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Equality of Autonomy? Physician Aid in Dying and Supported Decision Making

Megan S. Wright

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The legalization of physician aid in dying (“PAID”) has been spreading across the United States and is currently legal in ten jurisdictions. Meant to respect autonomy at the end of life, PAID legislation is modeled after the Oregon Death with Dignity Act, which permits only terminally ill adults with contemporaneous decisional capacity to choose to hasten death with PAID. Right-to-die advocates and legal scholars have critiqued the strict eligibility requirements, which although meant to function as safeguards against mistakes and abuse, can be autonomy thwarting. Advocates and scholars have thus proposed using advance directives for PAID to expand access to this end-of-life option. Such a reform would permit terminally ill persons with moderate dementia or other types of decisional impairments to access PAID.

To date, scholars have neglected another possibility for respecting autonomy at the end of life by expanding access to PAID for terminally ill persons with decisional impairments: supported decision-making. Supported decision-making legislation is also spreading across the United States as an alternative to guardianship and surrogate decision-making for persons with cognitive disabilities and is an option in nine jurisdictions. With this model of decision-making, a person with a cognitive disability receives decision-making assistance from supporters to facilitate the exercise of autonomy and retain legal capacity.

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This Article is the first to address whether terminally ill persons with cognitive impairments should be able to access PAID through supported decision-making. If provided with decision-making support, terminally ill persons with cognitive impairments may be able to elect PAID intentionally, voluntarily, and with understanding; that is, despite their impairments, such persons may be capable of autonomous end-of-life decision-making. This Article thus argues that the principle of equality demands that the law not exclude terminally ill supported persons with decisional impairments from PAID. This Article also argues that supported decision-making is a superior means for terminally ill persons with decisional impairments to access this end-of-life option compared to advance directives, which have numerous and well-documented problems.

This Article also considers how PAID and supported decision-making laws interact in the one jurisdiction that currently has both laws, the District of Columbia, and concludes that it may be permissible for a terminally ill person with a decisional impairment, which would otherwise preclude them from accessing PAID, to elect this end-of-life option with assistance from a supporter. The Article ends with considerations for policymakers about building additional safeguards into these laws to ensure that persons with cognitive disabilities do not mistakenly, without understanding, or after the application of undue pressure hasten death through PAID.

INTRODUCTION	159
I. LEGAL CONTEXT.....	161
A. Autonomy and the Right to Die.....	162
1. Physician Aid in Dying.....	163
2. Physician Aid in Dying and Advance Directives.....	166
B. Autonomy and Supported Decision-Making	168
II. EQUALITY OF AUTONOMY: PHYSICIAN AID IN DYING FOR TERMINALLY ILL SUPPORTED PERSONS.....	172
A. Autonomy at the Intersection of Supported Decision-Making and Physician Aid in Dying.....	172
1. Intent.....	174
2. Understanding.....	175
3. No Undue Influence or Coercion.....	176
4. Contextualizing Autonomy.....	179
B. Equality of Autonomy	182
III. ACCESSING PHYSICIAN AID IN DYING WITH SUPPORT IN THE DISTRICT OF COLUMBIA.....	185
IV. QUESTIONS MOVING FORWARD.....	188
A. Existing Safeguards.....	189
B. Building In Additional Safeguards?.....	194
CONCLUSION.....	196

INTRODUCTION

Right-to-die advocates have enjoyed recent success in their efforts to legalize physician aid in dying (“PAID”),¹ an end-of-life option that has spread to almost a fifth of the states and has strong public support.² Where PAID is legal, terminally ill adults with contemporaneous decisional capacity can voluntarily request a prescription for a medication that, when self-administered, will hasten death.³

One explicit purpose of PAID laws is to promote autonomy and dignity at the end of life by allowing people to avoid suffering by choosing the time, place, and manner of their deaths.⁴ But the laws do not permit everyone who may be interested in PAID the option of using it as a means of hastening death. For example, only adults may elect PAID, but mature minors who are facing a terminal illness arguably have self-determination and dignitary interests in how their lives end as well. Thus, PAID laws constrain the exercise of autonomy for some people at the end of life.

This Article focuses on another important way in which access to PAID is limited: the contemporaneous decisional capacity requirement. Terminally ill persons who are interested in PAID, but lack decisional capacity⁵ because they have, for instance, moderate dementia or decisional impairments due to a stroke, are not, under current law, able to choose PAID. Requiring contemporaneous decisional capacity for PAID is meant to function as a safeguard against mistake or abuse but reduces the end-of-life options available to persons with decisional impairments.

1. Physician aid in dying is also known as physician-assisted suicide or medically assisted dying. See David Orentlicher et al., *The Changing Legal Climate for Physician Aid in Dying*, 311 JAMA 1961, 1961 (2014) (describing different terminology).

2. Megan Brenan, *Americans’ Strong Support for Euthanasia Persists*, GALLUP (May 31, 2018), <https://news.gallup.com/poll/235145/americans-strong-support-euthanasia-persists.aspx> (describing how 65% of Americans believe PAID should be legal).

3. In many other countries that have legalized medically assisted dying, physician administration—i.e., euthanasia—is legal. See, e.g., GOV’T OF CANADA, *Medical Assistance in Dying*, <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html> (last visited Feb. 19, 2020). In the United States, euthanasia is illegal, which is why there is a self-administration requirement for using PAID. Despite the illegality of euthanasia, public opinion is more supportive of euthanasia (72%) than PAID (65%), although survey researchers caution that this result may be an artifact of the wording of the question. Brenan, *supra* note 2. However, the difference in support may reflect true preferences given that in other countries, persons opt for euthanasia instead of self-administration of the lethal medication. See, e.g., HEALTH CANADA, *FOURTH INTERIM REPORT ON MEDICAL ASSISTANCE IN DYING IN CANADA 5* (2019), <https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019/medical-assistance-dying-interim-report-april-2019-eng.pdf> (reporting that 1 out of 2,614 medically assisted deaths in 2018 resulted from self-administration).

4. See *Death with Dignity Acts*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/learn/death-with-dignity-acts/> (last visited Feb. 19, 2020).

5. This Article uses phrases such as “lack decisional capacity,” “decisional impairments,” and “cognitive disabilities” interchangeably.

The exclusion of persons with decisional impairments from PAID has led some scholars to advocate for using advance directives for this end-of-life option.⁶ Under such proposals, advance directives for PAID would function similarly to other types of written advance directives,⁷ which are a means to honor autonomy even after capacity has been lost. Once a patient with a decisional impairment becomes terminally ill (and thus eligible for PAID), surrogate decision-makers and physicians would consult the patient's advance directive to determine whether the patient desired PAID, and if so, the patient could be prescribed the lethal medication. Adopting this proposed reform would respect the *precedent* autonomy of persons with impaired decision-making.

But using advance directives causes several problems. For example, after the completion of an advance directive and subsequent loss of decisional capacity, a person may change their mind but be locked into their prior preferences. Additionally, advance directives may be difficult for others to interpret, and even when interpreted correctly, the directives are not always followed.⁸ If advance directives are not functioning as intended in other circumstances, it may be unwise to apply this problematic legal tool to another end-of-life context. Furthermore, the proposal to use advance directives for PAID does not acknowledge that persons with decisional impairments may be able to exercise autonomy upon becoming terminally ill.

A better way to ensure respect for (contemporaneous) autonomy at the end of life for persons with decisional impairments is with supported decision-making, which disability advocates have successfully convinced several state legislatures to adopt.⁹ With formal supported decision-making, persons with cognitive disabilities voluntarily enter into agreements with supporters who provide decision-making assistance. The person with a disability retains legal capacity despite decisional impairments that in the absence of these laws would enable others to decide on their behalf. Supported decision-making is meant to decrease use of guardianship and surrogate decisioning for persons with decisional impairments and facilitate the agency and respect the self-determination of persons with disabilities that impair cognition. Supported decision-making conceptualizes autonomy as relational in nature.

To date, scholarship has neglected the convergence of supported decision-making and PAID laws, both of which prioritize autonomous decision-making. PAID laws exclude persons with decisional impairments because the laws aim to respect autonomy, but this exclusion assumes that persons with decisional

6. See *infra* Section I.A.2.

7. Advance directives are executed prior to the onset of decisional impairments and provide healthcare instructions to be followed should a person be unable to make their own decisions in the future. See generally UNIFORM HEALTH-CARE DECISIONS ACT (UNIF. LAW COMM'N 1993) [hereinafter UHCDA] (describing advance directives).

8. See generally Thaddeus Mason Pope, *Legal Briefing: New Penalties for Disregarding Advance Directives and Do-Not-Resuscitate Orders*, 28 J. CLINICAL ETHICS 74 (2017).

9. See, e.g., Eliana J. Theodorou, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973, 998–1004 (2018) (discussing how disability advocates in Texas created a coalition in support of supported decision-making).

impairments are incapable of autonomous decision-making. The option of supported decision-making combined with understanding autonomy as relational troubles this assumption, however. If a person with decisional impairments can decide autonomously—intentionally, voluntarily, and with understanding—when they are assisted in decision-making, it is not obvious that such persons should be excluded from PAID.

This Article is the first to consider whether terminally ill persons with decisional impairments that would otherwise render them ineligible for PAID can and should be able to access this end-of-life option if they use supported decision-making to do so. Given that both PAID and supported decision-making laws are increasingly being adopted into state legislation, it is important to address these legal, ethical, and theoretical questions.

This Article proceeds as follows. Part I first describes PAID laws and the problematic proposals to expand access to PAID through use of advance directives. Part I then describes supported decision-making laws. Part II explores the question of whether terminally ill supported persons with decisional impairments *should* be able to hasten death through PAID. Part II first explores whether choosing PAID is consistent with autonomous decision-making for this population. After concluding that it is possible for some terminally ill persons with decisional impairments to autonomously choose this end-of-life option, Part II argues that the principle of equality demands that the law not exclude terminally ill supported persons with decisional impairments from PAID when this option is available to similarly situated individuals. Part III focuses on how PAID and supported decision-makings laws interact in the District of Columbia, the only U.S. jurisdiction with both types of laws. Presently, in the District of Columbia, it may be possible for a terminally ill person with a decisional impairment that may otherwise make them ineligible for PAID to choose this end-of-life option with the assistance of a supporter. Part IV analyzes the existing safeguards in PAID and supported decision-making laws to assess whether there is an appropriate balance between respecting the autonomy of terminally ill persons with decisional impairments while also ensuring they are protected from abuse. The Article concludes by arguing that supported decision-making is a superior means for terminally ill persons with decisional impairments to access PAID compared to advance directives.

I. LEGAL CONTEXT

This Part describes end-of-life decision-making and supported decision-making laws to provide a foundation for understanding their interaction. First this Part will describe PAID laws. Then it will describe the process of advance planning for healthcare decision-making upon future loss of capacity, along with current proposals to use advance directives to access PAID. Finally, this Part will describe supported decision-making laws in the United States.

A. *Autonomy and the Right to Die*

The common law and constitutional rights to refuse life-sustaining and life-saving medical treatments are based on respect for autonomy,¹⁰ a principle which is foundational to U.S. law.¹¹ Courts grappling with the contours of the right to refuse medical treatment, which can be considered a limited right to die, have discussed it in terms of liberty, dignity, privacy, bodily integrity, and self-determination¹²—all terms that are synonyms for, or components of, autonomy.

The right to refuse medical treatment, including the provision of artificial nutrition and hydration,¹³ survives loss of decisional capacity.¹⁴ The law allows for people to make future decisions about their medical treatment and end-of-life wishes through a process known as advance care planning. Advance care planning can include appointing a healthcare agent; completing a living will with written instructions about what an individual wants in the event of various medical scenarios or how others should make decisions on their behalf; discussing one's wishes or preferences with loved ones; or completing various medical orders such as a Physician's Order for Life-Sustaining Treatment.¹⁵ Advance care planning is meant to ensure that an individual's healthcare decision-making autonomy is respected throughout their life, even when they lack decision-making capacity, but it tends to privilege precedent rather than contemporaneous autonomy.

Not everyone who may wish to hasten death is dependent upon life-sustaining treatment such as artificial nutrition and hydration, meaning that although such persons have the legal right to refuse medical treatment, they are not in a position to exercise it and subsequently die, no matter how strong their autonomy interests in the time, manner, and setting of their death may be. Right-to-die advocates thus attempted to establish a constitutional right to hasten death with physician assistance for terminally ill persons who wanted to avoid a prolonged death in a hospital or long-term care facility, framing this preference in terms of respect for autonomy and dignity and as a natural extension of the right to refuse medical treatment.¹⁶

10. Megan S. Wright, *End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy*, 77 MD. L. REV. 1062, 1064–65 (2018) (describing source of rights).

11. See generally Bruce J. Winick, *On Autonomy: Legal and Psychological Perspectives*, 37 VILL. L. REV. 1705 (1992).

12. See, e.g., Wright, *supra* note 10, at 1069–72 (describing court cases establishing this right).

13. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 279 (1990) (“But for the purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition.”).

14. See UHCDA, *supra* note 7.

15. See Wright, *supra* note 10, at 1072–73 (describing advance care planning).

16. Brief of Respondents, *Washington v. Glucksberg*, 521 U.S. 702 (1997) (No. 96–110), 1996 WL 708925, at *10–28.

But advocates were unsuccessful in this endeavor.¹⁷ Instead, the Supreme Court delineated the bounds of individual autonomy interests in hastening death relative to state interests in promoting life, preventing suicide, maintaining the integrity of the medical profession, protecting vulnerable groups, and preventing harm to third parties.¹⁸

Several state governments have been sympathetic to autonomy-based arguments about PAID,¹⁹ however, adopting this end-of-life option into state legislation. Public support for this end-of-life option is also high,²⁰ and although few people die with PAID, those who do report that their reasons for so doing are related to autonomy and dignity concerns.²¹ The following Section describes PAID laws in the United States before considering proposals to expand access to PAID through the use of advance directives.

1. Physician Aid in Dying

PAID, which was first legalized in Oregon in the mid-1990s,²² has in recent years gained significant support across the country.²³ Advocates for legalization of this end-of-life option have successfully convinced legislators and voters that terminally ill, competent adult patients should have the right to “die with dignity,” which for some patients may include physician assistance in hastening their death.²⁴

17. *Glucksberg*, 521 U.S. at 735 (holding that there is no right to PAID under the Due Process Clause of the Fourteenth Amendment); *Vacco v. Quill*, 521 U.S. 793, 797 (1997) (holding that there is no right to PAID under the Equal Protection Clause of the Fourteenth Amendment).

