International University.

⁷⁶ See, e.g., Amicus Brief of Disability Rights Amici: Not Dead Yet, Adapt, Autistic Self Advocacy Network, Disability Rights Education and Defense Fund, National Council on Independent Living, and the United Spinal Association, *Morris v. Brandenburg*, 356 P.3d 564 (N.M. Ct. App. 2015) (No. 33,630).

⁷⁷ For outstanding discussion of the effort of some disability advocates to thwart Ms. Schiavo's wishes regarding life prolonging treatment, see Kathy L. Cerminara, *COLLATERAL DAMAGE: THE AFTERMATH OF THE POLITICAL CULTURE WARS IN SCHIAVO*, 29 W. NEW ENG. L. REV. 279 (2007), <http://digitalcommons.law.wne.edu/lawreview/vol29/iss2/2>; see also Kathy L. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. 147 (2005).

⁷⁸ See generally Kathy L. Cerminara, *Musings on the Need to Convince Some People with Disabilities that End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 LOY. U. CHI. L.J. 343 (2006).

there has been no disproportionate impact on, or harm to, “vulnerable populations,” including, specifically, persons with disabilities.⁷⁹

These reports are echoed by the experience of the Protection and Advocacy Organization in Oregon, Disability Rights Oregon (“DRO”), the state with the most experience with aid in dying.⁸⁰ DRO’s Executive Director submitted this testimony in policy proceedings of the American Public Health Association:

DRO has not received a complaint of exploitation or coercion of an individual with disabilities in the use of Oregon’s Death with Dignity Act. . . . Complaints have focused on the concern that the Dignity Act might discriminate against persons with disabilities who would seek to make use of the Act but have disabilities which would prevent self-administration, thereby denying these persons the ability to use the Dignity Act.⁸¹

The experience in Oregon has demonstrated that aid in dying puts neither patients nor people with disabilities at risk.⁸² A comprehensive report examined the Oregon experience to assess whether vulnerable populations were harmed, and it concluded that there was no evidence of this.⁸³ Oregon’s experience has caused even staunch opponents to acknowledge that continued opposition to such a law can only be based on personal, moral, or religious grounds.⁸⁴

⁷⁹ Battin et al., *supra* note 60, at 597; *see also* Anne Marie Su, *Physician Assisted Suicide: Debunking the Myths Surrounding the Elderly, Poor, and Disabled*, 10 HASTINGS RACE & POVERTY L.J. 145, 157 (2013) (Evidence from Oregon and Washington “allow[s] us to step outside the realm of hypothesis and form reasoned judgments as to the actual potential for abuse. The most recent empirical data show that commentators’ concerns for vulnerable groups are not justified.”).

⁸⁰ *See infra* notes 78–99 and accompanying text.

⁸¹ Joondeph Aff., Oct. 2007, on file with AM. PUBLIC HEALTH ASSOC. (declaration of Robert Joondeph, Executive Director Oregon Advocacy Center, testifying that no complaints about the Oregon law adversely impacting persons with disabilities have been received by OAC).

⁸² *See* Linda Ganzini et al., *Oregon Physicians’ Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act*, 285 J. AM. MED. ASS’N 2363, 2368 (2001); Melinda A. Lee & Susan W. Tolle, *Oregon’s Assisted Suicide Vote: The Silver Lining*, 124 ANNALS INTERNAL MED. 267, 267–69 (1996); Cassel & Quill, *supra* note 60, at 208–10 (2003); Kathryn A. Smith et al., *Quality of Death and Dying in Patients who Request Physician-Assisted Death*, 14 J. PALLIATIVE MED. 445, 446–47 (2011); Straton, *supra* note 60, at 482.

⁸³ Battin et al., *supra* note 60, at 591.

