



# West Virginia Developmental Disabilities Council

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Charleston, WV 25387

## **WV Developmental Disabilities Council Statement on The Dangers of the term “Quality of Life” 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.

It is very telling that HB 4035, which has a purported purpose of creating a State Advisory Coalition on “Quality of Life,” fails to define it in the definitions section. That is because “quality of life” is not a medical term and has no agreed upon definition.

“Quality of life” has always been used to describe conditions such as the quality of water, air, etc., and what impact those qualities would have upon a population.

“Quality of life” has become a term used in medicine, often to determine who should receive treatment and live and who should not, and die. Medical personnel are left to their own feelings and beliefs to decide what they believe the “quality” of someone’s life is currently, or what it may become in the future, and therefore, whether an individual is worthy of treatment or not.

“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”).

Joseph Fletcher, an alumnus of West Virginia University who went on to be a leader in the field of bioethics, proposed a formula to measure “personhood,” a tool to determine “quality of life.” Some of the qualities he believed were required to be defined as human included *memory*, *minimum intelligence*, and *communication*. He also served as the president of the Euthanasia Society of America and was a member of the American Eugenics Society and the Association for Voluntary Sterilization. Fletcher wrote (in *The Atlantic Monthly*, Apr. 1968), **“People [with children with Down’s Syndrome]...have no reason to feel guilty about putting a Down’s Syndrome baby away, whether it’s “put away” in the sense of hidden in a sanitarium or in a more responsible lethal sense. It is sad; yes. Dreadful. But it carries no guilt. True guilt arises only from an offense against a person, and a Down’s is not a person.”** He has also been quoted as saying, **“We need to educate people to the idea that the quality of life is more important than the mere length of life. Our cultural tradition holds that life has absolute value, but that is really not good enough anymore. Sometimes, no life is better.”**

While this might seem to be from a time gone by, if one reads the work of Peter Singer, B.Phil., professor of bioethics in the Center for Human Values at Princeton University, and others, one will see these ideas have not gone away.

The Council opposes the creation of any coalition to advise on the “quality of life” of WV citizens. HB 4035 is particularly troubling as the “advisory” coalition to be appointed is to be made up of one particular group, all of whom are involved in the medical field, and most specifically involved in the area of death and dying (palliative care, end-of-life care, and hospice care).

Forming an Advisory Council, sanctioned by the Legislature of the State of West Virginia, to develop a system for identifying patients or residents who could benefit from end-of-life care is the first step towards shortening the lives of devalued people through the use of physician assisted suicide and other means in this State.

The West Virginia Developmental Disabilities Council is opposed to HB 4035 because it is dangerous to the lives of people with developmental and other disabilities. The Council is in the process of developing a workshop designed to educate people on the dangers of physician assisted suicide and other methods used today to shorten the lives of devalued people. Surely there is no emergency requiring the passage of this bill during this session. We invite you to join us on September 6<sup>th</sup> in Charleston to hear more on this very important issue.

**For further information, contact the WV DD Council at 304.558.0416**

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