18. *Glucksberg*, 521 U.S. at 728–35.

19. See, e.g., Patrick McGreevy, *After Struggling, Jerry Brown Makes Assisted Suicide Legal in California*, L.A. TIMES (Oct. 5, 2015) (reporting that Governor Brown’s statement upon signing the California End of Life Option Act into law was “I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn’t deny that right to others.”).

20. Brenan, *supra* note 2.

21. Luai Al Rabadi et al., *Trends in Medical Aid in Dying in Oregon and Washington*, JAMA NETWORK OPEN, Aug. 9, 2019, at 1 (reporting results of a study that found that loss of autonomy was the most common reason for choosing PAID in Oregon and Washington).

22. Death with Dignity Act, OR. REV. STAT. ANN. §§ 127.800–.897 (West, Westlaw through 2020 Reg. Sess.).

23. See Brenan, *supra* note 2 (describing upward trend of support from the mid-1990s to present).

24. For patients who elect PAID in Oregon, over 90% say that they are concerned about loss of autonomy at the end of life, and two-thirds say they are concerned about loss of dignity. OR. HEALTH AUTH., PUB. HEALTH DIV., OREGON DEATH WITH DIGNITY ACT 2018 DATA SUMMARY 6, 12 (2019), <https://www.oregon.gov/oha/PH/PROVIDERPARTNERSOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>; see also Al Rabadi et al., *supra* note 21; Madeline Li et al., *Medical Assistance in Dying—Implementing a Hospital-Based Program in Canada*, 376 NEW ENG. J. MED. 2082 (2017) (reporting that the most common reason for requesting medical assistance in dying in Canada is loss of autonomy).

Washington legalized PAID in 2009,²⁵ followed by Vermont in 2013,²⁶ and Montana decriminalized PAID in 2009.²⁷ Since 2015, California,²⁸ Colorado,²⁹ the District of Columbia,³⁰ Hawaii,³¹ Maine,³² and New Jersey³³ have legalized PAID. Other states are currently considering PAID legislation.³⁴

PAID legislation in the United States is typically modeled after Oregon's Death with Dignity Act.³⁵ To be eligible for this end-of-life option, a patient must be a terminally ill³⁶ adult³⁷ who is a resident of a jurisdiction that has legalized this practice.³⁸ The patient must make multiple, voluntary requests to their physician, both oral and written, with the oral requests at least 15 days apart.³⁹ Patients must

25. Death with Dignity Act, WASH. REV. CODE ANN. §§ 70.245.010–.901 (West, Westlaw through 2020 Reg. Sess.).

26. Patient Choice at End of Life, VT. STAT. ANN. tit. 18, §§ 5281–5293 (West, Westlaw through 2020 Gen. Assemb.).

27. *Baxter v. State*, 224 P.3d 1211, 1221–22 (Mont. 2009) (holding that physician-assisted suicide is not contrary to Montana public policy, although this end-of-life option is not a state constitutional right).

28. End of Life Option Act, CAL. HEALTH & SAFETY CODE §§ 443.1–.22 (West, Westlaw through Ch. 372 of 2020 Reg. Sess.).

29. End-of-Life Options Act, COLO. REV. STAT. ANN. §§ 25-48-101 to -123 (West, Westlaw through 2020 Extraordinary Sess.).

30. Death with Dignity, D.C. CODE ANN. §§ 7-661.01–.16 (West, Westlaw through Dec. 3, 2020).

31. Our Care, Our Choice Act, HAW. REV. STAT. ANN. §§ 327L-1 to -25 (West, Westlaw through end of 2020 Reg. Sess.).

32. Death with Dignity Act, ME. REV. STAT. ANN. tit. 22, § 2140 (West, Westlaw through 2019 Second Reg. Sess. of 129th Leg.).

33. Aid in Dying for the Terminally Ill Act, N.J. STAT. ANN. §§ 26:16-1 to -20 (West, Westlaw through 2020).

34. *See In Your State*, COMPASSION & CHOICES, <https://compassionandchoices.org/take-action/in-your-state> (last visited Oct. 22, 2020) (mapping current PAID legislative activity).

35. There are minor variations in state PAID laws. For example, Hawaii requires a 20-day waiting period between oral requests, in contrast to the typical 15-day waiting period. HAW. REV. STAT. ANN. § 327L-2 (West, Westlaw through 2020 Reg. Sess.).

36. OR. REV. STAT. ANN. § 127.805(1) (West, Westlaw through 2020 Reg. Sess.). Terminal illness is defined as a prognosis of death occurring within six months due to an incurable disease. § 127.800(12). The terminal illness requirement differs from other jurisdictions such as Belgium and the Netherlands where persons hastening death with physician assistance need only have unbearable suffering with no prospect of improvement. *See, e.g.*, Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002) (Neth.).

37. § 127.805(1).

38. *Id.*

39. § 127.840. Additionally, the written form is provided by statute and must be witnessed. § 127.810. The time delay provides a cooling-off period to ensure that this option is truly what the patient wants. A patient may lose capacity or die during the waiting period, however. *Li, supra* note 24, at 2085 (describing how this is not uncommon in Canada, which has a 10-day “reflection” period). Oregon is in the process of amending its law to drop the 15-day requirement if a person is expected to die within that time frame.

also be able to self-administer the medication,⁴⁰ making this end-of-life option distinct from other countries, such as the Netherlands and Canada, which permit physicians to administer the medication to patients; i.e., PAID is distinct from euthanasia.⁴¹

PAID laws also impose many requirements on participating physicians.⁴² For example, physicians must certify that their patient is terminally ill and is making the request for PAID voluntarily.⁴³ Physicians must also inform their patients about the risks and benefits of and alternatives to PAID,⁴⁴ and refer them to counseling to treat mental health issues, if appropriate.⁴⁵ There are also state reporting requirements.⁴⁶

Most importantly for the purposes of this Article, physicians must also determine that their patient has contemporaneous decision-making capacity.⁴⁷ Generally, assessing decisional capacity requires a “professional clinical judgment as to whether a specific individual has the requisite cognitive, decisional, affective, and practical abilities to be judged to have the ability to complete a specific task . . . or make a specific decision.”⁴⁸ As part of this capacity assessment,

40. OR. REV. STAT. ANN. § 127.880 (“Nothing in ORS 127.800 to 127.897 shall be construed to authorize a physician or any other person to end a patient’s life by lethal injection, mercy killing or active euthanasia.”).

41. In such countries, when given a choice between self-administration and physician-administration, patients overwhelmingly choose euthanasia. *See, e.g.*, HEALTH CANADA, *supra* note 3, at 5.

42. Physicians can opt out of participating in PAID, as can healthcare organizations. OR. REV. STAT. ANN. § 127.885.

43. § 127.815.

44. *Id.*

45. § 127.825. Researchers have found that in Oregon and Washington, 4% of patients requesting PAID have received psychiatric referrals. Al Rabadi et al., *supra* note 21.

46. OR. REV. STAT. ANN. § 127.865.

47. § 127.815. Oregon’s statute uses the word “capable,” which means that “in the opinion of a court or in the opinion of the patient’s attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient’s manner of communicating if those persons are available.” § 127.800(3).

It is unknown how often formal capacity assessments for patients seeking PAID are conducted. Some gerontologists have noted that capacity assessments tend to be informal, however. Jennifer Moye & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62 J. GERONTOLOGY P3, P3 (2007). Additionally, studies of euthanasia in the Netherlands have found that physicians are not formally evaluating the capacity of incompetent patients who are euthanized, even though several patients had psychotic disorders. Samuel N. Doernberg et al., *Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands*, 57 PSYCHOSOMATICS 556, 559 (2016).

48. Jennifer Moye & Michelle Braun, *Assessment of Capacity*, in HANDBOOK OF ASSESSMENT IN CLINICAL GERONTOLOGY 581, 581 (Peter A. Lichtenberg ed., 2d ed. 2010). Note that the assessment is with respect to a specific task or decision. Linda Ganzini et al., *Pitfalls of Assessment of Decision-Making Capacity*, 44 PSYCHOSOMATICS 237, 241 (2003).

healthcare professionals evaluate a patient's ability to understand medical information and appreciate its significance, reason about the risks and benefits of various treatment options, and communicate a choice.⁴⁹

2. Physician Aid in Dying and Advance Directives

Current PAID statutes exclude many persons from accessing PAID. Persons who are seriously and chronically but not terminally ill, or persons who have impaired decision-making capacity because of dementia, for example, may desire to die with physician assistance but be unable to do so given existing eligibility requirements.⁵⁰ This Article does not argue that the terminal illness

A person thus may have capacity for some tasks and decisions, but not others. For example, someone may struggle to make financial decisions, but be fully capable of deciding whether they wish to undergo a particular medical treatment.

49. UHCDA, *supra* note 7, § 1(3) (“‘Capacity’ means an individual’s ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision.”); Paul S. Appelbaum & Thomas Grisso, *Assessing Patients’ Capacities to Consent to Treatment*, 319 NEW ENG. J. MED. 1635, 1635 (1988) (defining capacity as “communicating a choice, understanding relevant information, appreciating the current situation and its consequences, and manipulating information rationally”); Doernberg et al., *supra* note 47, at 557 (“Decisional competence means that the patient is able to understand relevant information about his situation and prognosis, consider any alternatives and assess the implications of his decision.”); Moye & Braun, *supra* note 48, at 585–86.

There are known problems with both the validity and reliability of formal capacity assessments because determinations of capacity depend upon the criteria used and the value judgments of the healthcare professional conducting the assessment. Doernberg et al., *supra* note 47, at 557; Ganzini et al., *supra* note 48, at 241. This leads to different physicians coming to different conclusions about a patient’s capacity. Doernberg et al., *supra* note 47, at 560 (describing results of a study where physicians disagreed about the capacity of a patient requesting euthanasia in the Netherlands in 12% of cases); Moye & Marson, *supra* note 47, at P7; *see also* Rebecca Dresser, *Autonomy and Its Limits in End-of-Life Law*, in THE OXFORD HANDBOOK OF U.S. HEALTH LAW 399, 402 (I. Glenn Cohen et al. eds., 2017) (describing how patients may mistakenly be determined to lack decisional capacity when they are actually afraid, upset, or have difficulty communicating); Irene Tuffrey-Wijne et al., *Euthanasia and Assisted Suicide for People with an Intellectual Disability and/or Autism Spectrum Disorder: An Examination of Nine Relevant Euthanasia Cases in the Netherlands (2012-2016)*, 19 BMC MED. ETHICS 17, 19 (2018) (noting that capacity assessments do not appropriately weigh other factors such as emotions and social context, and arguing that only professionals experienced with patients with developmental and intellectual disabilities should conduct capacity assessments of this patient population). Additionally, capacity may only be assessed upon disagreement with a healthcare provider’s recommendation, raising questions about the assessment’s purpose. Ganzini et al., *supra* note 48, at 238, 241. Finally, requiring a patient to tell others about their reasons for their decisions is arguably incompatible with respect for patient autonomy, given the imposition on the patient’s privacy.

50. *See* Orentlicher et al., *supra* note 1, at 1961–62 (explaining that the terminal illness requirement is intentional and that PAID is meant only for those who have no other option in the face of “suffering from irreversible and severe illness”).

requirement for PAID should be rescinded;⁵¹ instead, it focuses on the contemporaneous decisional capacity requirement.

There have been proposals to allow access to PAID through advance directives, so that if persons desiring PAID lose decision-making capacity, they are still able to hasten their death in this manner once they are otherwise eligible, e.g., upon becoming terminally ill.⁵² There are many problems with advance directives, however, which likely will also occur in the PAID context.⁵³

Most importantly, it is often impossible to predict what medical or end-of-life circumstances one will face in the future and what one's treatment preferences will be when one faces an illness or injury.⁵⁴ It is also quite possible that an individual's preferences will change over time, especially as they adapt to disability and illness.⁵⁵ But if an individual has completed an advance directive based on earlier preferences and has since acquired a decision-making impairment, they may be bound by past preferences that they no longer have or may not even remember; i.e., advance directives create lock-in.⁵⁶ If an advance directive for PAID was a legal possibility, a terminally ill person with moderate dementia who has a good quality of life may have completed an advance directive for PAID on the assumption that

51. See Leslie Pickering Francis, *Assisted Suicide: Are the Elderly a Special Case?*, in *PHYSICIAN ASSISTED SUICIDE: EXPANDING THE DEBATE* 75, 75 (Margaret P. Battin et al. eds., 1998) (arguing that a terminal illness should be a PAID requirement).

52. See generally Paul T. Menzel & Bonnie Steinbock, *Advance Directives, Dementia, and Physician-Assisted Death*, 41 *J. L. MED. & ETHICS* 484 (2013). Such advance directives for euthanasia are legal in the Netherlands. See generally David Gibbes Miller et al., *Advance Euthanasia Directives: A Controversial Case and Its Ethical Implications*, 45 *J. MED. ETHICS* 84 (2019).

Other proposals for hastening death in the absence of a terminal illness and upon loss of decisional capacity include advance directives declining food and water. See generally Paul T. Menzel & M. Colette Chandler-Cramer, *Advance Directives, Dementia, and Withholding Food and Water by Mouth*, 44 *HASTINGS CTR. REP.* 23 (May–June 2014).

53. One significant issue is that most persons never complete an advance directive, meaning this proposal will likely not have a significant effect on expanded access to PAID for persons who otherwise would not complete an advance directive. See generally Kuldeep N. Yadav et al., *Approximately One in Three U.S. Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 *HEALTH AFF.* 1244 (2017). For persons who are considering an advance directive for PAID, however, noncompletion is not a problem.

54. See, e.g., Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 *TEX. L. REV.* 1823, 1829–37 (2003) (describing problems with precommitment).

55. People routinely rate the quality of life of persons with disabilities lower than persons with disabilities rate their own quality of life. Additionally, when imagining a future with disability, people estimate that their quality of life will be low, but when they later acquire a disability, they often adapt and have a higher quality of life than they anticipated. Gary L. Albrecht & Patrick J. Devlieger, *The Disability Paradox: High Quality of Life Against All Odds*, 48 *SOC. SCI. & MED.* 977 (1999).

There is also research that demonstrates that people do change their minds about receiving medical assistance in dying, even after they have been successful in receiving approval to die in this manner. See, e.g., Li, *supra* note 24, at 2085 (discussing how some Canadians who were approved for medical assistance in dying changed their mind).