⁸⁴ Daniel E. Lee, *Physician-Assisted Suicide: A Conservative Critique of Intervention*, HASTINGS CTR. REP. 1, 1, 4 (2003). A recent statement opposing aid in dying adopted by the Conference of Catholic

The Oregon data, and, more recently, similar data from other states, shows that the dire predictions of those initially opposed to the Dignity Act were unfounded and that the option of aid in dying has not been unwillingly forced upon those who are poor, uneducated, uninsured, or otherwise disadvantaged.⁸⁵ In fact, the data shows just the opposite. For example, the reports reflect that patients choosing aid in dying have a high level of education,⁸⁶ are overwhelmingly insured (98% of patients opting for aid in dying had either private health insurance, Medicare, or Medicaid) and almost all (92%) were enrolled in hospice care.⁸⁷ Furthermore, the data demonstrates that aid in dying is rare: during the first eighteen years this option was openly available in Oregon, only 991 patients chose it.⁸⁸ Although there has been a gradual increase in the rate of those opting for aid in dying, the overall rate remains low: in 2015, 218 people received prescriptions, and 50 of those who received the medication did not end up ingesting it.⁸⁹ A 2000 survey of Oregon physicians found that they granted one in six requests for aid in dying, and only one in ten requests

Bishops reflects this as well. See United States Conference of Catholic Bishops, *To Live Each Day with Dignity: A Statement on Physician-Assisted Suicide*, USCCB.ORG (June 16, 2011), <http://www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/upload/bishops-statement-physician-assisted-suicide-to-live-each-day.pdf>.

⁸⁵ DEP'T OF HUMAN RES. OR. HEALTH DIV. CT. FOR DISEASE PREVENTION & EPIDEMIOLOGY, OREGON'S DEATH WITH DIGNITY ACT: THE FIRST YEAR'S EXPERIENCE 7 (1999), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year1.pdf> ("Patients who chose physician-assisted suicide were *not* disproportionately poor (as measured by Medicaid status), less educated, lacking in insurance coverage, or lacking in access to hospice care."); see also Battin et al., *supra* note 60, at 591; Kant Patel, *Euthanasia and Physician-Assisted Suicide Policy in the Netherlands and Oregon: A Comparative Analysis*, 19 J. HEALTH SOC. POL'Y 37, 51–52 (2004) (finding no empirical evidence of slippery slope in Oregon, but more potential for a slide in the Netherlands).

⁸⁶ See, e.g., DEP'T OF HUMAN RES. OR. HEALTH DIV. CT. FOR DISEASE PREVENTION & EPIDEMIOLOGY, THIRTEENTH ANNUAL REPORT ON OREGON'S DEATH WITH DIGNITY ACT 2 (2011), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year13.pdf> [hereinafter THIRTEENTH ANNUAL REPORT].

⁸⁷ *Id.*

⁸⁸ DEP'T OF HUMAN RES. OR. HEALTH DIV. CT. FOR DISEASE PREVENTION & EPIDEMIOLOGY, OREGON DEATH WITH DIGNITY ACT: 2015 DATA SUMMARY (2016), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf> [hereinafter ANNUAL REPORT FOR 2015]; see also David Orentlicher & Christopher M. Callahan, *Feeding Tubes, Slippery Slopes, and Physician-Assisted Suicide*, 25 J. LEGAL MED. 389, 390 (2004) (stating that some commentators have observed that legal medical interventions that will bring about death, such as removal of feeding tubes, are reluctantly taken, and have reasoned from this that the same would be true for aid in dying).

⁸⁹ ANNUAL REPORT FOR 2015, *supra* note 88.

resulted in hastened death.⁹⁰ Interestingly, more than one-third of patients who complete the process of seeking medications for aid in dying do not go on to consume them.⁹¹ Deriving comfort from having the option to control their time of death, these patients ultimately die of their disease without exercising that control.⁹²

Observers studying aid in dying in Oregon have concluded that the law poses no risk to patients. Leading scholars have concluded: “I [was] worried about people being pressured to do this But this data confirms . . . that the policy in Oregon is working. There is no evidence of abuse or coercion, or misuse of the policy.”⁹³

