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Comment: Further Consideration on the Relationship Between the Americans with Disabilities Act, Supported Decision-Making, and Medical Aid in Dying

Amitai Heller*

Ms. Rosen's considered examination and promotion of the supported decision-making model in the arena of end-of-life care provides a valuable contribution for people facing this consequential choice. While the extension of supported decision-making to end-of-life medical decisions may seem logical to people with disabilities and their network of supporters, the inclusion of the model in end-of-life decision-making has the potential to challenge healthcare professionals' pre-existing notions of competency and autonomy, as a communal approach to decision making may be at odds with a more individualized doctor-to-patient form of decision-making.

As such, the lack of familiarity with supported decision-making in the healthcare setting could lead healthcare providers to feel discomfort in participating in the end-of-life care of individuals who make use of the model. Such discomfort could result in both substandard care and incorrect determinations of eligibility for end-of-life options on the basis of a misunderstanding of the supported decision-making

* Senior Staff Attorney at Compassion & Choices. My interest in this issue stems from my experience as an attorney with the Louisiana protection and advocacy system, where I represented people with cognitive impairments who were fighting to gain equal access to nearly every service imaginable. Thank you to Brenna Rosen for asking me to contribute this Comment and for pushing the scholarship forward. Thank you to Kevin Díaz and Jess Pezley for supporting me in the work through your edits and discussion.

process. Further, some doctors may erroneously determine that an outright refusal to treat such patients is preferable to having to wrestle with unfamiliar frameworks for determining competency. The aim of this Comment is to expand on Ms. Rosen's Note by suggesting that acceptance of the use of the supported decision-making model for end-of-life care by healthcare providers is one that is likely required by the Americans with Disabilities Act (ADA).¹

While the bioethical and legal issues discussed in this Comment would apply to all end-of-life decision-making, they are considered in the medical aid-in-dying context in order to better complement Ms. Rosen's work. It is important to recognize that the questions related to medical aid in dying raised in both Ms. Rosen's Note and in this Comment are likely to only occur in rare circumstances. All U.S. medical aid in dying statutes contain safeguards to prevent the abuse or improper application of the end-of-life option. In the United States, medical aid in dying may only be accessed by adults with a terminal diagnosis expected to cause death within six months, the terminally ill individual must also be determined to have decision-making capacity and be able to self-ingest the medication.² Further, these individuals must make multiple requests for the medication. Usage of medical aid in dying is also uncommon. In Oregon, the state with the longest history with medical aid in dying, the 238 individuals who self-ingested the medication accounted for approximately 0.5% of all deaths within the state in its most recent reporting year.³

In all states where medical aid in dying has been authorized, a provider's determination of decisional capacity is a prerequisite for eligibility. While some persons with cognitive

1. 42 U.S.C. § 12101. It is also likely required by the Section 1973 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, and numerous state anti-discrimination laws. This Comment does not address those claims since an analysis of whether a denial of supported decision-making in end-of-life care would discriminate against a person with a disability would largely mirror the analysis under the ADA.

2. *Medical Aid in Dying*, COMPASSION & CHOICES, <https://perma.cc/325D-EBXR>.

3. Ctr. for Health Stats., Or. Pub. Health Div., OREGON DEATH WITH DIGNITY ACT 2021 DATA SUMMARY 5 (2022); see also *Annual Trends in Mortality*, OR. HEALTH AUTH. (2022), <https://perma.cc/5T5S-QFES>.

impairments will lack the requisite capacity to access the option, existing medical aid in dying statutes already encompass the notion that the use of a supported decision-making model does not foreclose a determination of capacity for the purposes of an individual's eligibility for medical aid in dying. Oregon's medical aid in dying statute⁴ requires a determination of mental capability to access the option and defines 'capable' as:

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.⁵

The inclusion of the clause concerning persons familiar with the patient can be applied to supported decision-making because the supported decision-making model necessarily incorporates communication with persons familiar with the patient into the decision-making process. The explicit mention of collective forms of communications in the statute suggests that the current statutory scheme for medical aid in dying already incorporates the adoption of supported decision-making in the medical aid in dying framework. Even if it were not incorporated via statute, provider participation in supported decision-making, where necessary on the basis of disability, is likely mandatory under federal law.