56. Dresser, *supra* note 54.

her quality of life under these circumstances would be poor; she may no longer remember her prior preferences or wish to use PAID.⁵⁷

Additionally, in some cases, it may be difficult to interpret a living will, which makes attempting to honor an incapacitated patient's wishes more difficult.⁵⁸ There are also reports that advance directives are sometimes disregarded by healthcare providers.⁵⁹ These issues raise questions about whether advance directives for PAID will have the intended effect of respecting patient autonomy, despite loss of decision-making capacity, in end-of-life decision-making.⁶⁰

Finally, advance directives would only expand access to PAID for persons who previously had the decisional capacity required to execute the directive, e.g., a person with typical cognitive abilities who executed an advance directive prior to the onset of dementia. Other persons with lifelong cognitive impairments may also have autonomy and dignitary interests in accessing PAID. But a PAID advance directive would not be an option for this population.

As the next Section explains, there are legal alternatives to advance directives that can account for current preferences and allow persons with most types of decisional impairments to make whatever healthcare or end-of-life decisions they prefer at the time each decision needs to be made.

B. Autonomy and Supported Decision-Making

The previous Section illustrated how end-of-life law has been shaped by autonomy concerns, and such concerns have also been important to the disability community. Disability advocates have emphasized the importance of respect for the autonomy of persons with disabilities, in part to counter stereotypes of persons with disabilities, particularly cognitive disabilities, as dependent on others and incapable

57. There is the additional problem that sometimes it may seem as if the person with decisional impairments for whom an end-of-life decision is being made is not the same person who wrote the advance directive, which raises questions about the moral authority of the advance directive. This is known as the problem of personal identity, which often arises in the case of persons who acquire dementia and may experience personality change or such profound memory loss that they are no longer recognizable as the person they once were. Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decision Making*, 79 MD. L. REV. 257, 314–19 (2020).

58. See generally, e.g., Ferdinando L. Mirarchi et al., *TRIAD-I—The Realistic Interpretation of Advanced Directives*, 4 J. PATIENT SAFETY 235 (2008) (describing issues with interpreting common terms on advance directives as well as results of original study demonstrating interpretive problems).

59. See, e.g., *State Fines St. Petersburg Nursing Home for Violating Residents' Do-Not-Resuscitate Order*, TAMPA BAY TIMES (June 4, 2014); Pope, *supra* note 8.

60. An important argument that advance directives may do a better job than the current, contemporaneous-capacity requirement in PAID does promoting patient autonomy at the end of life reflects the reality that some persons who qualify for PAID may hasten their death earlier than they desire because they fear losing capacity before they will be able to self-administer the medication. See Li, *supra* note 24, at 2087–88 (describing how some Canadians elect medical assistance in dying earlier than they prefer because they fear that if they wait, they will lose the ability to give informed consent, thus becoming ineligible for this end-of-life option).

of autonomy.⁶¹ Indeed, the findings section of the Americans with Disabilities Act (“ADA”), the most important piece of civil-rights legislation for persons with disabilities, expressly discusses the autonomy concerns of persons with disabilities.⁶² Autonomy is not only a dignitary good—i.e., respect for autonomy reflects respect for persons—but it is also linked to increased wellbeing.⁶³

An important component of autonomy is the freedom to make one’s own decisions. Advocates for persons with developmental and intellectual disabilities thus have been pushing for use of supported decision-making in order to respect the autonomy and personhood, and promote the wellbeing, of individuals with disabilities.⁶⁴ Fundamental to the philosophy of supported decision-making is that everyone should have equal legal capacity or equal power to exercise legal rights,⁶⁵ an ideal found in the Convention on the Rights of Persons with Disabilities.⁶⁶ The

61. See, e.g., Harlan Hahn, *Disputing the Doctrine of Benign Neglect: A Challenge to the Disparate Treatment of Americans with Disabilities*, in *AMERICANS WITH DISABILITIES: EXPLORING THE IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS* 269, 271 (Leslie Pickering Francis & Anita Silvers eds., 2000) (“Having to rely on others to secure one’s . . . needs is . . . characteristic of being subjected to paternalism. Dependence . . . prevents members of a disadvantaged group from achieving self-determination . . .”).

Prior scholarship has argued that persons with decisional impairments are capable of exercising autonomy if autonomy is conceptualized appropriately. See generally, e.g., Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value*, 28 *PHIL. & PUB. AFF.* 105 (1999) (defining autonomy as the capacity to value); Wright, *supra* note 57 (defining autonomy as relational agency).

62. 42 U.S.C. § 12101(a)(7) (2018) (“[T]he Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”).

63. Jaworska, *supra* note 61, at 109; Melanie H. Mallery et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin’s Work on Gerontological Theory, Policy, and Practice*, 54 *GERONTOLOGIST* 67, 68–69 (2014); Winick, *supra* note 11. Indeed, the PAID option “provides important psychological benefits for the terminally ill because it gives the terminally ill autonomy, control, and choice . . .” *Patients’ Rights to Self-Determination at the End of Life*, *AM. PUB. HEALTH ASS’N* (Oct. 28, 2008), <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life>.

64. See Theodorou, *supra* note 9, at 982–86.

65. See Lucy Series & Anna Nilsson, *Article 12 CRPD: Equal Protection before the Law*, in *THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: A COMMENTARY 2* (Ilias Bantekas et al. eds., 2018) (“The right to equal recognition before the law is concerned with legal personality – the ability to bear rights and duties under law, and legal capacity – whether and how one can exercise, claim or defend those rights, and the assumption of legal liability.”); see also KARRIE A. SHOGREN ET AL., *SUPPORTED DECISION-MAKING: THEORY, RESEARCH, AND PRACTICE TO ENHANCE SELF-DETERMINATION AND QUALITY OF LIFE* 123–24 (2019) (discussing plenary guardianship, which gives such power to others); Moye & Braun, *supra* note 48, at 583–85 (describing how legal capacity is something determined by judges, often in guardianship proceedings, or by lawyers, but that the term is vague and often defined in the negative).

66. G.A. Res. 61/106, U.N. Doc. A/RES/61/106, Convention on the Rights of Persons with Disabilities (CRPD), art. 12 (Dec. 13, 2006) (“States parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of

common practice of using the law to remove decision-making authority from a person with decisional impairments and to give this authority to a guardian or a family member⁶⁷ conflicts with the principle of equal legal capacity.

Supported decision-making provides an alternative to surrogate decision-making and guardianship.⁶⁸ Under this model, persons with cognitive impairments can choose to enter into agreements with others, known as supporters, whose role is to assist the person with the disability in making decisions about matters such as where to live, how to manage finances and property, where to go to school, and what medical treatment to choose, among other matters. Instead of deciding for the person with a disability, the supporter assists in information gathering, thinking through options, or communicating decisions to others.⁶⁹ This decision-making model can be informally used or can be memorialized in a formal, written agreement.⁷⁰

Supported decision-making legislation that recognizes and facilitates use of formal supported decision-making agreements began spreading across the country around the same time that PAID legislation did. In 2015, Texas became the first state to formalize supported decision-making in law,⁷¹ and it was followed by Delaware,⁷² Wisconsin,⁷³ the District of Columbia,⁷⁴ Indiana,⁷⁵ Alaska,⁷⁶ Nevada,⁷⁷ Rhode Island,⁷⁸ and North Dakota.⁷⁹

One purpose of adopting this legislation is to ensure that “[a]ll adults [are] able to live in the manner they wish and to accept or refuse support, assistance, or

life.”). See generally Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8 (2012).

67. See, e.g., UHCDA, *supra* note 7, § 5(a) (“A surrogate may make a health-care decision for a patient who is an adult or emancipated minor if the patient has been determined by the primary physician to lack capacity and no agent or guardian has been appointed or the agent or guardian is not reasonably available.”).

68. SHOGREN ET AL., *supra* note 65, at 138.

69. See Wright, *supra* note 57, at 286–95 (providing detailed overview of supported decision-making laws in the United States).

70. Nina A. Kohn et al., *Supported Decision Making: A Viable Alternative to Guardianship?*, 117 PA. ST. L. REV. 1111, 1121 (2013) (describing different models of supported decision-making).

71. TEX. EST. CODE ANN. §§ 1357.001–.102 (West, Westlaw through 2019 Reg. Sess.).

72. DEL. CODE ANN. tit. 16, §§ 9401(a)–9410(a) (West, Westlaw through ch. 292 of 150th Gen. Assemb. 2020).

73. WIS. STAT. ANN. §§ 52.01–.32 (West, Westlaw through 2019 Act 186).

74. D.C. CODE ANN. §§ 7-2131 to -2134 (West, Westlaw through Dec. 3, 2020).

75. IND. CODE ANN. §§ 29-3-14-1 to -13 (West 2019).

76. ALASKA STAT. ANN. §§ 13.56.010–.195 (West, Westlaw through ch. 32 of 2020 Reg. Sess.).

77. NEV. REV. STAT. ANN. §§ 162c.010–.330 (West, Westlaw through 32nd Special Sess.).

78. 42 R.I. GEN. LAWS §§ 66.13-1 to -10 (West, Westlaw through ch. 79 of the 2020 2d Reg. Sess.).

79. N.D. CENT. CODE ANN. §§ 30.1-36-01 to -08 (West, Westlaw through 2019 Reg. Sess.).

protection as long as they do not harm others and are capable of making decisions about those matters.”⁸⁰ Accordingly, in several states, a person with a cognitive impairment is able to act independently of the agreement,⁸¹ while at the same time, third parties, including healthcare professionals, are instructed to rely on the supported decision-making agreement.⁸² There are also corresponding limits to liability for good faith reliance on the agreement.⁸³

To protect against abuse, neglect, or exploitation of persons with cognitive disabilities, supported decision-making legislation contains safeguards. Such safeguards include prohibiting some persons from acting as supporters, such as those who have committed certain types of crimes;⁸⁴ limiting the scope of a supporter’s authority;⁸⁵ and advising third parties to contact the state agency responsible for ensuring the welfare of older persons or persons with disabilities if they suspect abuse or neglect of the person with a disability.⁸⁶

Although research is sparse on the use of supported decision-making,⁸⁷ scholars have been calling for its application beyond persons with developmental and intellectual disabilities to include, for example, persons with mental illness,⁸⁸ severe brain injury,⁸⁹ and dementia,⁹⁰ as well as older adults.⁹¹ Scholars have also argued that for persons with acquired disabilities, supported decision-making is preferable to reliance on advance directives because this decision-making model can account for changed preferences, avoiding the issue of lock-in that advance directives create.⁹²

80. DEL. CODE ANN. tit. 16, § 9402A(b)(1)–(4) (West, Westlaw though ch. 292 of the 150th Gen. Assemb.). Another purpose, at least in some states that have adopted this legislation, is to save costs associated with decreased use of guardianship for aging adults. Theodorou, *supra* note 9, at 1006.

81. Wright, *supra* note 57, at 287.

82. *Id.* at 293.

83. *Id.* at 293–94.

84. *Id.* at 287–88.

85. *Id.* at 289–90.

86. *Id.* at 290–92, 294.

87. Kohn et al., *supra* note 70. For a review of research, see SHOGREN ET AL., *supra* note 65; Karrie A. Shogren et al., *Supported Decision Making: A Synthesis of the Literature Across Intellectual Disability, Mental Health, and Aging*, 52 EDUC. & TRAINING AUTISM & DEVELOPMENTAL DISABILITIES 144 (2017).

88. See, e.g., Dilip V. Jeste et al., *Supported Decision Making in Serious Mental Illness*, 81 PSYCHIATRY: INTERPERSONAL & BIOLOGICAL PROCESSES 28 (2018).

89. See, e.g., Tamar Ezer, Megan S. Wright & Joseph J. Fins, *The Neglect of Persons with Severe Brain Injury in the United States: An International Human Rights Analysis*, 22 HEALTH & HUM. RTS. J. 265, 272–73 (2020).

90. See generally Wright, *supra* note 57; Megan S. Wright, *Dementia, Healthcare Decision Making, and Disability Law*, 47 J.L. MED. & ETHICS 25 (2019); Megan S. Wright, *Dementia, Cognitive Transformation, and Supported Decision Making*, 20 AM. J. BIOETHICS 88 (2020).

91. Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L.J. 495 (2016).

92. Wright, *supra* note 57, at 314–17.

A question that has not yet been addressed by scholars, legislators, or judges is how PAID and supported decision-making laws interact. As noted previously, under current PAID laws, contemporaneous decision-making capacity is required for patients to be eligible to hasten their death in this manner. This requirement assumes that one could be deemed to lack capacity. But this assumption conflicts with supported decision-making legislation that asserts that persons who enter into these agreements retain legal capacity and can make decisions about their lives despite the presence of decisional impairments.⁹³

The remainder of this Article examines the interaction of supported decision-making and PAID laws. The following Part focuses on the normative question of whether terminally ill supported persons with decisional impairments should be eligible for PAID. Given that one important purpose of both laws is to promote autonomy, and given the importance of equal treatment under the law for persons with disabilities, I argue that persons with decisional impairments should not be denied access to PAID if they wish to end their lives in this manner and meet all other PAID eligibility requirements.

II. EQUALITY OF AUTONOMY: PHYSICIAN AID IN DYING FOR TERMINALLY ILL SUPPORTED PERSONS

Should the law permit terminally ill supported persons with decisional impairments to hasten death with PAID? Assessing the normative foundations for PAID and supported decision-making laws provides insight. Both sets of laws are meant to respect and promote autonomy; it is thus imperative to analyze whether this end is achieved at their intersection.

This Part first analyzes whether a supported person with decisional impairments seeking PAID can meet the requirements for autonomous decision-making once they become terminally ill (rather than via advance directive). After concluding that this contemporaneous choice can be autonomous, this Part argues that the principle of equality demands that the law not exclude terminally ill supported persons with decisional impairments from this end-of-life option.

A. Autonomy at the Intersection of Supported Decision-Making and Physician Aid in Dying

If the goal of both PAID and supported decision-making laws is to respect and promote autonomy, then it is necessary to ask whether a terminally ill supported person with a decisional impairment can autonomously elect to hasten death through

93. See, e.g., ALASKA STAT. ANN. § 13.56.150(b) (West 2018) (“An adult who enters into a supported decision-making agreement may act without the decision-making assistance of the supporter.”); IND. CODE ANN. § 29-3-14-4(c) (West 2019) (“The existence of an executed supported decision making agreement does not preclude the adult from acting independently of the supported decision making agreement.”).

