



West Virginia Developmental Disabilities Council

110 Stockton Street
Charleston, WV 25387

WV Developmental Disabilities Council Statement on Senate Revisions to HB 4035

The WV Developmental Disabilities Council is a 31 member organization consisting of citizens with developmental disabilities, family members, and representatives from State and private organizations concerned with the provision of services to people with developmental disabilities. Over 60% are citizen members who are appointed by the Governor.

The mission of the Council is to assure that West Virginians with developmental disabilities receive the services, supports, and other forms of assistance needed to achieve independence, productivity, integration, and inclusion in the community. One of the ways the Council carries out its mission is to provide information to policymakers on issues that may affect people with developmental disabilities.

The Council has no opposition to the formation of a State Advisory Coalition for the purpose of studying and improving access to **palliative care services in the State.**

The Council had grave concerns about HB 4035 as it was originally introduced. Rather than forming an advisory coalition on palliative care, it was written to form a coalition on “quality of life.”

“Quality of life” is a construct that the WV DD Council opposes being used to evaluate humans. It has been used throughout history as a prelude to the death of individuals with developmental and other disabilities, the frail elderly, and other people who are perceived to be of low value (“devalued”). The Council opposes the creation of any coalition to advise on the “quality of life” of WV citizens.

For further information, contact the WV DD Council at 304.558.0416

February 22, 2018

HCS4035 S H&HR AM #1

Johnson 7909

The Committee on Health and Human Resources moved to amend the bill by striking out everything after the enacting clause and inserting in lieu thereof the following:

ARTICLE 54. STATE ADVISORY COALITION ON PALLIATIVE CARE.

§16-54-1. Purpose.

The purpose of the coalition created under this article is to improve quality and delivery of patient centered and family focused palliative care in West Virginia.

§16-54-2. Definitions

As used in this article:

"Appropriate" means consistent with applicable legal, health, and professional standards; the patient's clinical and other circumstances; and the patient's reasonably known wishes and beliefs.

"Medical care" means services provided, requested, or supervised by a physician or advanced practice nurse.

"Palliative care" means patient and family centered medical care that optimizes quality of life by anticipating, preventing, and treating suffering caused by serious illness throughout the continuum of illness, involves

addressing physical, emotional, social, and spiritual needs, and facilitates patient autonomy, access to information, and choice.

“Serious Illness” means any medical illness or physical injury or condition that substantially impacts quality of life for more than a short time.

§16-54-3. Creation of the State Advisory Coalition on Palliative Care.

There is created the State Advisory Coalition on Palliative Care. The administrative functions of the coalition are the responsibility of staff assigned to the Joint Committee on Health.

§16-54-4. Members of the Advisory Coalition on Palliative Care.

(a) The Advisory Coalition on Palliative Care consists of the individuals appointed by the President of the Senate and the Speaker of the House of Delegates who are health professionals having palliative care work experience and/or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings and with a variety of populations, including pediatric, youth, and adults.

(b) The members include:

(1) A physician who practices palliative care in this state and is licensed pursuant to the provisions of §30-3-1 et seq. of this code, who shall serve

as chair of the coalition for the first meeting until a chairman is selected by the Advisory Coalition;

(2) A physician;

(3) A registered professional nurse;

(4) A social worker;

(5) A pharmacist;

(6) A spiritual advisor;

(7) A patient advocate;

(8) A family caregiver advocate;

(9) One additional palliative care practitioner; and

(10) The Executive Director of the Center for End of Life Care, or his or her designee.

(c) The co-chairs of the Joint Committee on Health serve as nonvoting members, ex-officio.

(d) Membership on the coalition shall be distributed among the congressional districts of the state, and each congressional district shall be represented in the membership of the coalition.

§16-54-5. Powers and duties.

(a) The coalition shall consult with and advise the Legislature on matters related to the establishment, maintenance, operation, and outcomes evaluation of palliative care initiatives in the state. The coalition may:

(1) Meet at least quarterly or at the call of the chairman. A quorum is a simple majority of the coalition;

(2) Keep accurate records of the actions of the coalition;

(3) Make recommendations to the Legislature as required by this article;

(4) Provide guidance to the Legislature on potential statutory solutions relative to regulation of palliative care;

(5) Establish workgroups and clinical advisory committees as the coalition considers necessary to address pertinent issues related to palliative care and to provide consistency in the development of further regulation;

(6) Consult with entities and persons with expertise as the coalition considers necessary in the fulfillment of its duties. This can include public and private sector partnerships;

(7) Establish a system for identifying patients or residents who could benefit from palliative care;

(8) Provide information about and facilitate access to appropriate palliative care; and

(9) Offer any additional guidance to the Legislature which the coalition sees is within its scope which would further enhance the palliative care.

(b) The coalition shall report its findings to the Joint Committee on Health by December 31, 2019, and annually after that until the coalition terminates pursuant to the provisions of this article. The report shall include, at a minimum, the following:

(1) Conclusions and recommendations to promote a better means for palliative care;

(2) Recommendations for statutory and regulatory modifications;

(3) Identification of any action which may be taken by the Legislature to better foster awareness of palliative care issues in this state;

(4) A means to raise palliative care awareness; and

(5) Any other ancillary issues relative to palliative care.

§16-54-6. Cooperation with the coalition.

The Department of Health and Human Resources, the West Virginia Insurance Commission, the Public Employees Insurance Agency, the Center for End of Life Care, and all other entities of state government shall cooperate with the coalition in the exchange of data, information, and expertise if so requested by the coalition, including, but not limited to:

(1) Providing the entity's plans to improve palliative care in West Virginia;

(2) Sharing information on the financial impact of palliative care on the State of West Virginia;

(3) Providing an assessment of the benefits of implemented programs and activities aimed at bettering palliative care;

(4) Assisting in the development or revision of detailed action plans to improve palliative care; and

(5) Providing resources required to implement the plan.

§16-54-7. Sunset.

The coalition terminates on December 31, 2021, unless continued by act of the Legislature.

Adopted

Rejected