While participation in medical aid in dying is optional for healthcare providers, it does not grant a license to discriminate. All states where medical aid in dying has been authorized via legislation have statutory language which states that participation in medical aid in dying is optional. Oregon's Death with Dignity Act explains that "[n]o health care provider shall be under any duty, whether by contract, by statute or by any

4. OR. REV. STAT. ANN. §§ 127.800–897 (West 2022). Oregon's Death with Dignity Act is used in this Comment as a stand-in for a generic medical-aid-in-dying statute because the Act was both first in the country and is the legislation that all existing medical-aid-in-dying statutes have been modeled off of.

5. OR. REV. STAT. ANN. § 127.800(3) (West 2022).

other legal requirement to participate in the provision to a qualified patient of medication to end his or her life in a humane and dignified manner.”⁶ Pursuant to the clear language of this statute, it would be reasonable for healthcare providers to believe that they may opt out of treating otherwise qualified patients with cognitive impairments solely due to their preconceived impressions of how their impairments impact their ability to make decisions. Because federal law supersedes state law, however, such statutes are subject to federal laws that restrict this ability. Specifically, providers who elect to otherwise participate in medical aid in dying are likely precluded from declining participation solely based on a legally competent (a person whose rights to decision-making have not been formally removed through a guardianship) patient’s cognitive impairment without an individualized assessment of their decision-making capacity. Providers who opt to decline to treat people within these populations on the basis of an incorrect determination that they do not have the mental capacity to make the decision, without making an individualized determination of their decision-making capacity, are likely subjecting themselves to an unnecessary risk of violating the Americans with Disabilities Act.

The ADA prohibits discrimination against people with disabilities in both state services and places of public accommodation. This prohibition applies to both private and public doctors’ offices, hospitals, and nursing facilities.⁷ The ADA’s regulatory scheme requires that healthcare providers ensure that a person with a disability can equally access

6. *Id.* § 127.885(4).

7. 42 U.S.C. §§ 12131, 12181(7). This Comment considers the application of the ADA to both public and private entities in conjunction. While the language of the regulations varies (for example, Title II regulations refer to “reasonable modifications” while Title I regulations refer to the same concept but use the term “reasonable accommodations”), case law and guidance from the Department of Justice has largely cross-applied the concepts examined in this comment to both entities. As such, verbiage and specific regulations are used interchangeably to apply to both public and private entities. Practitioners reviewing this Comment should review the relevant case law within their jurisdiction accordingly.

services,⁸ communicate effectively,⁹ and be provided with reasonable modifications to policies, practices, and procedures where needed to provide equal access.¹⁰ All of these requirements are mandatory for nearly all doctors. Each of these requirements independently provides a cause of action for disability discrimination against participating healthcare providers who outright refuse to qualify a patient for medical aid in dying to an otherwise eligible person solely on the basis of their disability or for those who refuse to engage in the supported decision-making process when required.

The ADA requires that persons with disabilities be provided equal access to medical services.¹¹ While the ADA does not create a federal cause of action for medical malpractice, it does guarantee equal opportunity to access to services.¹² This requirement suggests that for persons with disabilities, providers must, at a minimum, engage in an individualized assessment of the appropriateness of a specific treatment prior to making determinations on the basis of disability.¹³ In the context of medical aid in dying, this means that a participating provider may not exclude a person with cognitive impairments solely on the basis of their disability prior to engaging in an assessment of their eligibility for the treatment. An individual assessment of this variety would have to consider an individual's decision-making capacity to ensure that the participating provider comports with the authorizing statute. So, while the ADA may not present a cause of action for making an incorrect determination of decisional capability, it would present a viable cause of action for those entirely excluded from participation in medical aid in dying based on preconceived notions of how one's disability impacts their decision-making capabilities.

The ADA's mandate of effective communication for people with disabilities requires participating healthcare providers to

8. 28 C.F.R. § 36.201(a) (2022).

9. *Id.* § 35.160(a)(1).

10. *Id.* § 35.130(b)(7)(i).

11. *Id.* § 36.201(a).

12. *Bryant v. Madigan*, 84 F.3d 246, 249 (7th Cir. 1996).