PAID; that is, whether they can decide with intent and understanding and without control or undue influence being exercised upon them.⁹⁴

Some may assert that it is not possible for persons with some types of cognitive disabilities to ever be contemporaneously autonomous.⁹⁵ At the extreme end of cognitive disability, this is indeed true. For example, if someone is in a chronic vegetative state where they lack awareness,⁹⁶ they will not be able to make their own decisions. But in many other cases, despite decisional impairments, a person will be able to communicate preferences and act autonomously in relation to others, making them capable of autonomy as defined by feminist- and disability-studies scholars.⁹⁷

Indeed, my prior scholarship has argued for a more accurate understanding of autonomy, one that accords with the realities of decision-making, in healthcare decision-making law.⁹⁸ Research has demonstrated that many persons, regardless of disability status, prefer to make serious and late-life healthcare decisions relationally—in consultation or collaboration with others and perhaps after accounting for others’ interests—and still view themselves as deciding autonomously.⁹⁹ Further, empirical studies have shown that many persons struggle to make healthcare decisions that further their interests because of cognitive biases, limited options, power imbalances, and difficulty understanding complex medical information.¹⁰⁰ I have thus argued that autonomous decision-making in the healthcare context is better described as relational agency and that through supported decision-making, autonomy so conceptualized can be exercised by persons with cognitive impairments such as mild to moderate dementia.¹⁰¹ With this understanding of autonomy, the exclusion of persons with decisional impairments from PAID is problematic.

94. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 104 (7th ed. 2013).

95. Anita Silvers, *Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Vulnerable Groups*, in *PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE* 133, 138–39 (Margaret P. Battin et al. eds., 1998) (“[T]he principle of self-determination itself rules out individuals with dementia, retardation, or other impairments that substantially limit their relevant cognitive functioning from being assisted in suicide.”).

96. See generally Sunil Kothari, *Chronic Disorders of Consciousness*, in *NEUROPALLIATIVE CARE* 37 (Claire J. Creutzfeldt et al. eds., 2018).

97. See generally *RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF* (Catriona Mackenzie & Natalie Stoljar eds., 2000); JENNIFER NEDELSKY, *LAW’S RELATIONS: A RELATIONAL THEORY OF SELF, AUTONOMY, AND LAW* 3 (2011); Harold Braswell, *Can There Be a Disability Studies Theory of “End-of-Life Autonomy”?*, 31 *DISABILITY STUD. Q.* (2011).

98. Wright, *supra* note 10; Wright, *supra* note 57.

99. Wright, *supra* note 10, at 1082–93; Wright, *supra* note 57, at 272–74.

100. Wright, *supra* note 10, at 1096–101; Wright, *supra* note 57, at 279–80.

101. Wright, *supra* note 57. But see Margaret Isabel Hall, *Dementia, Autonomy and Guardianship for the Old*, in *THE LAW AND ETHICS OF DEMENTIA* 339, 347–48 (Charles Foster et al. eds., 2014) (“[N]o amount of support will render every individual capable of making his or her ‘own’ decisions.”).

But the analysis of whether choosing to hasten death with PAID is an autonomous decision may depend upon the supported person's type of cognitive impairment. Determining whether end-of-life decision-making for supported persons with decisional impairments can be contemporaneously autonomous may differ based on whether someone was previously considered competent to make their own decisions.¹⁰² The next Subsections will analyze whether previously capacitated and never capacitated persons with decisional impairments can, with or without supported decision-making, satisfy baseline requirements for autonomous decision-making when seeking to hasten death through PAID.

1. Intent

If a terminally ill supported person with a decisional impairment makes the requests required for PAID, then the first requirement for autonomous decision-making—intent—seems to be easily satisfied. As described previously, to use PAID, a patient must make one written and two oral requests.¹⁰³ Expressing a desire to die to a healthcare provider likely is not a sufficient oral request. Rather, the request must be for PAID as the manner of death. Making two such requests, along with completing a signed and witnessed form making the same request, constitutes

102. It may be instructive to think about decision-making capacity with respect to four categories of persons with cognitive impairments. Some persons with decisional impairments may not have had previous cognitive disability and will not regain their cognitive abilities because of the progressive nature of their disability, e.g., dementia; such acquired disabilities may be disruptive to personal identity. Others may have had lifelong decisional impairments, and the degree of their disability (and their identity) may remain relatively constant throughout their life, e.g., Down Syndrome. In other cases, someone may have impairment that fluctuates because of a disability, e.g., schizophrenia. Finally, some persons may acquire a disability that impairs cognition, but could possibly regain function, e.g., traumatic brain injury. These are broad categories, but it is important to remember that there will be significant variation in each category based on an individual's personal and social characteristics.

This Article focuses on capacity and autonomy primarily with respect to the first two categories of disability, especially given the terminal illness requirement for PAID. With respect to fluctuating capacity, while there may not be sufficient time to restore capacity through medical treatment given the terminal prognosis, for the purposes of analysis, because the person has had capacity in the past, they can be considered similar to persons with an acquired, progressive disability. If fluctuating capacity is due to being over-sedated, it may be advised to reduce or discontinue the medication so the person can regain the ability to make their own healthcare decisions. If fluctuating capacity is due instead to mental illness, providers may attempt to treat the mental illness to try to restore capacity.

Given the short period of time to make a contemporaneous decision to use PAID, i.e., six months or less, attempts to regain function from rehabilitation after, for example, a stroke and then arranging for use of supported decision-making makes this category of decisional impairment less relevant for the above analysis. The final category of decisional impairments would be relevant to analyze a country that permits medically assisted dying for persons who are not terminally ill and for persons with psychiatric disorders that impair capacity, e.g., the Netherlands.

103. See, e.g., OR. REV. STAT. ANN. § 127.840 (West, Westlaw through 2020 Reg. Sess.).

intent,¹⁰⁴ regardless of whether the requests are made with or without a supporter's assistance. Whether a person previously had no decisional impairments, e.g., a person who acquired dementia, or had a lifelong intellectual disability, e.g., Down Syndrome, does not alter the analysis; in both cases, intent manifests.

2. Understanding

More difficult questions arise with respect to the second requirement for autonomous decision-making—understanding. If a person has cognitive impairments significant enough that in the absence of supported decision-making they would be deemed incapacitated by physicians or a court, doubts may arise about whether they are capable of understanding what they are choosing when they request PAID, regardless of whether they receive decision-making support.

On a philosophical level, it may be impossible to know whether something is understood. On a more practical level, however, the requirement of understanding is difficult for all persons making medical and end-of-life decisions, as ample scholarly literature has documented,¹⁰⁵ so it is unclear why there should be higher demands for understanding for persons with decisional impairments.¹⁰⁶

Confidence about whether a person with a decisional impairment understands PAID may depend on whether they acquired their cognitive impairment or have had lifelong cognitive impairments. Perhaps evidence about the person's prior ability to understand death and PAID, along with their years of experience

104. Indeed, the three request requirement is a much stricter standard for intent than in other serious, and perhaps life-ending, healthcare decision-making contexts where some empirical research has demonstrated that patients report not making any decisions about what happens to them, despite many decisions having been made. Theresa S. Drought & Barbara A. Koenig, "Choice" in *End-of-Life Decision Making: Researching Fact or Fiction?*, 42 GERONTOLOGIST 114, 121 (2002).

Further, other research has shown that patients who elect PAID make more than three requests, make the requests forcefully, and refuse other healthcare interventions. Linda Ganzini et al., *Oregon Physicians' Perceptions of Patients Who Request Assisted Suicide and Their Families*, 6 J. PALLIATIVE MED. 381, 384 (2004). If terminally ill supported persons with decisional impairments act similarly to individuals in this study, the case for intent is even stronger.

105. See, e.g., Wright, *supra* note 10, at 1096–99 (explaining that people do not understand medical decisions because the information is complex, their reasoning is flawed, and they are often sick and scared at the time of the decision).

106. Some scholars have argued that the capacity requirements for PAID should be heightened because it is serious and irrevocable. Francis, *supra* note 51, at 78; Tuffrey-Wijne et al., *supra* note 49, at 14–17. Such arguments are based on the principle that the more serious or risky the decision, the more evidence of competency to make the decision is required. James F. Drane, *Competency to Give an Informed Consent: A Model for Making Clinical Assessments*, 252 JAMA 925 (1984). It is not obvious why the decision to use PAID differs from other serious end-of-life decisions such as having a DNR/DNI order or completing an advance directive instructing refusal of life-sustaining or saving treatment. Additionally, these arguments cannot justify treating persons with cognitive disabilities differently by requiring them to meet a much higher standard for understanding than the standard required of all others. Tuffrey-Wijne and her coauthors recognize this point, and so have argued for heightened capacity requirements for all patients, arguing that equal treatment in this respect will benefit everyone. Tuffrey-Wijne et al., *supra* note 49.

making their own decisions, would make others more comfortable that the person with decisional impairments understands their present request, particularly if that request is consistent with their views on end of life prior to the onset of their cognitive disability. In contrast, there may be less confidence that a person understands PAID if that individual has had lifelong difficulty understanding various medical treatments or concepts such as death, has had lifelong difficulty engaging in causal inference, or has not had as much experience or skill in making their own decisions.¹⁰⁷ If a person with an intellectual or developmental disability that impairs cognition had lengthy experience being supported in decision-making, however, there may be reason to think that they are more adept at making and understanding serious decisions with support than a person with an acquired decisional impairment who may not be as experienced in receiving support to increase their level of understanding.

But for the purposes of assessing understanding of PAID for patients with cognitive impairments, if the patient can communicate (with or without support) that they understand that choosing PAID will result in immediate death, and not using PAID will keep them alive for some period of time until they die from their underlying illness, this requirement of autonomous decision-making is likely met. Indeed, unlike trying to understand complex medical interventions that may be used to sustain life, e.g., various types of surgical interventions, it seems to be a relatively low cognitive burden to understand that ingesting a drug will cause death.¹⁰⁸ For all healthcare and end-of-life decisions, however, physicians should attempt to provide their patients, with and without disabilities, information in an accessible manner¹⁰⁹ and fully communicate all alternatives to PAID.¹¹⁰

3. No Undue Influence or Coercion

The last requirement for autonomous decision-making—the absence of coercion or undue influence—likely raises the most concerns that a terminally ill

107. See Tuffrey-Wijne et al., *supra* note 49 (discussing how in the Netherlands physicians evaluate the consistency of their incapacitated patients' request for euthanasia for insight into whether their patient understands what they are requesting, but arguing that this is misguided and physicians should instead be assessing reasoning and appreciation).

108. It is possible, though, that a person will not understand what death is, in which case they would evidence a lack of understanding what of PAID is, so choosing PAID would not be an autonomous choice. Recent ethnographic research has demonstrated, however, that some persons with moderate dementia in a locked dementia care unit engage in conversation with nursing staff and other residents about who will be the next resident to die, indicating the possibility of understanding death for some persons with moderate to severe decisional impairments. Cindy L. Cain, *Sacred Selves of People with Dementia: Interactional Orders that Support and Undermine Personhood* (Feb. 3, 2020) (on file with author). *But see* Norman L. Cantor, *The Relation between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS HEALTH L. 37, 49 (2004) (“[A] profoundly disabled person with the mental function of a small child cannot grasp the concepts of a continued existence and death necessary to form a judgment or preference regarding life-sustaining medical intervention.”).

109. Tuffrey-Wijne, *supra* note 49, at 18.

110. This requirement is legally mandated. *See, e.g.*, OR. REV. STAT. ANN. § 127.815(1)(c) (West, Westlaw through 2020 Reg. Sess.). Persons with cognitive impairments may need their healthcare providers to spend more time discussing options, however, before an informed decision can be made. Tuffrey-Wijne, *supra* note 49, at 18.

supported person with decisional impairments choosing PAID would not be doing so autonomously. Given the relative vulnerability of persons with disabilities generally,¹¹¹ and cognitive impairments specifically, there are serious concerns that such persons may not be able to assert their preferences about the manner and time of their death against their physicians', family members', and supporters' preferences, thus experiencing undue influence that is inconsistent with autonomy.¹¹² Indeed, disability rights activists have long viewed PAID with suspicion or hostility because they are concerned that the lives of patients with disabilities are not valued,¹¹³ and thus patients with disabilities will be pressured by

111. When enacting the ADA, Congress drew attention to the vulnerable status of persons with disabilities. 42 U.S.C. § 12101(a)(6) (2018) (“[C]ensus data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally.”).

Scholars have also described various ways in which persons with disabilities are vulnerable. As a group, persons with disabilities have lower levels of educational attainment, lower incomes, and less political influence than persons without disabilities. Andrew I. Batavia, *Ten Years Later: The ADA and the Future of Disability Policy*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 283, 283; Jerome E. Bickenbach, *The ADA v. the Canadian Charter of Rights: Disability Rights and the Social Model of Disability*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 342, 352; Lennard J. Davis, *Go to the Margins of the Class: Hate Crimes and Disability*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 331, 332; Francis, *supra* note 51, at 80. Persons with disabilities are also more socially isolated and victims of crime. Richard K. Scotch, *Making Change: The ADA as an Instrument of Social Reform*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 281, 281; Davis, *supra*, at 332; Francis, *supra* note 51, at 80. They also have higher rates of depression and have to combat negative stereotypes and discrimination. Francis, *supra* note 51, at 80; Scotch, *supra*, at 281.

It is important to remember, however, that just because a group of persons tends to be more vulnerable, not all members of that group are vulnerable. BEAUCHAMP & CHILDRESS, *supra* note 94, at 267–68. Additionally, even persons without decisional impairments are likely to be vulnerable when they are terminally ill.

112. This vulnerability to coercion is not only with respect to death-hastening, however. It may be the case that a person with decisional impairments truly wants to hasten death with PAID, but their physicians and family members are opposed to it. Given their impairments, they may be unable to find another physician willing to assist them with death in this manner, or they may be unable to fight their family's efforts to keep them alive.

Furthermore, it is necessary to distinguish influence from undue influence. When others influence an individual's decisions, this is not necessarily inconsistent with autonomy. Wright, *supra* note 10. Indeed, persons without decisional impairments making important late-life medical decisions often desire others to be involved in the decision-making and may also account for others' interests when making decisions. *Id.* at 1081–94. It is not clear why persons with cognitive disabilities should be prevented from similarly deciding.

