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HB933: End-of-Life Option Act
(The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)
Health and Government Operations Committee
March 10, 2023

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.

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 provisions**.

HB933 components and safeguards address several of our 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, and as we sit here today, 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 careⁱ. 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.

To safeguard against a person relying on the medical opinion of one doctor (or practice by extension), we recommend 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.** This is important as our members are not aware of a situation where doctors from the same practice have disagreed with the opinion of another doctor in their practice. It is unlikely to happen. We believe this is why, **when someone wants a second opinion, they do not shop for that second opinion in the same practice. To truly be a safeguard, we believe the amendment below is needed** (identical to 2019 bill as amended) to require an impartial second opinion. While we understand some may consider this a barrier, we do not see it as a hindrance to exercising this option- rather, we see it as a necessary practice to meet the intention of this second review, as an independent opinion. As the "End of Life Option" would be an irreversible action, we should want to ensure this safeguard is in place.

Another amendment request relates to the **need for data collection and reporting.** According to a recently testimony given to the Massachusetts Legislature by Anne Sommers McIntosh, Executive Director, National Council on Disabilityⁱⁱ, 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.

We request an **amendment to require the collection and report of data related to the use of this end of life option.** We have concerns there may be disparate use of this option by people with disabilities, in addition to other marginalized populations. **We are aware that the proponents feel there is not disproportionate use of medical aid in dying in other states and they cite a lack of any evidence as proof. Unfortunately, because other states do not keep data, there would not be evidence either supporting or disputing this claim. Where other states have failed to protect people by collecting this data, we believe it is critical that Maryland commit to keeping an eye on who/what demographics of people are accessing this option.** This information can inform future preventative care, training, and other interventions. The wording that was included in the 2019 bill as amended is what we request be added into the current bill (see below for amendment language.)

In closing, we implore our representatives to continue to work to address the marginalization of people with disabilities that persists and affects even basic access to quality healthcare. While we understand there is interest and momentum to advance the bill this year, we hope this committee ensures the safeguards contained in the bill, AND these two additional safeguards are put into place before considering a vote.

Respectfully submitted,
Ande Kolp, Executive Director

Reference for amendment language:

https://mgaleg.maryland.gov/2019RS/amds/bil_0001/SB0311_46867201.pdf

Amendment 1: Add:

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

Amendment 2: Add required reporting with specific data points:

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.

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>