

**Maryland Disability Law Center**  
**Letter of Opposition**  
**HB 30**

January 26, 2009

Honorable Peter A. Hammen, Chairman  
Health & Governmental Operations Committee  
House Office Building, Rm 241  
Annapolis, MD 21401

Re: HB 30

Dear Chairman Hammen and Members of the Committee:

Maryland Disability Law Center (MDLC) wishes to express its concerns about provisions within HB 30, Health-Terminal Condition-Counseling. To the extent that the legislation is intended to provide information on advanced directives, palliative care and hospice care, we have no issue. We are in accord that such information and services should be more widely available. However, we have grave concerns about certain language, definitions and requirements of the bill. As drafted, we believe that persons with disabilities may be pressed to end their lives or have their lives ended in a way not intended by the legislation.

A. Inadequate definitions:

1. "End-stage-condition" HB 30 raises great alarm as applied to persons with disabilities. It simply lacks adequate safeguards. For many persons with disabilities, there is no medical treatment that will reverse their condition. Their disabilities may be progressive or may couple with other illnesses to render them less able or incompetent but that should not place them at the "end stage" of life. Consider the definition of "end-stage condition":

"End-stage condition" means an advanced, progressive, irreversible condition caused by injury, disease, or illness:

- (1) That has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and
- (2) For which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.

This definition does NOT require that a person's death be imminent. There are children, as well as adults, who are not fully competent and who are physically dependant with progressive, illnesses who may be subject to this law by proxy. Given the stereotypes and prejudices that prevail about the poor quality of life for persons with disabilities, we are concerned that people with disabilities or their proxies may find that the required "counseling" is subtly directed towards ending life.

2. Lack of definition for providers of counseling services. HB 30 provides that

the care counseling identified in the bill is provided by a hospice provider, health care provider, or “other organization that specializes in end-of-life condition case management and consultation.” There is no oversight, licensing or professional requirement to support the definition of an “organization that specializes in end-of-life condition case management and consultation.” This is extremely problematic as the organization is to counsel persons and their proxies about their option including the right of the proxy to refuse or withdraw the person from any life sustaining procedure and to make decisions about treatment. These decisions may have different legal ramifications and the lack of any regulation or even definition of the organizations to which medical personnel MUST provide a referral is extremely troubling. (If there are not sufficient hospice services, what organizations will receive referrals, will they be charging fees for their services, will they be qualified to give advice on the rights of a proxy, how are they staffed or trained to provide this critical service?).

B. Reference in law to provide costs of treatment options. HB 30 requires the counseling service to provide referrals to appropriate entities for information on the costs of treatment options for persons facing end of life conditions.

We are not a country where everyone has equal access to health care. For some, the challenges of payment for support services necessary to live full lives with disabilities are particularly challenging. As obtaining financial support can be a lengthy and complicated process, we are concerned about the focus on this information at a time when a person is being counseled about their end of life options (again please recall that end of life does not require imminent death). The bill requires that organizations that specialize in end of life consultation refer the person or their proxy to financial information about the costs of various treatment options. Because people have access to the costs of their care at any point in time and because the counseling service providers are not required to provide this information directly, we would ask that this reference be stricken from the bill. It appears to suggest that people consider a cost benefit analysis to living. Advocates for persons with disabilities are acutely aware that the benefits of life for people with disabilities have been historically undervalued. In our view the reference of the costs of treatment is an issue that is best addressed without the legislation, which only provides a referral back to a health care provider or insurer who already has an obligation to provide this information. The inclusion of this portion of the bill is of strong concern for the subtle and unintended message it may promote. Fears of lost capacity and financial burden compound a scenario wherein people are making difficult decisions. Certainly they may have the financial information upon request without a legislative mandate with its questionable message.

C. Mandatory transfers. MDLC believes in choice. The legislation appears to value a person’s ability to make choices about their lives by insisting that certain information be available to them. However, the legislation does not clearly to provide a person the right to remain with their current treatment provider if that provider does not wish to comply with the requirements of HB 30. As drafted, the health care provider who elects not to follow HB 30 “shall”: “refer or transfer the patient to another health care provider”. MDLC requests that this language be modified to be clear that a patient is **not** required to transfer to another provider if they prefer to remain with their existing provider. Continuity of care is especially important for many persons with disabilities, and obtaining care from providers familiar with their disability can be

challenging. Certainly the person must retain the ability to remain with their provider, regardless of whether the provider chooses to comply with HB 30.

In sum, this bill appears to be too broad to effectively accomplish goals that MDLC can endorse. At MDLC we continue to see death certificates that label the cause of death as a person's disability, such as "Cerebral Palsy" or "Mental Retardation". These disabilities do not, on their own, cause death. In the disability community it is common to share stories where a person with a disability has been told that they have a short time to live, and the child or adult gets the last laugh by outliving their projected death. The lack of understanding about the nature of disability and the uncertainty about when a person may be facing death is complicated. Compounding this situation is the fact that discrimination or lack of value for persons with disabilities is a significant unresolved social problem in our country. The history of health care for persons with disabilities is replete with examples of discriminatory and horrific treatment. For the reasons stated, MDLC opposes HB 30. MDLC believes that the intent of the legislation can be met by supporting hospice and palliative care and increased education and outreach for these services as well as increased education and opportunity for advanced directives.