113. See, e.g., Dan W. Brock, *Health Care Resource Prioritization and Discrimination Against Persons with Disabilities*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 223; David Orentlicher, *Utility, Equality and Health Care Needs of Persons with Disabilities:*

their doctors and families to end their lives; i.e., the legal right to die becomes a duty for persons with disabilities to die,¹¹⁴ or that patients' preferences for a hastened death reflect a sense of being a burden on others.¹¹⁵

When the Supreme Court considered whether there was a constitutional right to PAID, the Justices also expressed concerns about the compromised autonomy of persons with disabilities who, in the Court's view, could be coerced into hastening death with PAID.¹¹⁶ The Court noted, "An insidious bias against the handicapped . . . makes them especially in need of . . . statutory protection." The state's interest here goes beyond protecting the vulnerable from coercion; it extends

Interpreting the ADA's Requirement of Reasonable Accommodations, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 236 (discussing how the lives of persons with disabilities may literally be worth less in a cost-effectiveness or quality-adjusted life years analysis); Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 GA. ST. U. L. REV. 893 (2017) (summarizing the concerns of persons with disabilities about end-of-life decisions); Beth Haller & Sue Ralph, *Not Worth Keeping Alive? News Framing of Physician-Assisted Suicide in the United States and Great Britain*, 2 JOURNALISM STUD. 407, 415–16 (2001) (finding that news articles covered PAID through the frame of "better dead than disabled").

114. See, e.g., *Not Dead Yet Disability Activists Oppose Assisted Suicide as a Deadly Form of Discrimination*, NOT DEAD YET, <http://notdeadyet.org/assisted-suicide-talking-points> (last visited Jan. 6, 2020) (arguing that physicians underestimate the quality of life of persons with disabilities, which will lead physicians to assist with their patient's suicide, and that family influence on the PAID decision constitutes elder abuse); NAT'L COUNCIL ON DISABILITY, THE DANGER OF ASSISTED SUICIDE LAWS 11–12 (Oct. 9, 2019), https://ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf.

Scholars have also summarized this view as follows:

[L]egalizing assisted dying by attempting to establish an absolute right to bodily autonomy may undermine other individual and group rights, and . . . creating one class of people for whom life is expendable, that particular view may be extended by society to all groups possessing such attributes (such as permanently disabled people). They fear that there would be a risk to the rights of such vulnerable groups in the form of society being less willing to provide for their care and support.

Tuffrey-Wijne et al., *supra* note 49. See generally Crossley, *supra* note 113. A variation on this argument is that because persons with disabilities are treated poorly by society, they will be suicidal and thus more likely to want to hasten death, and that physicians will likewise disregard the worth of the lives of their suicidal patients with disabilities and be more likely to accede to PAID requests. Silvers, *supra* note 95, at 136.

115. Felicia Ackerman, *Assisted Suicide, Terminal Illness, Severe Disability, and the Double Standard*, in PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE, *supra* note 95, at 149, 154–58; NAT'L COUNCIL ON DISABILITY, *supra* note 114, at 10–11. And indeed, being a burden on others is one reason people report choosing PAID. OR. HEALTH AUTH., *supra* note 24, at 12; Al Rabadi et al., *supra* note 21, at 5 ("Reasons patients choose to pursue MAID include . . . in a small percentage, financial concerns.").

116. *Washington v. Glucksberg*, 521 U.S. 702, 731–32 (1997) ("The risk of harm is greatest for the many individuals in our society whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, advanced age, or membership in a stigmatized social group." (quoting N.Y. STATE TASK FORCE ON LIFE AND THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT 120 (1994))).

to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and societal indifference.”¹¹⁷

There may be more reason to be concerned about coercion or undue influence in the context of an acquired disability that impairs cognition, such as dementia, because unlike the case of a person who has always had decisional impairments, a person with an acquired disability may have accumulated significant assets prior to the onset of impairment; receive care from informal caregivers; or seem like a different person than they were prior to their decisional impairments. These factors may result in greater conflicts of interest with family members who may not care as much about overriding the supported person’s current preferences.

Although these concerns are warranted, there are safeguards built into both PAID and supported decision-making laws that decrease the likelihood of undue influence and coercion. Such safeguards include, for example, having at least two physicians involved in the PAID process and directions to third parties to contact state protective services if abuse or neglect of the supported person is suspected.¹¹⁸ If the multiple healthcare professionals and the lay witnesses involved in the legally required PAID process do not report abuse or neglect as mandated by supported decision-making legislation and continue their role in the process of assisting a terminally ill supported person with decisional impairments to hasten death with PAID, this seems like sufficient evidence that there has not been coercion or undue influence exercised upon the person with decisional impairments.¹¹⁹

4. Contextualizing Autonomy

There may be concerns that the analysis of whether terminally ill supported persons with decisional impairments can autonomously elect to hasten death with PAID focuses too much on the micro level of autonomy, ignoring the macro-level constraints on autonomous decision-making. Both PAID and supported healthcare

117. *Id.* at 732 (quoting *Compassion in Dying v. Washington*, 49 F.3d 586, 593 (9th Cir. 1995)). Although the Supreme Court in this case was concerned about bias against persons with disabilities, other courts have affirmed the autonomy rights of persons with physical disabilities while simultaneously assuming that such persons have a low quality of life. *See, e.g., Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 304–05 (Ct. App. 1986) (“She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She cannot be faulted for so concluding. If her right to choose may not be exercised because there remains to her, in the opinion of a court, a physician or some committee, a certain arbitrary number of years, months, or days, her right will have lost its value and meaning.”).

It is unclear, however, the degree to which there is bias against persons with disabilities relative to other groups such that persons with disabilities are more vulnerable. Indeed, Congress has expanded legislative protections for persons with disabilities by amending the ADA to cover more people, and states are adopting supported decision-making legislation, which seems to indicate some degree of political influence.

118. *See infra* Part IV.

119. Additionally, if the terminally ill person with a decisional impairment is acting without the assistance of a supporter, this may also decrease concerns about undue influence and coercion, although concerns about understanding may increase. For a discussion of a person with decisional impairments deciding in the absence of support, *see infra* Part III.

decision-making laws focus on individual choice in the context of relationships with physicians and supporters. But decisions are made in a larger context that shapes what options are available to decision-makers. Admittedly, the discussion about autonomy with respect to healthcare decision-making, and more specifically using a supported decision-making agreement to gain access to PAID, is rather narrow. A richer discussion of autonomy would examine factors that affect the available options from which a person can choose.¹²⁰

The primary reasons that persons report electing PAID are loss of autonomy and dignity and the inability to do things that made life enjoyable.¹²¹ But importantly, not wanting to be a burden on family and friends was listed as an end-of-life concern by over half of persons who sought PAID in Oregon in 2018.¹²² This concern may be because the United States does not have a good system of formal, high-quality care for persons in late life, and the available options are prohibitively expensive.¹²³

So, when faced with the reality of expensive or nonexistent long-term care or relying on informal family caregivers who must take time out of the labor force, terminally ill persons may prefer hastening death through PAID. But if other options were available, such as low-cost medical and nursing care, then perhaps people who currently choose PAID would prefer to live until they die from other causes.¹²⁴

120. See, e.g., Susan Sherwin, *Relational Autonomy and Global Threats*, in *BEING RELATIONAL: REFLECTIONS ON RELATIONAL THEORY AND HEALTH LAW* 13, 19 (Jocelyn Downie & Jennifer J. Llewellyn eds., 2012) (“Often . . . people fail to act with full autonomy because the options that are meaningfully available to them do not include a choice that is compatible with their deepest values and needs.”); Francis, *supra* note 51, at 83 (“Autonomy requires not only the capacity for reasoned decision-making, but a reasonable range of alternatives among which to choose. . . . [E]conomic insecurity, family rejection or pressures, or availability of social services such as home care may significantly reduce the range of available options.”); Wright, *supra* note 10, at 1100 n.203 (“The background conditions of social and economic inequality decrease true autonomy.”).

121. OR. HEALTH AUTH., *supra* note 24, at 12. These are the concerns of people who had capacity when hastening death with PAID. It is unknown whether terminally ill persons without decisional capacity would have the same end-of-life concerns. Persons with dementia, for example, may no longer care about autonomy when they become terminally ill and thus eligible for PAID, and so may be less likely to pursue PAID based on autonomy concerns compared to others. Persons with lifelong cognitive impairments may not experience end of life as losing autonomy, and they may require no more care than they have throughout their lives, which may also make them less likely to choose PAID or to have different reasons for choosing this end-of-life option.

122. *Id.*

123. Crossley, *supra* note 113, at 905–09 (discussing the problem of privileging autonomy when persons with disabilities do not have access to support). See generally Allison K. Hoffman, *Reimagining the Risk of Long-Term Care*, 16 *YALE J. HEALTH POL’Y L. & ETHICS* 239 (2016).

124. Indeed, Oregon invested significant resources into ensuring that residents in their state have access to high-quality hospice and palliative care so that terminally ill patients have more options than PAID at the end of life. Francis, *supra* note 51, at 83–84. This may be the reason why in 2017, 20% of persons who were prescribed life-ending medication under Oregon’s Death with Dignity Act did not use their prescription and died from other causes. OR. HEALTH AUTH., *supra* note 24.

Indeed, there may not be a concern about anyone, regardless of disability status, being pressured into hastening their death against their will if it was ensured that persons could live a good quality of life without depleting their assets or relying on informal caregivers.¹²⁵ This would require significant government intervention to ensure access to high quality, affordable long-term care to decrease burdens on informal caregivers.¹²⁶ Investing resources to ensure both autonomy and equality for persons with disabilities¹²⁷ necessarily implicates distributive justice concerns.¹²⁸

Additionally, persons contemplating a future where they have a cognitive disability such as dementia may want the option of using PAID because they cannot imagine having a good quality of life with this type of disability. Recent scholarship has demonstrated that living with cognitive impairments in late life is not necessarily incompatible with a good quality of life, however.¹²⁹ Both cultural and structural changes, such as changing attitudes towards persons with cognitive impairments and providing low-cost long-term care, would be necessary to convince persons otherwise.

125. Indeed, some scholars have argued that the focus should not be on legalizing PAID, but on expanding access to healthcare. *See, e.g.*, John D. Arras, *Physician-Assisted Suicide: A Tragic View*, in *PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE*, *supra* note 95, at 279, 294 (“[W]e should attack the problem at its root with an ambitious program of reform in the areas of access to primary care and the education of physicians in palliative care. . . . [W]e should thus first see to it that the vast majority of people in this country have access to adequate, affordable, and nondiscriminatory primary and palliative care. . . . [W]hen we finally have an equitable, effective, and compassionate healthcare system in place . . . then we might well want to reopen the discussion of PAS and active euthanasia.”); Patricia A. King & Leslie E. Wolf, *Lessons for Physician-Assisted Suicide from the African-American Experience*, in *PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE*, *supra* note 95, at 91, 105 (“This conversation should be about changes and modifications that are required in the training of healthcare providers and the delivery of healthcare services before we can be confident that all patients will have the opportunity to die with dignity.”). It is unclear whether scholars with this view are open to PAID as an end-of-life option now that access to healthcare has increased since the enactment of the Affordable Care Act.

126. *See, e.g.*, Eva Feder Kittay, *At Home with My Daughter*, in *AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS*, *supra* note 61, at 64, 74 (discussing barriers to home-based care for persons with significant disabilities and asking “how many more families would be able and willing to [provide care in] their own home if a truly full array of supportive services were to be made available not only to the individual for medical treatment . . . but to the family to continue keeping [the individual with a disability] at home”). Disability organizations that oppose PAID also advocate for more resources, specifically long-term care supports. NAT’L COUNCIL ON DISABILITY, *supra* note 114, at 13.

127. Bickenbach, *supra* note 111, at 353 (“Inequality is exemplified in concrete and practical terms by the absence of resources and opportunities that make it realistically possible for a person to achieve what he or she wishes to achieve.”).

128. *Id.* at 354 (“Antidiscrimination laws such as the ADA are shaped by social and legal forces that, perhaps inevitably, turn their attention away from distributional issues.”); Batavia, *supra* note 111, at 290–91 (arguing that the ADA—although necessary to ensure equality of opportunity—is insufficient because other interventions addressing poverty are necessary for equality of opportunity).

129. *See generally* TIA POWELL, *DEMENZA REIMAGINED: BUILDING A LIFE OF JOY AND DIGNITY FROM BEGINNING TO END* (2019).

The solution to cultural and structural constraints on autonomy is not to decrease, but rather increase choice. Although it may be autonomy-promoting to permit terminally ill supported persons with decisional impairments to access PAID to hasten death, should this be their preference, it is more autonomy-promoting to increase the available choices for persons facing serious illness. An increased availability of healthcare choices is important, not just with respect to end-of-life choices, but with respect to accessing the care persons need to live a good quality of life and mitigating their concerns about burdening their families. Even if these conditions changed, however, some terminally ill persons with decisional impairments may still prefer to hasten death through PAID, and the law should permit this autonomous choice.

B. Equality of Autonomy

Although supported decision-making may seem to only apply to persons with cognitive disabilities, this model also accords with the healthcare decision-making preferences of persons without cognitive disabilities who prefer to make serious and late-life healthcare decisions in a relational manner. In the specific context of end-of-life decision-making, both groups—persons with and without decisional impairments—are similarly situated in terms of their decision-making preferences and need for decision-making assistance and thus should be treated equally.

If equal treatment under the law for persons with disabilities, including persons with decisional impairments, is valued, then they should be afforded all legal options available to persons without disabilities. Equality could mean that no one is permitted to hasten death with PAID,¹³⁰ or equality could mean that everyone who meets the PAID eligibility requirements can elect this end-of-life option.¹³¹ This Article argues for the latter option: all persons, regardless of disability, should be allowed to exercise autonomy with respect to end-of-life decision-making, even if they require support to do so. That is, the law should respect the capacity of persons to exercise autonomy, i.e., relational agency, regardless of whether they have a cognitive disability.

When it comes to disability rights, arguments about equality and autonomy are tightly linked.¹³² Disability advocates were influential in garnering support for the ADA's passage, which prohibits discrimination on the basis of disability and

130. See, e.g., *Washington v. Glucksberg*, 521 U.S. 702, 732 (1997) (“The State’s assisted-suicide ban reflects and reinforces its policy that the lives of terminally ill, disabled, and elderly people must be no less valued than the young and the healthy, and that a seriously disabled person’s suicidal impulses should be interpreted and treated the same way as anyone else’s.”).