Indeed, rather than posing a risk to patients or the medical profession, the open availability of aid in dying has galvanized significant improvements in the care of those terminally ill and dying in Oregon. Oregon physicians report that since aid in dying has been openly available, they have worked hard to improve end-of-life care, taking educational courses on how to treat pain in the terminally ill and how to recognize depression and other psychiatric disorders, and more frequently referring patients to hospice.⁹⁴ Surveyed on their efforts to improve end-of-life care since aid in dying became available, 30% of responding physicians had increased referrals to hospice care and 76% made efforts to improve their knowledge of pain management.⁹⁵ Hospice nurses and social workers surveyed in Oregon observed an

⁹⁰ Linda Ganzini et al., *Physicians' Experiences with the Oregon Death with Dignity Act*, 342 NEW ENG. J. MED. 557, 557, 561 (2000) (finding that the availability of palliative care led some, but not all, patients to change their mind about hastening death).

⁹¹ See ANNUAL REPORT FOR 2015, *supra* note 88.

⁹² See *id.* (showing number of recipients of prescription each year, compared to number of deaths from use of prescription).

⁹³ William McCall, *Assisted-Suicide Cases Down in '04, Terminally Ill Oregonians Took Lethal Drug Doses*, COLUMBIAN, Mar. 11, 2005, § C2, at 37 (quoting Arthur Caplan, then Director of the Center for Bioethics at the University of Pennsylvania School of Medicine); see also Straton, *supra* note 60, at 481–82.

⁹⁴ See Ganzini et al., *supra* note 82, at 2367–68; Lee & Tolle, *supra* note 82, at 267–69; Cassel & Quill, *supra* note 60, at 209; see also Lawrence J. Schneiderman, *Physician-Assisted Dying*, 293 J. AM. MED. ASS'N 501 (2005) (reviewing PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE (Timothy E. Quill, & Margaret P. Battin eds., 2004)) (“Indeed, one of the unexpected yet undeniable consequences of Oregon’s Death with Dignity Act permitting physician aid in dying is that ‘many important and measurable improvements in end-of-life care’ occurred following the Act’s implementation. Rather than becoming the brutal abattoir for hapless patients that some critics predicted, the state is a leader in providing excellent and compassionate palliative care.”).

⁹⁵ Ganzini et al., *supra* note 82, at 2363.

increase in physician knowledge of palliative care and willingness to refer to hospice.⁹⁶

In addition to the improvement of end-of-life care, the option of aid in dying has psychological benefits for both the terminally ill and the healthy.⁹⁷ The availability of the option of aid in dying gives the terminally ill autonomy, control, and choice—the overwhelming motivational factor behind the decision to request assistance in dying.⁹⁸ Healthy Oregonians know that if they ever face a terminal illness, they will have this additional end-of-life option.

Furthermore, the data demonstrates that the option of aid in dying has spurred improvements in end-of-life care and benefited all terminally ill Oregonians.⁹⁹ A central argument against allowing patients access to aid in dying is that certain risks would arise if the option were available, such as subtle coercion, undue influence, and deprivation of autonomy.¹⁰⁰ Experience disproves this, however, undermining arguments against aid in dying¹⁰¹ and leading a growing number of national medical

⁹⁶ Elizabeth R. Goy et al., *Oregon Hospice Nurses and Social Workers' Assessment of Physician Progress in Palliative Care Over the Past 5 Years*, 1 PALLIATIVE & SUPPORTIVE CARE 215, 218 (2003).

⁹⁷ Kathy L. Cerninara & Alina Perez, *Empirical Research Relevant to the Law: Existing Findings and Future Directions, Therapeutic Death: A Look at Oregon's Law*, 6 PSYCHOL. PUB. POL'Y & L. 503, 512–13 (2000).

