Testimony in Support of The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass End-of-Life Option Act (SB0926/HB1328) - FAV

Hearing Date: March 5, 2025

My name is Seth Morgan. I reside in Maryland and am a Board-Certified Fellow of the American Academy of Neurology, an advocate for people with disabilities, and a person living with disabilities. I strongly support SB926/HB1328; End-of-Life Option Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act).

Contrary to the alarmist claims of the legislation's opponents, this bill provides strong protections to all residents of Maryland, including people with disabilities. The bill is, in large part, similar to state laws enacted in ten other States and Washington, D.C. over the last twenty-eight years.

Disability Rights Oregon (DRO) is the Oregon state agency in charge of the legally-based protection and advocacy for individuals with disabilities and has a mandate under Federal law to investigate complaints of abuse or neglect of individuals with disabilities, including inappropriate actions taken to hasten the death of an individual. Its Executive Director, Bob Joondeph, reports that since the passage of the Oregon Death with Dignity Act in 1997, DRO has never received a complaint that a person with disabilities was coerced to make use of the Act. (1) In fact, there have been no reports of abuse or coercion.

Thus, concerns that medical aid in dying would lead to abuse and coercion of people with disabilities are unfounded. The safeguards in the legislation are rigorous and preclude any individual with a cognitive disability from being eligible to access medical aid in dying. The bill specifically states that: "An individual is not a qualified individual solely due to age, disability, or a specific illness."

It has been suggested that potential heirs of a person with a disability could be witnesses to a request for medical aid in dying and thereby misuse this end-of-life care option for their benefit. However, the required written request for medical aid in dying must be witnessed by at least one adult who is not "a relative of the individual by blood, marriage or adoption," nor an individual who "at the time the written request is signed by the individual, [is] entitled to any benefit on the individual's death." Furthermore, the patient's attending physician is precluded from being a witness.

The current practice of palliative sedation does not provide any of the safeguards that are required for medical aid in dying under this proposed law. Palliative sedation is the practice of giving a terminal, hospitalized patient increasing sedation for pain control. Not infrequently, palliative sedation becomes terminal sedation and results in death. It is the family, not the patient, who is asked for permission to use terminal sedation.

The suggestion put forward (most frequently by self-appointed advocacy groups that claim to speak for all individuals with disabilities) that people with disabilities are against medical aid in dying is wrong.

People with disabilities are not a monolithic group. Many are capable of making self-care decisions and do not need an umbrella advocacy group to speak for them. In addition, the disability rights and end-of-life care movements share the core values of self-determination, personal autonomy, and the right to independence. The strict eligibility criteria for medical aid in dying have protected people with disabilities for 28 years since Oregon's Death with Dignity Act took effect in 1997 and will continue to protect them in the future. Activists in the disability community (such as *Us for Autonomy*) are some of the strongest supporters of all end-of-life care options for people with disabilities who have capacity to make self-care choices. These include, in the appropriate setting, medical aid in dying. A quantitative study by researchers at Rutgers University determined that one in ten politicians in the United States were people with disabilities which underscores that not all people with disabilities are unable to self-advocate or make personal health care decisions. (2)

Yes, there are individuals both with and without disabilities for whom the proposed legislation is not an option they would want to avail themselves of. But, many others, facing a foreseeable imminently terminal condition, might want to have the opportunity to be able to avail themselves of this option. The decision should be, and would be, solely in control of the dying individual.

Advocacy group representatives should be clear that they speak for the position of their Boards of Directors and acknowledge that individual people with disabilities may take a different personal position. These advocacy groups can only speak for some of the people they advocate for and not for all people with disabilities.

Nearly 8 out of 10 U.S. residents (79%) who self-identify as having a disability agree that "medical aid in dying (MAID) should be legal for terminally ill, mentally capable adults who chose to self-ingest medication to die peacefully," according to February 2023 survey by Susquehanna Polling & Research. (3)

A 2023 poll of Maryland residents found "71% of Maryland voters think a mentally sound adult with an incurable, terminal illness, who only has six months or less to live, should have the legal option of medical-aid-in-dying." (4)

In 2019, the American Medical Association (AMA), a longtime opponent of medical aid in dying, adopted a new policy position recommended by the Council (CEJA 2-A-19 Report) that physicians can provide medical aid in dying "according to the dictates of their conscience without violating their professional obligations." (5)

In addition, when asked in a 2020 Medscape poll, "should physician-assisted dying be made legal for terminally ill patients?" 55% of the 5,000 doctors surveyed nationwide said "yes," compared to 28% who said "no," and 17% who said, "it depends."

The poll concluded: "Acceptance of this concept has grown over the decade. More specialists (57%) than primary care physicians (51%) are in favor of physician-assisted dying being legal." (6)

Those of us in favor of the passage of this bill are asking to be allowed to make a decision if the situation arose in which medical aid in dying was a legal option we could consider. For anyone for whom this is not an option they would want, no one will be forced to use it. Paradoxically, the availability of medical aid in dying in those states where it has been legalized has, in fact, served to help many terminally ill individuals to fight on in the setting of impending death. About one-third of prescriptions for medical aid in dying in Oregon are never utilized. (7) The comfort of knowing that it is available if the person's suffering were to become too severe is enough to let them feel safe to fight on longer.

Sincerely,

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CITATIONS

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4. Gonzales Maryland Poll, Gonzales Polls, Inc. January 2023
5. 2019 Annual Meeting Opinion, Ethical and Judicial Affairs, OPINION OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, p. 248. Available from: https://www.compassionandchoices.org/docs/default-source/default-document-library/a19-ceja-reports.pdf?sfvrsn=bf825036_1
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