13. *See McGugan v. Aldana-Bernier*, 752 F.3d 224, 231 (2d Cir. 2014).

use supported decision-making, should it be necessary to facilitate effective communication. The ADA's regulations require that appropriate steps be undertaken to ensure that communications with people with disabilities are as effective as communications with others.¹⁴ This creates an affirmative requirement upon covered entities to furnish auxiliary aids to facilitate communication.¹⁵ While auxiliary aids can refer to the provision of tactile devices such as closed captioning, talking calculators, or braille alternatives, the requirement also requires the use of other persons as aids such as notetakers or American Sign Language interpreters to facilitate communication. Furthermore, primary consideration must be given to the specific type of communication aid requested by the person with a disability.¹⁶ In my view, there is no legally significant difference between the use of an interpreter and the use of a person's supported decision-making network when it comes to ensuring that communication needs are met for a person considering their end-of-life options. In both instances, these aids are necessary to ensure that communications with the person with a disability is effective. Thus, when a supported decision-making network is necessary to afford a person with a disability effective communication, the use of the model should be considered mandatory on any healthcare provider participating in a request for medical aid in dying.

The ADA's requirement of reasonable modifications should be interpreted to require healthcare providers to participate in supported decision-making when such modifications are necessary to provide equal access to end-of-life care. Pursuant to the regulation, entities must "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."¹⁷ As noted above, while the ADA does not necessarily provide relief for a misdiagnosis or an

14. 28 C.F.R. § 35.160 (a)(1) (2022).

15. *Id.* § 35.160(b)(1).

16. *Id.* § 35.160.

17. *Id.* § 35.130(b)(7).

inaccurate medical determination, reasonable modifications of existing policies or procedures are required in healthcare settings to ensure that persons with cognitive impairments are provided with equal access to participation in the medical decision-making process.¹⁸ As articulated in Ms. Rosen's Note, the use of supported decision-making has the potential to afford persons with cognitive impairments the ability to access medical decision-making, so even though the model may fall outside the typical practices or procedures of end-of-life practitioners, it is likely not a significant enough deviation to be considered a fundamental alteration, and could therefore be a reasonable accommodation necessary to effectuate equal access to end-of-life care.

Working with people at the end of life presents unique challenges. While daunting at first blush, medical providers must still engage with contemporary methodology for making determinations of a cognitively impaired individual's decision-making capacity. The medical literature is replete with best practices and scientifically validated assessment tools that would be appropriate to guide such determinations; furthermore, referrals to practitioners would also be appropriate if making such assessments fall outside the normal practice of an end-of-life care provider.¹⁹

The need to adapt to alternative decision-making processes is not sufficient grounds for denying the opportunity to access medical aid in dying. To comport with the ADA, practitioners who would provide medical aid in dying to persons without cognitive impairments, who receive a request for medical aid in dying from a person with cognitive impairments, must meet and assess the potential patient's decision-making capacity and must also be willing to engage in the supported decision-making model while doing so. As with all medical decisions, providers

18. *S.L. ex rel. D.L. v. City Hosp., Inc.*, 377 F. Supp. 3d 626, 628 (N.D. W. Va. 2019) (stating that participation in medical decision-making processes for a person with intellectual disability is covered by the ADA's requirement to provide reasonable modifications).

19. *See, e.g.*, OR. REV. STAT. ANN. § 127.825 (West 2022) (requiring patients experiencing "psychiatric or psychological disorder or depression causing impaired judgement" to be referred to counseling). I believe it would be best practice for a similar referral to be made when determinations of incapacity are being made by practitioners based on cognitive impairments if they do not have the proper medical training to do so.

should take care and in the context of medical aid in dying, if there are doubts or a need for supported decision making, they should seek out expert help as necessary.

As Ms. Rosen's Note explains in further detail, the use of supported decision-making creates an opportunity for persons with cognitive impairments to participate more fully in their end-of-life care. While this Comment focuses on the legal requirement for healthcare providers to serve people with cognitive impairments at the end of life, the tenets of patient autonomy, self-determination, and the dignity of risk must be integrated into end-of-life practice to provide guidance where legal requirements are absent or ambiguous. The use of the supported decision-making model in end-of-life care will only succeed when healthcare providers participate in an open-minded manner. It is only through this type of engagement that we empower individuals with cognitive disabilities to participate fully in their own end of life journey.