⁹⁸ *Id.* (acknowledging concerns about negative effects of aid in dying, but the data from Oregon in one year justifies optimistic view); Smith et al., *supra* note 82, at 445, 449. See also Linda Ganzini et al., *Oregon Physicians' Perceptions of Patients who Request Assisted Suicide and Their Families*, 6 J. PALLIATIVE MED. 381, 381 (2003) (finding physicians receiving requests for lethal medication perceive patients as wanting to control their deaths); Linda Ganzini et al., *Experiences of Oregon Nurses and Social Workers with Hospice Patients who Requested Assistance with Suicide*, 347 NEW ENG. J. MED. 582, 582 (2002) (showing nurses and social workers rated desire to control circumstances of death as most important reason for requesting aid in dying).

⁹⁹ Smith et al., *supra* note 82, at 445–49.

¹⁰⁰ See, e.g., *Washington v. Glucksberg*, 521 U.S. 702, 732 (1997) (“We have recognized . . . the real risk of subtle coercion and undue influence in end-of-life situations.”).

¹⁰¹ See Orentlicher & Callahan, *supra* note 88, at 409. Other reasons have been offered which put to rest the fear that availability of aid in dying will put patients at risk. For example, one commentator studied the reluctance of patients and providers to withdraw feeding tubes, an option legal in every state. *Id.* at 399. He concluded that the data show that feeding tubes are over utilized, demonstrating reluctance to take steps that will precipitate death, and that such reluctance will apply in context of aid in dying. *Id.* at 398–99; see also Kathryn L. Tucker, *The Chicken and the Egg: The Pursuit of Choice for a Human Hastened-Death as a Catalyst for Improved End-of-Life Care; Improved End-of-Life Care as a Precondition for Legalization of Assisted Dying*, 60 N.Y.U. ANN. SURV. AM. L. 355, 377–78 (2004).

and health policy organizations to conclude that aid in dying is an important end-of-life option and to adopt policies supportive of the practice.¹⁰²

Oregon's experience with successfully integrating aid in dying into end-of-life options available to patients proved to be influential in the successful campaign to enact similar laws in Washington in 2008, Vermont in 2013, California in 2015, and Colorado in 2016.¹⁰³ Some disability rights groups, and other organizations with commitment to both disability rights and the civil liberties of the terminally ill, have taken a close look at this data and begun to advocate for expanding end-of-life liberty. The American Public Health Association, which takes keen interest in public health, patient rights, and disability rights, gave careful consideration to the data—in particular whether it reflected any danger to persons with disabilities—and adopted a policy supportive of aid in dying in 2008.¹⁰⁴ More recently, ALS advocates have begun openly supporting the right of terminally ill persons to be empowered to choose a more peaceful death through aid in dying.¹⁰⁵ And still more recently the New York Civil Liberties Union undertook careful examination of the matter. It adopted a policy affirming support for terminally ill patients to have access to aid in

¹⁰² See AM. COLL. LEGAL MED., *ACLM Policy on Aid in Dying 2* (2008) (“[T]he ACLM recognizes patient autonomy and the right of a mentally competent, though terminally ill, person to hasten what might otherwise be objectively considered a protracted, undignified, or painful death”); AM. MED. STUDENT ASS'N, *Constitution and Bylaws*, <http://www.amsa.org/wp-content/uploads/2015/03/2016-CBIA.pdf> (last visited Dec. 5, 2016); AM. PUB. HEALTH ASS'N, *Patients' Rights to Self-Determination at the End of Life*, POL'Y STATEMENT DATABASE (Dec. 28, 2008), <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/10/13/46/death-with-dignity> (“A small fraction of dying people confront a dying process so prolonged and marked by such extreme suffering that they determine hastening impending death to be the best alternative. Many Americans believe that the option of death with dignity should be open to those facing a terminal illness marked by extreme suffering.”). See also AM. MED. WOMEN'S ASS'N, *American Medical Women's Association Position Paper on Aid in Dying 1–2* (2007), https://www.amwa-doc.org/wp-content/uploads/2013/12/Aid_in_Dying1.pdf (supporting the passage of aid in dying laws which empower mentally competent, terminally ill patients and protect participating physicians, such as that passed in Oregon, the Oregon Death with Dignity Act).

