The Arc
Maryland

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HB1328: End–of–Life Option Act
(The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)
House HGO and Judiciary Committees
March 3, 2025

Letter of Information and Request for 2 Amendments

The Arc Maryland is a statewide disability advocacy organization that is dedicated to the preserving the rights, and improving the quality of life, of individuals with intellectual and developmental disabilities.

We believe additional safeguards must be added to safeguard against improper, irreversible actions and for the health and safety of not only people with IDD, but all people. We respectfully propose bill amendments to 1.) revise the definition of Consulting Physician and 2.) an amendment to add a more detailed data collection and reporting requirement than what is suggested in this legislation.

Amendment 1 under Section 5-6A-05: Change to the definition and powers of a consulting physician.
To safeguard against a person relying on the medical opinion of one doctor (or one medical practice by extension), we request the addition of a requirement that stipulates that ***the consulting physician and/or mental health professional may not be in the same practice as the attending physician.***

THE ATTENDING PHYSICIAN, THE CONSULTING PHYSICIAN, AND THE LICENSED MENTAL HEALTH PROFESSIONAL MAY NOT:
(I) BE IN THE SAME GROUP PRACTICE, AS DEFINED IN § 1- 301 OF THE HEALTH OCCUPATIONS ARTICLE; OR
(II) HAVE ANY AGREEMENT OR SYSTEM INVOLVING REMUNERATION

This amendment is important. It is a matter of common practice that doctors from the same practice will more likely than not, agree with the opinion of another doctor in their practice. Doctors of the same practice routinely confirm each other's opinions and therefore, allowing the consulting physician to be of the same practice would not provide the safeguard intended. We believe this is why people, who want a true second medical opinion, do not shop for that second opinion in the same practice.

Amendment 2: Data Collection and Reporting Requirement. Section 5-6A-09.
Another amendment request relates to the need for additional data collection and reporting beyond that which is included in HB1238. This proposed language is modeled after the 2019 legislation as amended.

THE REPORT PRODUCED BY THE DEPARTMENT UNDER THIS SECTION SHALL INCLUDE, FOR THE STATE AND DISAGGREGATED BY COUNTY:
(1) THE NUMBER OF PRESCRIPTIONS WRITTEN FOR AID IN DYING MEDICATION;
(2) THE NUMBER OF PHYSICIANS WHO WROTE PRESCRIPTIONS FOR AID IN DYING MEDICATION;
(3) THE NUMBER OF INDIVIDUALS WHO RECEIVED A PRESCRIPTION FOR AID IN DYING;
(4) FOR EACH INDIVIDUAL WHO REQUESTED AID IN DYING:

(I) THE INDIVIDUAL’S AGE AT DEATH;
(II) THE INDIVIDUAL’S EDUCATION LEVEL;
(III) THE INDIVIDUAL’S RACE;
(IV) THE INDIVIDUAL’S SEX; AND
(V) WHETHER OR NOT THE INDIVIDUAL HAD INSURANCE AND, IF SO, THE INDIVIDUAL’S TYPE OF INSURANCE;
(5) WHETHER OR NOT THE INDIVIDUAL WAS ENROLLED IN HOSPICE AT THE TIME THE REQUEST WAS MADE;
(6) WHETHER OR NOT THE INDIVIDUAL HAD DISABILITY, AS DEFINED IN 42 U.S.C. § 12102, BEFORE THE INDIVIDUAL WAS DIAGNOSED WITH A TERMINAL ILLNESS;
(7) THE INDIVIDUAL’S TERMINAL ILLNESS;
(8) THE NUMBER OF KNOWN INDIVIDUALS WHO DIED FOLLOWING THE SELF– ADMINISTRATION OF MEDICATION FOR AID IN DYING; AND
(9) THE INDIVIDUAL’S STATED REASON FOR SEEKING AID IN DYING.

According to a testimony given to the Massachusetts Legislature by Anne Sommers McIntosh, Executive Director, National Council on Disability[ii]**,** the top five reasons doctors give for their patients’ assisted suicide requests are not pain or fear of future pain but psychological issues that are eerily familiar to many in the disability community: 95% fear a “loss of autonomy” and being “less able to engage in activities”, 87% fear a loss of dignity”, 56% said they feared “losing control of their bodily functions”. Fifty-two percent (52%) reported feeling like a burden on family and caregivers was their reason for requesting lethal drugs.

These are all common feelings of many with disabilities and influenced by experiences of people with disabilities both by nature of their disability and related care needs, and societal representations and treatment of people with disabilities.

This amendment to require the collection and report of data related to the exercise of the end-of-life option will help us ascertain if there is disparate use of this option by people with disabilities, in addition to other marginalized populations.

We are aware that the proponents’ position is that there is no proof of disproportionate use of medical aid in dying in other states, citing a lack of any evidence to the contrary. Unfortunately, because other states do not keep data, there would not be evidence to either support or dispute a claim of disparate use of the End-of-Life option. Where other states have not collected this important data, we believe it is critical that Maryland commit to keeping an eye on who/what demographics of people are accessing the End-of-Life option.

This information can inform future preventative care, training, and other interventions.

Reference for amendment language proposed in this testimony:
https://mgaleg.maryland.gov/2019RS/amds/bil_0001/SB0311_46867201.pdf

As per our National charter, The Arc of the United States, The Arc Maryland has historically come in with opposition testimony to the End-of-Life Options Act bills. Over the years, however, and with a heightened recognition of the importance of preserving individual body autonomy, our Maryland membership has divided views on the matter. While some of our members oppose this legislation, some would like to see a form of this legislation pass, but **only with adequate protections and data collection provisions**.

HB1328 components and safeguards address several of the concerns to which we have testified in the past. We appreciate the conversations we have had with sponsors that resulted in many of the changes made to bill language, definitions and procedures, and feel that the differences will matter to people with IDD and their families.

That said, many people with disabilities still face devaluation, a lack of understanding, and barriers to accessing appropriate medical treatment. While improvements have been made, we still have a long way to go before we can be confident that practices of discrimination, as well as disparate treatment practices that affect people with intellectual and developmental disabilities end.

In the first several months of the pandemic, NPR conducted an investigation into how and why people with IDD were denied care[i]. Sarah McSweeney was a young woman with cerebral palsy who loved shopping trips and hanging out with friends. She went to the hospital on April 21, 2020 with what she thought was Covid-19. She experienced fever and chills. The hospital determined that she did not have Covid, but had developed aspiration pneumonia. The pneumonia progressed to the point that Sarah needed a ventilator. The doctor questioned whether it was worth doing, however, citing Sarah’s “quality of life.” She was not put on a ventilator and later died of sepsis related to the aspiration pneumonia. **The lives of people with disabilities matter and should be safeguarded to the best of our abilities.**

In closing, we implore our representatives to continue to work to address the marginalization of people with disabilities. Inequalities and lack of access to healthcare continue for many in this cohort of humans.

We appreciate the Committee’s commitment to safeguarding our community and consideration of these amendments.

Respectfully submitted,
Ande Kolp, Executive Director

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[i] https://www.npr.org/2020/12/21/946292119/oregon-hospitals-didnt-have-shortages-so-why-were-disabled-people-denied-care

[ii] https://www.ncd.gov/newsroom/2021/ncd-testimony-MA-legislature-assisted-suicide