

**CREATING CHANGE · IMPROVING LIVES** 

## **House Health and Government Operations Committee**

February 16, 2024

HB 403: End-of-Life Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)

Letter of Information

The Maryland Developmental Disabilities Council (Council) creates change to make it possible for people with developmental disabilities to live the lives they want with the support they need. Examples of developmental disabilities include autism, intellectual disability, and cerebral palsy, among others.

The Council seeks to ensure that people with developmental disabilities have the same rights, opportunities, choices, and protections as other citizens. People with developmental disabilities may need support with activities of daily living, decision-making, and participating in the community in order to lead full lives integrated and included in society. Our goal is to ensure equality for all Marylanders with developmental disabilities.

There are as many strong and diverse opinions about this issue and this bill among people with developmental disabilities and their families and allies as there are within the general community. In their most basic sense, these arguments range from the perspective that if aid in dying is to be available, it should also be available to people with developmental disabilities, to the deeply held belief that it is not possible to ensure adequate protections for people with significant disabilities whose lives are too often undervalued.

The Council is not taking a position about whether a physician in Maryland should be permitted to aid someone in dying as defined in the bill. Instead we seek to outline concerns that some people with developmental disabilities, their families, and allies share:

- Fears are expressed about coercion, harm, and discrimination. The concern is that some people with developmental disabilities could be led into making a life-ending decision because they are considered a burden financially or otherwise. One family explained, "My son is so trusting that he would take his own life without understanding what he was doing. We won't always be here to protect him." These families are concerned that there is not adequate protection from abuse.
- People with intellectual and developmental disabilities often receive support both subtle and overt with decision-making. Opponents of the bill believe this would leave people with significant disabilities more vulnerable, especially if the quality of their life is not valued.
- Prognoses are not always definitive and accurate timelines are not always possible. Treatment that is not
  possible at one institution could be possible elsewhere. Science and medicine continue to evolve at a rapid
  pace.
- People with significant disabilities may be at particular risk within a for-profit health care system because of life-long disability-related costs. They can be viewed as a liability and opponents see no way to safeguard against this.
- Individuals and families who oppose the bill feel strongly that there is too much risk for people with developmental disabilities when these decisions have such a fatal consequence. They believe there is no way to ensure adequate protections to address their concerns.

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