¹⁰³ See Washington Death with Dignity Act, WASH. REV. CODE ANN. § 70.245 (West) (2009); Vermont Patient Choice at End of Life Act, VT. STAT. ANN. tit. 18, §§ 5281–5293 (West) (2013); California End of Life Option Act, CAL. HEALTH & SAFETY CODE §§ 443–443.22 (West) (2016); Colorado End of Life Options Act, COLO. REV. STAT. ANN. § 25-48-101–25-48-123 (West) (2016).

¹⁰⁴ Am. Pub. Health Ass'n, *Patients' Rights to Self-Determination at the End of Life*, Pol'y Statement Database (Dec. 28, 2008), <http://www.apha.org/advocacy/policy/policysearch/default.htm?id=1372>.

¹⁰⁵ Amicus Curiae Brief of the ALS Association New Mexico Chapter in Support of Plaintiffs-Appellees, *Morris v. Brandenburg*, 356 P.3d 564 (N.M. Ct. App. 2015) (No. 33,630).

dying, while being careful to recognize disability concerns, and it filed an amicus brief in a case seeking to expand end-of-life liberty in New York.¹⁰⁶

Others, despite the evidence, continue to oppose this position.¹⁰⁷ It is possible that they do so because of the phenomenon known as “cognitive-dissonance avoidance,” which commentators have observed “will steel individuals to resist empirical data that either threatens practices they revere or bolsters ones they despise, particularly when accepting such data would force them to disagree with individuals they respect.”¹⁰⁸ In light of this, reconsideration of the issue by respected disability advocates, and the emergence of support from them, seems potentially useful to evolving the polarization on this issue. Researchers have observed that “when subjects see the argument they are disposed to reject being made by the advocate whose values they share . . . polarization shrinks to the point of disappearing.”¹⁰⁹ “Having a principled debater whose cultural worldview matches that of the audience is an important part of assisting the audience in crediting the version of the facts that a policymaker believes to be true.”¹¹⁰

Oregon served the function of a “laboratory,” which the U.S. Supreme Court invited in *Washington v. Glucksberg*, demonstrating to other states how the practice of aid in dying works. Oregon’s experience, later mimicked by other states, reveals

¹⁰⁶ See Brief of Amicus Curiae New York Civil Liberties Union, *Myers v. Schneiderman*, 140 A.D.3d 51 (N.Y. App. Div. 2016) (No. 1511622015) [hereinafter Brief of NYCLU].

¹⁰⁷ See, e.g., 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, *Myers v. Schneiderman*, 140 A.D.3d 51 (N.Y. App. Div. 2016) (No. APL-2016-00129) [hereinafter Brief of Disability Rights Amici].

¹⁰⁸ Kathy Cerminara, *Law, Perception, and Cultural Cognition Near the End of Life*, 55 WASHBURN L.J. 597, 632 (2016) (citing Dan M. Kahan & Donald Brahm, *Cultural Cognition and Public Policy*, 24 YALE L. & POL’Y REV. 149, 165 (2006)). The phenomenon of a vocal fraction of the populace opposing a practice for the stated reason that it could pose a risk of harm, despite evidence that no harm presents, is not unique to this issue. It can also be seen, for example, in the arena of vaccination.

¹⁰⁹ Dan M. Kahan et al., *Who Fears the HPV Vaccine, Who Doesn’t, and Why? An Experimental Study of the Mechanisms of Cultural Cognition*, 34 L. HUM. BEHAV. 501, 511 (2010).