131. For a different type of equality argument about PAID, see Ackerman, *supra* note 115 (arguing that PAID should be available to everyone regardless of whether they are terminally ill, or no one at all).

132. Jerome E. Bickenbach, *Disability and Life-Ending Decisions*, in *PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE*, *supra* note 95, at 123, 131 (“The fact of the social devaluation of the life of persons with disabilities, as a matter of both attitude and practice, demands that the governing moral principle ought to be equality, and in particular equality of autonomy.”); Scotch, *supra* note 111, at 275.

mandates reasonable accommodations so that persons with disabilities can be self-determining and fully included in society.¹³³ The ADA thus connects equal treatment under the law with respect for the autonomy of persons with disabilities.¹³⁴

But what does equality mean for persons with decisional impairments? Should persons with cognitive disabilities be treated the same as persons without cognitive disabilities with respect to healthcare and end-of-life decision-making?¹³⁵ Or because they have cognitive disabilities, which is perhaps a meaningful difference with respect to decision-making, should they be treated differently in order to have equality of opportunity or equal access to desirable goods,¹³⁶ including the exercise of autonomy?

Arguably, the ADA and other types of disability-specific legislation, such as supported decision-making, accommodate multiple understandings of equality.¹³⁷ The notion that persons with disabilities should have the same options as persons without disabilities—e.g., in obtaining employment, in accessing buildings, in making their own decisions, etc.—is grounded in formal equality, while the recognition of and mandate to accommodate differences in order to access these options—e.g., access to assistive devices, wheelchair ramps, supporters, etc.—is grounded in substantive equality.

Tying together equality and autonomy leads to the conclusion that the law should not prevent terminally ill supported persons with decisional impairments from hastening death with PAID.¹³⁸ Excluding such persons from this end-of-life

133. Compare Bickenbach, *supra* note 111, at 345 (describing how the ADA connected nondiscrimination and equality to the independence and nonpaternalistic treatment of persons with disabilities in the labor force), with Kittay, *supra* note 126, at 77–78 (critiquing the connection between equality and independence in disability law because some persons with disabilities are never going to be capable of independence).

134. See *supra* note 62; 42 U.S.C. § 12101(a)(8) (2018) (“[T]he continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.”).

135. Equal treatment is formal equality, and many nondiscrimination laws are premised upon this conceptualization of autonomy. See *Equality of Opportunity*, STAN. ENCYCLOPEDIA OF PHIL. (Mar. 25, 2015), <https://plato.stanford.edu/entries/equal-opportunity/>.

136. Substantive conceptualizations of equality recognize that treating different groups the same, particularly marginalized groups, may lead to unequal outcomes. *Id.*; see also LESLIE PICKERING FRANCIS & ANITA SILVERS, AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 163 (“Equality appears to require setting difference aside, but to be neutral with respect to a difference such as disability ignores ways in which differences are relevant.”); Iris Marion Young, *Disability and the Definition of Work*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 61, at 169, 169–70.

137. Young, *supra* note 136.

138. This Article does not argue that terminally ill persons with decisional impairments should hasten death with PAID; instead, this Article argues that PAID should be

option violates formal equality. And if such persons use supporters to make healthcare and other decisions to achieve the capacity required to make these decisions, preventing them from accessing PAID with support violates substantive equality. Indeed, supported decision-making can be seen as a reasonable accommodation under the ADA so that persons with decisional impairments can autonomously make their own healthcare, including end-of-life, decisions.¹³⁹ Using supported decision-making to exercise autonomy and achieve equal legal capacity is also consistent with the Convention on the Rights of Persons with Disabilities.¹⁴⁰

available as an option to this population. *Cf.* Tuffrey-Wijne et al., *supra* note 49, at 14 (“In a society where [assisted dying] is legalized and a clearly viable option in the eyes of a large proportion of the population, as is the case in the Netherlands . . . there should be clear and compelling reasons if a person with an intellectual disability or autism spectrum disorder is to be denied this option.”).

139. Wright, *supra* note 90, at 30; *see also* Tuffrey-Wijne, *supra* note 49, at 19 (“For disabled citizens to have equal rights (including the right to [assisted dying] in jurisdictions where this is a legal option), there must be ‘reasonable adjustments’ in place to ensure that the standard procedures do not leave them at a disadvantage.”).

Some scholars argue that “profoundly mentally disabled” persons—i.e., some persons with significant lifelong intellectual or developmental disabilities—are incapable of self-determination and autonomy, and that the law should not afford them the same healthcare decision-making rights as persons who were once considered competent to make their own decisions. *See, e.g.*, Cantor, *supra* note 108, at 40; Silvers, *supra* note 95, at 139. But this view neglects the possibility that autonomy is possible through the provision of support.

140. United Nations Convention on the Rights of Persons with Disabilities art. 12, Mar. 30, 2007, 2515 U.N.T.S. 3.

Prominent disability activists may argue that PAID is incompatible with equal treatment or respect for the autonomy of persons with disabilities. NOT DEAD YET, *supra* note 114. But organizations purporting to represent the views of the disability community may not actually do so. Indeed, some organizations note that persons with disabilities have diverse views, but then argue that the important viewpoint is that of disability organizations and not individuals with disabilities. NAT’L COUNCIL ON DISABILITY, *supra* note 114, at 12.

Empirical research has demonstrated a diversity of views among persons with disabilities about PAID. In one study, a sizeable minority of persons with physical disabilities reported feeling positive about PAID legislation, and close to half of research participants reported feeling ambivalent. Pamela Fadem et al., *Attitudes of People with Disabilities Toward Physician-Assisted Suicide Legislation: Broadening the Dialogue*, 28 J. HEALTH POL. POL’Y & L. 977, 985–87 (2003). Almost all study participants said that autonomy and self-determination were important to them, but also expressed that they had experienced discrimination on the basis of their disability that led to some concerns about PAID. *Id.* at 987–89. Importantly, however, persons in the study did not want any positive view of legalizing PAID to be known because they feared criticism from disability activists. *Id.* at 991–93. Because the study only included persons with physical disabilities, it is unclear what the views of persons with cognitive disabilities are with respect to PAID. *Id.* at 982.

It should not be surprising that people grouped together on the sole basis of their disability status have different views. Not only do the experiences of disability differ by type of disability, but persons with disabilities will also have other individual characteristics and social statuses that lead to different views on issues such as the legalization of PAID. Caution should be exercised in assuming that organizations such as Not Dead Yet represent the views of all persons with disabilities about PAID, especially persons with disabilities who

III. ACCESSING PHYSICIAN AID IN DYING WITH SUPPORT IN THE DISTRICT OF COLUMBIA

Examining how PAID and supported decision-making laws intersect has more than just theoretical import given that both laws are spreading across the United States, and these laws currently overlap in one U.S. jurisdiction: the District of Columbia. This leads to the pressing question of whether in the District of Columbia a terminally ill patient with cognitive impairments sufficient to result in a physician determining that the patient lacked decision-making capacity could elect PAID¹⁴¹ under the D.C. Death with Dignity Act if they had a supported decision-making agreement. Answering this question requires close examination of the D.C. Death with Dignity Act and supported decision-making laws.

The District of Columbia's supported decision-making law explicitly permits persons with decisional impairments to be supported in healthcare decision-making.¹⁴² Assuming that a decision to elect PAID is considered a healthcare decision,¹⁴³ then a supported person should be able to receive assistance with

do not identify as disabled. *See* 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, 348 (2006) (asserting that disability activists do not necessarily represent the range of views of persons with disabilities about end-of-life decision-making).

Regardless of whether disability organizations' opposition to PAID is in the best interests of persons with disabilities, the anti-PAID view has implications for choices available to persons without disabilities. Alicia Ouellette, *Disability and the End of Life*, 85 OR. L. REV. 123, 126 (2006) ("[T]he crusade by disability rights activists against freedom in medical decisionmaking is [not] in fact in the best interests of people living with physical and mental challenges, and . . . in seeking to protect members of the disability community from perceived and real threats, the activists would limit options for all of us by declaring how we must, or, more correctly, how we must not die."). Further, these organizations' opposition to PAID and other end-of-life options could harm the interests of persons with disabilities in avoiding unwanted medical interventions. Cerminara, *supra*, at 381.

141. The District of Columbia, like Oregon, requires that a person requesting PAID is "capable," which means that "a patient has the ability to make and communicate health care decisions to health care providers." D.C. CODE ANN. § 7-661.01(2) (West, Westlaw through Dec. 8, 2020). The District of Columbia's definition differs from Oregon's in that it does not add "including communication through persons familiar with the patient's manner of communicating if those persons are available." OR. REV. STAT. ANN. § 127.800(3) (West, Westlaw through 2020 Reg. Sess.). In fact, Oregon's Death with Dignity Act definition of "capable" encompasses one of the key elements of supported decision-making: assistance with communicating a decision to third parties. Oregon's law is also consistent with the ADA, which requires reasonable accommodations for persons with disabilities. 42 U.S.C. § 12182(b)(2)(A)(iii) (2018). As noted previously, supported decision-making can be a reasonable accommodation under the ADA for persons with cognitive impairments. Wright, *supra* note 90, at 30.

142. This includes physical, mental, and behavioral health. D.C. CODE ANN. § 7-2132(d).

143. Some may object that electing PAID is not a healthcare decision, but an end-of-life decision. Given the way jurisdictions in the United States have legalized aid in dying, which requires involvement from physicians and other healthcare professionals, e.g.,

choosing PAID, and assuming all other PAID eligibility requirements are met, not be prevented from dying in this manner. In brief, in the District of Columbia a terminally ill supported person with a decisional impairment may be able to elect PAID with assistance from a supporter.

The question of whether a terminally ill supported person with a decisional impairment could elect PAID in the District without assistance from a supporter is more difficult to answer. Unlike supported decision-making laws in Indiana and Alaska, which explicitly state that a supported person can act independently of their agreement, and unlike supported decision-making laws in Delaware and Wisconsin, which presume capacity for supported persons,¹⁴⁴ the District's supported decision-making law is silent on whether supported persons with decisional impairments can make decisions without assistance. If PAID were legal in these other states, there would be a stronger case that the terminally ill supported person with a decisional impairment would be able to choose PAID even if no decision-making support were provided; this is because these states' supported decision-making laws, in essence, direct that the person with a disability retains legal capacity. In the District of Columbia, however, it may be the case that the supported decision-making law's silence on this issue would be interpreted by judges and healthcare providers to prohibit the person with a cognitive disability from making decisions, including PAID, without support.¹⁴⁵

There are other components of the D.C. Death with Dignity Act that may make it less likely that a terminally ill supported person with a decisional impairment would be eligible for this end-of-life option. For example, the written request for the aid-in-dying medication must be witnessed by two people who declare that the

pharmacists, mental health providers, etc., this decision is arguably both an end-of-life and a healthcare decision. Furthermore, many life-ending decisions are also decisions to refuse or discontinue medical treatment, which again erases the distinction between some healthcare decisions and end-of-life decisions.

144. See Wright, *supra* note 57, at 287 (describing presumption of capacity in most supported decision-making laws).

145. This raises the question of *what* in the model of formal supported decision-making provides legal capacity: the existence of the agreement with its declaration that the person with a disability can act independently of the agreement or the provision of support to assist in decision-making that leads to choices that further the interests of the person with a disability (as defined by the person with a disability). I am grateful to Nina Kohn and Bob Dinerstein for their insight on this question.

In the former case, no capacity assessment should ever be conducted because the results are irrelevant; they have legal capacity regardless of what an assessment would reveal. In the latter case, however, the important question is whether the provision of support would increase decisional capacity to the point of passing a clinician-administered assessment. That is, does the provision of decision-making assistance lead to an increase in the understanding, appreciation, and reasoning abilities of the principal? If not, the principal would be ineligible to make the particular decision, in this case to hasten death with PAID.

Case law is sparse on this issue, but courts in Texas view the abilities of a person with a cognitive disability in light of the provision of support to determine whether the person with a cognitive disability has legal capacity; that is, in Texas, the agreement is insufficient to grant legal capacity, although this may differ in other states. *Guardianship of A.E.*, 552 S.W.3d 873, 889 (Tex. App. 2018).

person making the request “[a]ppears to be of sound mind and not under duress, fraud, or undue influence.”¹⁴⁶ It is unclear whether two witnesses would be willing to attest that a person with moderate dementia, for example, who was seeking to use PAID was of “sound mind.” Perhaps these witnesses would have a broader interpretation of “sound mind” if the person had supporters, however, and would be willing to attest that the supported person with decisional impairments met the other Death with Dignity Act requirements.¹⁴⁷

But the immunities and limitations on liabilities contained in both the D.C. Death with Dignity Act and supported decision-making laws may increase the likelihood that a terminally ill supported person with decisional impairments could hasten their death through PAID. The District of Columbia supported decision-making legislation contains the following provision: “Neither a person nor a District agency shall be subject to criminal or civil liability, nor shall a person be considered to have engaged in professional misconduct, for an act or omission done in good faith and in reasonable reliance on a supported decision-making agreement.”¹⁴⁸ This is coupled with the directive to third parties who are presented with the agreement to “rely on the agreement, unless the person . . . has substantial cause to believe that the supported person is an adult in need of protective services.”¹⁴⁹ And the D.C. Death with Dignity Act states: “[N]o person shall be subject to civil or criminal liability or professional disciplinary action for . . . [p]articipating in good faith compliance with this chapter.”¹⁵⁰ Read together, these provisions imply that if a physician was presented with a copy of a supported decision-making agreement by their terminally ill patient who was requesting PAID, and in the absence of any signs of undue influence or coercion by a supporter, the physician could rely on the agreement and may not be liable for prescribing medication under the D.C. Death with Dignity Act if the other parts of the PAID process required by law were followed.

Still other provisions of these laws interact in unknown ways. For example, the D.C. Death with Dignity Act contains the following: “A provision in a contract, will, or other agreement executed on or after the effective date of this act, whether written or oral, is not valid if the provision would affect whether a person may make or rescind a request for a covered medication.”¹⁵¹ Under a conventional reading of this statutory text, a supported decision-making agreement would constitute a “contract” or “other agreement” that “would affect whether a person may make . . . a request” for PAID. This is because the supported decision-making agreement permits a person who otherwise would be ineligible to make their own decisions (because of their cognitive disability) to make decisions with assistance from

146. D.C. CODE ANN. § 7-661.02(c) (West, Westlaw through Dec. 8, 2020).

147. Another question on which the District of Columbia’s supported decision-making law is silent is whether a supporter could act as a witness for PAID. According to D.C. law, supporters can still act as power of attorneys and healthcare agents/surrogates. § 7-2132(d).

