## Written Testimony of Chai R. Feldblum in Support of the Maryland End-of-Life Option Act (HB 1328/SB 926) February 28, 2025

I am writing in support of the Maryland End-of-Life Option Act (HB 1328/SB 926).

I have been a disability rights advocate my entire professional life. I led the legal team that worked with Congress to draft and negotiate the Americans with Disabilities Act of 1990 (ADA) and the ADA Amendments Act of 2008, and as a Commissioner of the Equal Employment Opportunity Commission (EEOC), I was instrumental in the agency's issuance of regulations to advance the employment of people with disabilities in the Federal government.

As a result of my work, I have witnessed the discrimination faced by people with disabilities across many aspects of society. For example, the discrimination faced by people with disabilities in the health care arena is significant. Sometimes this is due to the low esteem in which health care providers hold people with disabilities, particularly regarding their view of the quality of life experienced by people with disabilities.

I recognize that, for many people in the disability community, discrimination by medical providers is the reason they oppose laws such as HB 1328/SB 926). They are understandably afraid that medical providers will be too quick to assume that individuals with disabilities have such a low quality of life that death is inherently a preferable option for such individuals.

I come to the opposite conclusion. For me, the paramount principle is autonomy—the right to make choices about one's own body when faced with a terminal illness. This right is as important for people with disabilities as for anyone else. The right to make this decision is not connected to a disability that the person may have lived with their entire life. It is a decision that becomes relevant only when the person has a terminal illness and decides they would like to end their lives with dignity and at a time and place of their choosing.

I am acutely aware that many mainstream disability rights groups (and indeed, many of my colleagues and friends over the years) hold a different point of view on this subject. For that reason, I do not submit this testimony lightly. But I believe people with disabilities do not hold a monolithic view on this issue. I believe many of us would like the right to make the choice to die with dignity and on our own terms under the limited circumstances set out in HB 1328/SB 926.

The advocacy by disability rights groups over the years regarding "right-to-die" laws has been very important in ensuring there are safeguards built into these laws to ensure that people with disabilities are not coerced into making the choice to die. These are the type of safeguards that are in HB 1328/SB 926. There must be at least two medical professionals who independently determine the person is making the choice to die of their own free will. The person must sign an affidavit to that effect and the witnesses cannot be a family member or anyone else who might benefit from the person's death.

I also note that the law, as it presently stands, does not preclude individuals from hastening the death of a family member, albeit through less than obvious ways. Someone who has a terminal illness and is in pain can be given palliative sedation for pain control. Palliative sedation often becomes permanent sedation and the person is able to die without pain. I am thankful that this option of palliative sedation exists. But it is usually the family that is asked for permission to provide the patient with palliative sedation, rather than the patient who may no longer be able to consent to such treatment.

No law is perfect. But to me, HB 1328/SB 926 represents the best of public policy. If enacted, the law would enable people with terminal illnesses to choose how to die with dignity and independence. The law establishes a structured and formal process for an individual to think through and grapple with that most important decision. That is an autonomy right that we all deserve.