¹¹⁰ Cerminara, *supra* note 108, at 635. Professor Cerminara urges that advocates “recognize the different roles . . . skeptics play and employ cultural cognition theory to work with the mixture of opinions and facts being debated.” *Id.* at 636.

that making aid in dying available poses no danger—specifically to people with disabilities—nor does it undermine good end-of-life care.¹¹¹

The disability community has, in other contexts, insisted that if disparate treatment is going to be allowed toward a person with a disability, it must be justified on sound evidence that a real risk supports it—it has argued against discrimination of people with disabilities where there is scant basis to justify discrimination. For example, in a case brought before the U.S. Supreme Court, disability advocates argued against the ability of a dentist to deny care to a person with HIV, a disability, based on an unfounded fear that treating him would put the dentist or staff at risk.¹¹² Dr. Bragdon, a dentist, refused to fill a cavity of a patient with HIV asserting that treating him would pose a “direct threat” to his health and safety, that of his staff, and other patients.¹¹³ The Court articulated a very stringent standard for such discrimination: The dentist could refuse treatment only if treating the patient posed a “significant risk” based on “objective, scientific information.”¹¹⁴ In determining whether such a risk exists, the Court declared, “the views of public health authorities, such as the U.S. Public Health Service, CDC, and the National Institutes of Health, are of special weight and authority.”¹¹⁵ The Court emphasized that health care practitioners could not demand the elimination of *all* risks.¹¹⁶ “Because few, if any, activities in life are risk free,” the Court said, “the ADA do[es] not ask whether a risk exists, but whether it is significant.”¹¹⁷ On remand, the lower court concluded that the risk of HIV transmission through an accidental needlestick did not justify the discrimination.¹¹⁸ *Bragdon* guarantees the rights of patients with HIV to receive medical care without discrimination.¹¹⁹ Applying this reasoning to the end-of-life liberty context, the chance that the availability of aid in dying to competent terminally ill patients will pose a significant risk to people with disabilities is, as established by empirical evidence, so small that it ought not be grounds to deny patients access. Respecting this notion is important to the continued validity of the

¹¹¹ See *supra* notes 78–99, 103 and accompanying text.

¹¹² See *Bragdon v. Abbott*, 524 U.S. 624 (1998).

¹¹³ *Id.* at 624.

¹¹⁴ *Id.* at 649.

¹¹⁵ *Id.* at 650.

¹¹⁶ *Id.* at 649–50.

¹¹⁷ *Id.* at 649.

¹¹⁸ See *Abbott v. Bragdon*, 163 F.3d 87 (1st Cir. 1998).

¹¹⁹ See *Bragdon v. Abbott*, 524 U.S. 624 (1998); *Abbott v. Bragdon*, 163 F.3d 87 (1st Cir. 1998).

reasoning on which *Bragdon* is based. It behooves the disability community to do so.

IV. RECONCILING THE DISABILITY COMMUNITY ADVOCACY WITH THE END-OF-LIFE LIBERTY MOVEMENT

In light of the common principles underlying the movements for disability rights and end-of-life liberty, it is incongruous that these movements do not often actively support each other. Failure to respect the autonomy of an individual to make their own informed decisions about their own bodies, lives, and course of medical treatment jeopardizes respect for such autonomy across a range of applications. If it is acceptable to deny the autonomy of a competent terminally ill patient to choose how much suffering to endure prior to death, does it become conceivable to deny the autonomy of a person with a disability to choose how much medical treatment to pursue regardless how extreme the disability? This is a real risk, and one that the disability community ought to take seriously.

Fortunately, signs of an emerging evolution of views can be seen. Organizations with longstanding commitment to both patient rights and disability rights—ranging from the American Public Health Association, to the American Civil Liberties Union, to groups representing people with disabilities with a rapid trajectory to death such as ALS—are taking a close look at the evidence emerging from the laboratory of the states and concluding that the evidence shows that the rights of terminally ill patients are properly respected when end-of-life liberty is expanded, and that doing so poses no threat to people with disabilities. Accordingly, support for aid in dying is growing among civil liberties organizations concerned with both the rights of the disabled and the terminally ill. As noted by the New York Civil Liberties Union in an amicus brief filed in a case seeking to establish access to aid in dying in New York: “[I]t is important to acknowledge that certain bedrock principles, including both personal and medical autonomy, underlie both the disability rights movement and the end-of-life rights movement.”¹²⁰

¹²⁰ Brief of NYCLU, *supra* note 106, at 4.