148. § 7-2133(e).

149. § 7-2133(d).

150. § 7-661.11.

151. § 7-661.09. Oregon’s statute contains a similar provision. OR. REV. STAT. ANN. § 127.870(3)(12) (West, Westlaw through 2020 Reg. Sess.).

supporters, which may then make the person eligible for PAID. While this section of the Death with Dignity Act, modeled after Oregon's, likely did not contemplate supported decision-making, its plain meaning suggests that a supported decision-making agreement may not be used to expand access to PAID for persons with impaired decision-making capacity.

Because the issue of whether a terminally ill supported person with a decisional impairment can access PAID has not been litigated in the District of Columbia, however, it is unclear how these laws interact, and it is an open question about whether such a person would be eligible for PAID in the District.¹⁵² But given the real possibility that terminally ill persons with decisional impairments may seek to hasten death with PAID in jurisdictions with both laws, policymakers should consider whether these laws should be changed both to promote autonomy and provide sufficient protection for persons with cognitive impairments.

IV. QUESTIONS MOVING FORWARD

The prospect of terminally ill supported persons with decisional impairments accessing PAID may make stakeholders, such as lawmakers, persons with disabilities and their advocates, healthcare providers, and the public, uneasy given the vulnerability of this population. That is, if choosing between freedom and safety, legislators may decide to weigh safety more heavily for persons with cognitive impairments and prohibit them from being able to choose PAID.¹⁵³ But equality of autonomy is important for persons with disabilities, and so it is necessary to try to address stakeholder concerns about permitting terminally ill persons with decisional impairments to hasten death with PAID so that this end-of-life option is available to this population.

Conducting research on PAID and disseminating the results widely may help reduce concerns. When legalization of PAID was being debated prior to its recent spread across the United States, scholars and bioethicists were concerned that members of marginalized groups would be pressured to hasten death with PAID.¹⁵⁴ To date, however, research has overwhelmingly found that patients who are members of vulnerable groups have not been hastening death with PAID at a higher

152. It is also unclear what would happen if a person executed a supported decision-making agreement in a jurisdiction that recognizes such agreements and then tried to access PAID in a different jurisdiction that does not have supported decision-making legislation.

153. If stakeholders view the possibility of coercion, undue influence, or mistakes in electing to hasten death through PAID as unacceptably high for terminally ill persons with decisional impairments, laws may prohibit supported persons accessing this end-of-life option. It is unclear, however, whether courts would find such prohibitions to violate ADA or constitutional rights.

154. See, e.g., King & Wolf, *supra* note 125, at 105 (predicting that the power difference between physicians and their African-American patients coupled with racism and unconscious bias would possibly render PAID safeguards ineffective for this patient population).

rate compared to other patients,¹⁵⁵ and this information should be shared with the public to assuage concerns.

Additionally, support for making all end-of-life choices available to terminally ill persons with decisional impairments may increase if there are safeguards to ensure that the requirements of autonomous decision-making—intent, understanding, and voluntariness—are satisfied. This Part first examines existing safeguards and then examines whether there should be additional safeguards built into both PAID and supported decision-making laws to ensure respect for autonomy of patients with cognitive disabilities at the end of life.

A. Existing Safeguards

There are existing safeguards and policies that limit unintended negative consequences in both PAID and supported decision-making laws that may prevent mistakes, undue influence, or their negative effects for terminally ill supported persons with decisional impairments electing PAID. One existing policy in PAID laws is the terminal-illness requirement to access PAID, restricting eligibility to those at the end of life.¹⁵⁶ This ensures that a supported person with decisional impairments would not be able to unintentionally or without understanding elect PAID prior to becoming terminally ill, and a supporter or a physician would be unable to pressure the person with a cognitive disability to use PAID unless the

155. See, e.g., Al Rabadi et al., *supra* note 21, at 5 (“These data reinforce the belief that MAID has not been directed toward traditionally vulnerable populations based on age, race/ethnicity, level of educational attainment, or insurance status.”); 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, 591 (2007) (finding no evidence of increased use of PAID for “the elderly, women, the uninsured . . . people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities”); Orentlicher et al., *supra* note 1, at 1962 (“Vulnerable patients are not succumbing to aid in dying.”). *But see* I.G. Finlay & R. George, *Legal Physician-Assisted Suicide in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups: Another Perspective on Oregon’s Data*, 37 J. MED. ETHICS 171, 173 (2011) (questioning whether vulnerability is properly understood in the PAID context and suggesting that older persons and persons with depression may be more vulnerable to PAID).

Given that several studies have found that older persons and persons with cognitive disabilities have not disproportionately used PAID, there may be reason to expect that terminally ill older persons with cognitive disabilities are likewise not being pressured to hasten death with PAID.

156. Orentlicher et al., *supra* note 1, at 1961 (arguing that the terminal-illness requirement is appropriate because it ensures PAID is a “last resort”).

Although some disability advocacy organizations point to anecdotes about insurance companies denying treatments that will sustain lives while covering aid-in-dying medication as evidence that persons with disabilities are coerced into hastening death with PAID, their argument does not recognize that the terminal illness requirement still applies. NAT’L COUNCIL ON DISABILITY, *supra* note 114, at 11. That is, if PAID laws are followed, then no person with a disability will have access to PAID unless they are also terminally ill.

Other scholars have drawn attention to the flawed arguments against PAID made by disability activists. See, e.g., Ouellette, *supra* note 140, at 127 (“The theory that laws allowing choice in dying perpetuate disability discrimination is flawed by conflation, inflation, misidentification, and a misplaced operational definition of disability.”).

person had an estimated six months or less to live. While there may be mistakes, and undue influence could be exerted upon a supported person with decisional impairments once they were terminally ill, the cost would be limited to the very end of life.¹⁵⁷

Other parts of PAID laws require involvement from other parties, who can slow down the process or alert authorities to violations of the law, which also is an existing safeguard.¹⁵⁸ A second physician is required to confirm all of the eligibility requirements for PAID prior to a patient gaining access to this end-of-life option;¹⁵⁹ this increases the likelihood that mistakes, misunderstanding, or undue influence by a supporter or the attending physician would be noticed and the PAID process stopped. Additionally, physicians are required by law to refer their patients who may be depressed or have other psychiatric disorders that may be affecting their decision to use PAID to counseling prior to prescribing the medication.¹⁶⁰ This adds yet another party to the decision-making process who would be able to observe mistakes, misunderstanding, coercion, or undue influence, and could slow the PAID process down or stop it entirely. Moreover, the written request for PAID has to be witnessed by two parties, one of whom is not related to the patient making the PAID request,¹⁶¹ which provides another opportunity to observe that the request is being made intentionally, voluntarily, and with understanding.

157. Some advocates for persons with disabilities are concerned that anyone dependent upon life-sustaining medical interventions would be pressured to hasten death with PAID, potentially missing out on decades of life. Unless the person with a disability was terminally ill, they would not qualify for PAID regardless of whether they were reliant upon medical technology to live. They could elect to withdraw treatment, however, hastening death despite the prospect of many more years of life, as established in cases such as *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ct. App. 1986).

158. Indeed, out of various end-of-life decisions, PAID is perhaps the most protective of patient autonomy. Other life-ending decisions may not have as many persons involved who can intervene if there is a mistake or wrongdoing on the part of healthcare providers or surrogate decision-makers. In particular, the PAID process should be contrasted with palliative sedation (previously known as terminal sedation), which occurs when a patient is sedated and then artificial nutrition and hydration or other life-saving measures, such as a ventilator, are withheld or withdrawn. In fact, none of the procedural safeguards present in PAID are present in palliative sedation, which does not even have a terminal-illness requirement. Jonathan F. Will, *Dying with Dignity; Living with Laws (and Ethics)*, 49 HASTINGS CTR. REP. 6, 6–7 (2019). Other scholars have also noted problems with palliative sedation compared to PAID, including that it prolongs the dying process, forces the patient to die in the hospital, lacks a terminal illness requirement, and can be done without patient knowledge and consent. David Orentlicher, *The Supreme Court and Terminal Sedation: An Ethically Inferior Alternative to Physician-Assisted Suicide*, in PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE, *supra* note 95, at 301, 302, 306–07 (“Terminal sedation serves fewer of the purposes of right-to-die law while posing greater risks of abuse than assisted suicide.”).

159. D.C. CODE ANN. § 7-661.03(b) (West, Westlaw through Dec. 8, 2020).

160. § 7-661.04.

161. § 7-661.02(b)(3).

Additionally, PAID laws require physicians to discuss all alternatives to PAID,¹⁶² field multiple requests for this end-of-life option,¹⁶³ and ask their patients if they would like to rescind their request prior to the patient's second oral request,¹⁶⁴ which ensures that a supported patient would know they can change their mind and provides the opportunity for them to do so. Furthermore, if physicians follow ethical advice from Oregon Health & Science University, which directs that physicians should not initiate conversations about PAID with their patients,¹⁶⁵ then many patients, supported or not, may not know about this particular option, which functions as a safeguard against mistaken or coerced opt-in. But following this guidance also inhibits autonomy for patients who may otherwise be interested in this end-of-life option.¹⁶⁶

Moreover, any healthcare provider can opt out of participating in PAID,¹⁶⁷ and individual or organizational opt outs can function as safeguards. Because physicians are not required to participate in PAID, even if they were otherwise willing to prescribe PAID medication, they may decline to do so for some of their terminally ill supported patients with decisional impairments if they did not believe their patient's request was autonomous.

162. Alternatives include "comfort care, hospice care, and pain control." § 7-661.03(a)(2)(E). Many patients are unaware of their end-of-life options, and the request for PAID can serve as a catalyst for educating them. David Orentlicher et al., *Clinical Criteria for Aid in Dying*, 19 J. PALLIATIVE MED. 259, 260 (2016).

163. The three-documented-requests requirement is also a much stronger procedural safeguard against mistake or abuse than the safeguards available under other end-of-life options such as withholding or withdrawing life-sustaining treatment or palliative sedation. *See supra* note 158.

164. § 7-661.03(a)(8).

165. THE TASK FORCE TO IMPROVE THE CARE OF TERMINALLY-ILL OREGONIANS, THE OREGON DEATH WITH DIGNITY ACT: A GUIDEBOOK FOR HEALTH CARE PROFESSIONALS § 15.41 (2007) ("Avoid exerting any influence over the patient's decision to request medication or to revoke a rescission of such a request. Discussions concerning the Act should be initiated by patients."). Vermont requires physicians to discuss all end-of-life options with their patients, however. VT. STAT. ANN. tit. 18, § 1871 (West, Westlaw through Acts 1-180, M-1-M-12 of the 2019–2020 Gen. Assemb.).

166. The American Public Health Association also recognizes this issue. AM. PUB. HEALTH ASS'N, *supra* note 63 ("Empirical and anecdotal evidence reflect that health care providers do not inform terminally ill patients of all options legal in the state in which the patient is receiving care. As a result, patients are not able to make fully informed decisions about care at the end of life. APHA rejects providing only partial information on which to base health decisions.").

167. D.C. CODE ANN. § 7-661.10(a) ("No health care provider shall be obligated under this act, by contract, or otherwise, to participate in the provision of a covered medication to a qualified patient."). While the D.C. supported decision-making legislation does not have a conscience opt out, it does permit third parties to refuse to rely on the agreement if they think the supported person needs protective services. § 7-2133(e). Other statutes or D.C. common law may provide conscience exceptions to healthcare providers being required to rely on supported decision-making agreements. In other states with supported decision-making legislation, there are some conscience opt outs for third parties presented with a supported decision-making agreement. *See* Wright, *supra* note 57, at 301–23 (describing laws).

Also, organizational policy mediates access to PAID.¹⁶⁸ It may be the case that physicians would be willing to prescribe PAID medication to their terminally ill supported patients with decisional impairments, but the healthcare organization with which they or their patient is affiliated opts out of participating in PAID entirely,¹⁶⁹ or the organization has a policy that prohibits terminally ill supported persons with decisional impairments from accessing PAID without additional measures taken to ensure the patient's request is voluntary.

There is also a "natural" safeguard with respect to PAID in that very few people choose this end-of-life option,¹⁷⁰ meaning that legally expanding access to currently ineligible persons may not result in significant uptake. In the District of Columbia, for example, in 2017, the first year of PAID implementation, no one used PAID.¹⁷¹ In 2018, four people were prescribed PAID drugs.¹⁷² While there is no data on the number of persons who have supported decision-making agreements in this jurisdiction, in order for it to be a significant concern that terminally ill supported persons with decisional impairments would access PAID unintentionally, without understanding, or because of the undue influence of others, it would have to be assumed that very large numbers of persons currently ineligible for PAID due to a decisional impairment would enter a supported decision-making agreement and then choose PAID.¹⁷³ Even if larger jurisdictions such as California were to pass supported decision-making legislation that may make it possible for terminally ill persons deemed incapacitated to access PAID, the number of persons presently electing PAID in California is sufficiently low that the possibility of nonautonomous use of PAID for terminally ill supported persons with decisional impairments would also be extremely low.¹⁷⁴ The benefits of expanding access to PAID to terminally ill

168. See generally Cindy L. Cain et al., *Hospital Responses to the End of Life Option Act: Implementation of Aid in Dying in California*, 179 JAMA INTERNAL MED. 985 (2019) (describing hospital policies created in response to legalization of PAID in California).

169. Organizational opt out of PAID is a barrier to patient autonomy at the end of life. If a patient is not geographically close to an organization that has opted into PAID, or their health insurer does not contract with such an organization, their set of end-of-life choices is reduced.

170. Orentlicher et al., *supra* note 1, at 1962.

171. DC HEALTH, DISTRICT OF COLUMBIA DEATH WITH DIGNITY ACT 2017 SUMMARY 3, https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/DWD%20Report%202017%20Final%20%20208-2-2019.pdf.

172. DC HEALTH, DISTRICT OF COLUMBIA DEATH WITH DIGNITY ACT 2018 SUMMARY 2, https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/DWD%20Report%202018%20Final%20%20208-2-2019.pdf.

173. Given that so few people have advance directives, it seems highly unlikely that supported decision-making as a form of advance care planning will be widely adopted.

174. In 2018, there were 452 aid-in-dying medication prescriptions that resulted in 337 deaths. The total number of deaths in California in 2018 was 268,474. CAL. DEP'T OF PUB. HEALTH, CALIFORNIA END OF LIFE OPTION ACT 2018 DATA REPORT 3 (2019), <https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH%20End%20of%20Life%20Option%20Act%20Report%202018-FINAL.pdf>. In states that have a longer history of PAID, usage is similarly low.

Moreover, taking an intersectional approach to vulnerability demonstrates that racial and ethnic minorities are not being pressured to hasten their deaths through PAID, in

supported persons with decisional impairments who seriously desire this option and for whom using PAID would be autonomy-promoting may thus outweigh risks of mistake, misunderstanding, or undue influence.

Turning to safeguards in supported decision-making laws, an existing safeguard is directions to third parties contained in copies of supported decision-making agreements to report suspected abuse, neglect, or exploitation of the supported person,¹⁷⁵ a report that could be made by any of the many actors who would know about and be involved in the PAID process, e.g., physicians, nurses, pharmacists, healthcare organizations, long-term care facilities, etc. Furthermore, certain types of people are ineligible to be supporters, such as individuals who have harmed older persons or have been convicted of fraud,¹⁷⁶ which prevents persons who may be more likely to exert undue influence for their own interests from being involved in the decision of a terminally ill supported person with decisional impairments to seek PAID.

Additionally, the D.C. supported decision-making legislation does not contain a liability waiver for supporters. This lack of immunity may lead a supporter

contrast to what was feared prior to adoption of PAID. Patricia A. King & Leslie E. Wolf, *Empowering and Protecting Patients: Lessons for Physician-Assisted Suicide from the African-American Experience*, 82 MINN. L. REV. 1015, 1015 (1997) (describing how African Americans are concerned that healthcare providers do not value their lives as much as whites, and arguing that African Americans are concerned that legalization of PAID will not function to further their autonomy, but rather to result in their hastened deaths). In the racially and ethnically diverse state of California, 88.4% of all persons who died using PAID in 2018 were white whereas whites make up 36.8% of the state's population. Asian PAID users accounted for 5.9% of PAID deaths while Asians comprise 15.3% of population; Hispanic PAID users accounted for 3.9% of PAID deaths while Hispanics comprise 39.3% of the population; African-American PAID users accounted for less than one percent of PAID deaths while African Americans comprise 6.5% of the population; and persons who identify as "other" or "multiple race" accounted for less than 1% of PAID deaths while this group comprises 3.9% of the population. No Native Americans, Hawaiians, or Pacific Islanders used PAID, groups which comprise 2.1% of the population. Other states show similar demographic statistics of PAID users, with an overrepresentation of whites. Whether the low number of persons using PAID and the very low number of racial-ethnic minorities using PAID is due to preferences or other factors (such as lack of access to or knowledge about this option) is unknown, but from these statistics it can be inferred that terminally ill supported persons with decisional impairments who are members of racial and ethnic minority groups would likewise not be pressured to use PAID if this were an available option. All population statistics are from the U.S. Census and California Department of Public Health. U.S. CENSUS BUREAU, *QuickFacts: California (2018)*, <https://www.census.gov/quickfacts/CA>; CAL. DEPT. OF PUB. HEALTH, *supra*.

175. D.C. CODE ANN. § 7-2132(d) (West, Westlaw through Dec. 8, 2020) ("IF A PERSON WHO RECEIVES A COPY OF THIS AGREEMENT OR IS AWARE OF THE EXISTENCE OF THIS AGREEMENT HAS CAUSE TO BELIEVE THAT THE ADULT NAMED AS A SUPPORTED PERSON IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY THE SUPPORTER, THE PERSON MAY REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE CITYWIDE CALL CENTER AT 311, METROPOLITAN POLICE DEPARTMENT AT 911, ADULT PROTECTIVE SERVICES AT (202) 541-3950.").

176. § 7-2132(b)(1)(A).

to decline to provide decision-making assistance with respect to PAID because they fear liability for participating in the process (either under the supported decision-making statute or the provision of the PAID statute that criminalizes coercion or undue influence).¹⁷⁷ Even in jurisdictions that do limit liability for supporters who assist the supported person with decisional impairments in good faith, supporters are expressly prohibited from “exerting influence upon” the supported person,¹⁷⁸ and fear of a finding of undue influence may prevent supporters from assisting with a decision to pursue PAID. Finally, supported decision-making agreements can be revoked by either party at any time,¹⁷⁹ and so supporters may generally opt not to assist in the PAID decision for reasons of conscience. Importantly, however, supporters’ fears of the legal consequences of providing decision-making assistance are problematic if the terminally ill person with decisional impairments relies on supported decision-making to exercise autonomy.

B. Building In Additional Safeguards?

Policymakers considering adding other legal safeguards to ensure terminally ill supported persons with decisional impairments do not hasten death through PAID by mistake or after being unduly influenced would have to expressly confront the intersection of PAID and supported decision-making laws.¹⁸⁰ One possible safeguard to address concerns about undue influence of supporters would be to restrict what type of assistance supporters can provide with respect to the PAID process. Perhaps supporters would be ineligible to communicate a request for aid-in-dying medication on behalf of the supported person to ensure that the supporters are not substituting their judgment for the person with the disability. Or supporters could be prohibited from being present when the patient made the oral request to their physician so that the physician could assess the voluntariness of their patient’s request. Or supporters could be disqualified from being witnesses for the written PAID request, which would necessitate even more people being involved in the process and assessing the voluntariness of the request.

The first two safeguards conflict with the entire premise of supported decision-making, however, especially when persons with decisional impairments require assistance with communicating decisions to third parties. The third possible

177. § 7-661.13.

178. *E.g.*, DEL. CODE ANN. tit. 16, § 9406A(c)(1) (West, Westlaw through ch. 292 of the 150th Gen. Assemb.).

179. D.C. CODE ANN. § 7-2132(d).

180. Scholars studying jurisdictions where persons with developmental and intellectual disabilities can access medical assistance in dying have argued for stricter capacity assessments, *i.e.*, higher evidence of capacity, for this decision for *all* persons as a procedural safeguard against mistake or abuse, given that this decision is serious and irrevocable. Tuffrey-Wijne, *supra* note 49. I do not make similar arguments because while this proposal promotes equal treatment of persons with and without disabilities, if implemented, it also potentially undermines autonomy.

safeguard may thwart the autonomy of persons without an expansive network, an all too common situation many older persons find themselves in.¹⁸¹

Policymakers may consider requiring monitoring of supporters, however, a practice that occurs in other countries with supported decision-making.¹⁸² The practice of supported decision-making itself could be routinely monitored, or the start of the PAID process for a supported person could trigger an audit of whether the supported person is acting autonomously with respect to this end-of-life decision.¹⁸³ But requiring monitoring may slow down the PAID process, which could result in the terminally ill supported person dying from other causes before they can die with PAID.

States may also choose to modify their supported decision-making agreement forms to include a section on whether the supported person desires decision-making assistance at the end of life. If the supported person indicates that they would like assistance with choosing whether to hasten death with PAID upon becoming terminally ill, this may provide more assurance that a later decision to do so is autonomous.

Given the extensive existing safeguards in both PAID and supported decision-making laws together with the reality that adding in additional safeguards may undermine the autonomy of terminally ill supported persons with decisional impairments, I argue that, excepting the possible addition of monitors or revising the form of the supported decision-making agreement, no additional legal safeguards are necessary.¹⁸⁴ But if policymakers or judges allow terminally ill supported persons with decisional impairments to choose PAID, then it will be necessary to limit liability for a supporter's assistance with this decision.¹⁸⁵ If there are no liability limitations, then as discussed in the previous Section, supporters may

181. Marshall B. Kapp, *Distinctive Factors Affecting the Legal Context of End-of-Life Medical Care for Older Persons*, 33 GA. ST. U.L. REV. 869, 874–75 (2017); Thaddeus Mason Pope, *Unbefriended and Unrepresented: Better Medical Decision Making for Incapacitated Patients Without Healthcare Surrogates*, 33 GA. ST. U. L. REV. 923, 946–47 (2017).

182. MICHAEL BACH & LANA KERZNER, LAW COMM'N OF ONT., A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 145 (2010). Scholars have recommended use of monitors for supported decision-making in the United States. Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 173 (2010); Wright, *supra* note 57, at 310.

183. If monitoring of supporters is not routine, but specific to end-of-life decisions, then monitoring should extend to supported decisions for palliative sedation or to withhold or withdraw life-sustaining medical treatment, given that these other decisions currently lack extensive procedural safeguards against mistake or abuse but have the same serious and irrevocable consequence as PAID does.

184. Other remedies, such as wrongful death lawsuits, remain available in the case of mistake or abuse. While the focus of this Article is on law, it is possible to add safeguards to clinical practice. For example, as noted previously, it is a good idea for healthcare providers to try to increase understanding for all of their patients by providing information on various end-of-life options in the most accessible manner possible. *See supra* Section II.A.2.

185. Wisconsin limits liability for supporters who act prudently and in good faith. WIS. STAT. ANN. § 52.30(8) (West, Westlaw through 2019 Act 186).

fear assisting in this particular decision, which would make it more difficult for a terminally ill supported person with decisional impairments seeking PAID to access this end-of-life option. That is, while much of the preceding discussion has focused on potential harms to patient autonomy from supporters assisting in the PAID decision, there are also potential autonomy harms from supporters not assisting in the PAID decision.

CONCLUSION

Both PAID and supported decision-making laws, premised on respect for autonomy, are becoming increasingly common in the United States. To date, however, their intersection has been neglected. Indeed, the use of supported decision-making to expand access to PAID for terminally ill persons with cognitive impairments is likely far beyond how disability advocates intended this decision-making model to be used.

This Article has evaluated whether autonomy is promoted for individuals who hope to take advantage of both of these laws and has demonstrated that it may be autonomy-promoting to allow terminally ill supported persons with decisional impairments to choose to hasten death with PAID. That is, if autonomy is conceptualized as relational agency, which is consistent with the model of supported decision-making, persons with decisional impairments may be able to decide to hasten death with PAID autonomously—intentionally, voluntarily, and with understanding—with supporters' assistance.

Indeed, allowing terminally ill supported persons with decisional impairments to elect PAID may do a better job at respecting autonomy and promoting equality than existing PAID laws and proposed reforms to PAID. Currently, terminally ill persons who are deemed incapacitated by their physicians are not eligible to elect PAID, but this contemporaneous capacity requirement discriminates against some persons, denying them choices available to similarly situated others, e.g., other adults enduring a terminal illness,¹⁸⁶ violating the principle of equal treatment under the law and disrespecting their agency. And in contrast to recent proposals to use advance directives to access PAID, should one not have decision-making capacity upon becoming terminally ill,¹⁸⁷ supported decision-making avoids problems with lock-in or misunderstanding that advance directives create and allows for current preferences to be factored into the decision to seek PAID, emphasizing present rather than precedent autonomy.¹⁸⁸ Finally, given the numerous procedures that must be followed to hasten death with PAID, dying with PAID may be a death more likely to occur with the patient's consent than

186. Persons who do not have a disability associated with decisional impairments, such as dementia, may actually have similar cognitive (dis)function when terminally ill, e.g., late stage cancer, further eroding the differences between these groups of individuals at the end of life. Furthermore, it may be the case that PAID laws as applied could violate the ADA. Indeed, scholars have argued that commonly accepted laws, such as guardianship, violate the ADA. Salzman, *supra* note 182.

187. Menzel & Steinbock, *supra* note 52, at 24.

188. Supported decision-making also expands access to PAID for persons who have never been considered to have the legal capacity required to execute an advance directive.

other types of medically assisted dying, e.g., withholding or withdrawing life-sustaining treatment or palliative sedation.¹⁸⁹

Although there are valid concerns about terminally ill persons with disabilities, particularly cognitive disabilities, not autonomously choosing PAID, e.g., electing this end-of-life option through mistake or after being coerced, these concerns should not be addressed by denying such persons the opportunity to choose.¹⁹⁰ Indeed, excluding terminally ill persons with decisional impairments from this end-of-life option out of a desire to protect them from harm is paternalistic and reinforces stereotypes of persons with disabilities as weak and incapable of autonomy.¹⁹¹ As the Congress that passed the ADA noted, “[I]ndividuals with disabilities continually encounter various forms of discrimination, including . . . overprotective rules and policies.”¹⁹²

This Article has argued that there should instead be equality of autonomy at the end of life for persons with cognitive disabilities and that terminally ill persons with decisional impairments should have the same end-of-life options as persons without disabilities. Further, such persons should be able to use supported decision-making if necessary to make their end-of-life decisions autonomously. It remains important to consider how structural and cultural conditions, such as lack of access to high-quality long-term care, impact end-of-life decision-making, however, and to invest resources to increase the number of options available to everyone at the end of life. But in brief, permitting supported persons with cognitive impairments to make life or death decisions is anti-paternalistic, autonomy respecting, and equality promoting.

189. Helga Kuhse, *From Intention to Consent*, in *PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE*, *supra* note 95, at 252, 262–63 (describing results of a study that compared physician-assisted death in a jurisdiction where euthanasia is legal and a jurisdiction where euthanasia is not legal and found that there is a significantly lower rate of euthanasia in the absence of patient consent in the jurisdiction where this practice is legal than the jurisdiction where the practice is illegal).

190. Restricting choices guarantees that some persons will not have their autonomy respected at the end of life. Making all end-of-life options available, especially in light of PAID safeguards, decreases the likelihood that autonomy will not be respected.

191. Silvers, *supra* note 95, at 135 (“[T]he history of marking marginalized groups as needing special protection is replete with instances in which to characterize a class of persons as weak is to deprive them of the power of self-determination.”); *id.* at 144 (“[F]raming the issue so that state interest is more significant than personal interest devalues rather than defends people on the basis of their disabilities.”); Young, *supra* note 136, at 169–70 (noting that treating people differently may “reinscribe differences”).

192. 42 U.S.C. § 12101(a)(5) (2018); *see also* Silvers, *supra* note 95, at 142 (“[R]egardless of whether individuals with disabilities are competent to decide if their suffering should be prolonged, no one of them may do so in order to safeguard other members of their class from nondisabled people who desire their suicides.”); Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 *HARV. J.L. & GENDER* 425 (2006) (discussing end-of-life and reproductive choices in the context of disability).

