

**Division of Disability and Aging Services  
Office of Public Guardian  
Ethics Committee**

**WHY WE NEED AN ETHICS COMMITTEE**

In the past, the lives of people with developmental disabilities have been devalued. People with developmental disabilities have been separated, segregated, sterilized, and shunned. In Nazi Germany, people with disabilities were classified as having “lives not worth living” and were targeted for extermination.

Our present system of services is premised upon a repudiation of the concept that the worth of a person is judged by his/her cognitive or physical abilities. Our system is premised on the assumption that the lives of all people, regardless of their level of abilities, are worth living, and worth living well. We strive to be creative in finding ways to support participation in home and community life for all people, including those who have profound handicaps.

One of the “gurus” of our field, Wolf Wolfensberger, popularized the concept of “normalization,” and then renamed it “social role valorization.” Wolfensberger, who emigrated from Germany, continually challenges people to use their best skills to “valorize” – surround with worth – the lives of people with severe disabilities. In recent years, he has also preached that the State and its social services systems have a tendency toward “death-making” when dealing with devalued people.

These concerns became highly politicized during the Reagan years when Baby Doe regulations established strict oversight of hospitals and medical personnel to assure life-sustaining treatment for babies with handicapping conditions.

Reflecting these forces and ideologies, the Division of Disability and Aging Services, until recently, insisted upon full medical treatment for all people we serve, under virtually all circumstances.

However, part of participation in community life implies sharing in changing values and ideologies. In communities throughout Vermont, elderly people are insisting upon the right to reject intrusive or painful medical treatment, and the right to die with dignity, in comfort, and in familiar surroundings.

Many of our staff became increasingly uncomfortable with a policy which barred our clients from the same opportunities to die with dignity and at home that many Vermonters who were not handicapped were choosing. The federal government entered the scene again (this time at the other end of the spectrum from Baby Doe regulations) by requiring consideration of Advanced care Directives when people are admitted to hospitals or nursing homes.

We have adopted the Critical Health care Decision Policy to provide our staff with the option of choosing something less than full medical treatment for people who are terminally ill. Treatment-no-matter-what is no longer our policy. BUT, we recognize that decisions in this area are fraught with peril.

- Most of the time, we are making decisions for people who are incapable of deciding for themselves. Thus, personal choice (the touchstone of most policies regarding critical care decisions) cannot drive these decisions, or does so as interpreted or represented by others.
- We are the State, and state action requires special scrutiny if it departs from the mandate to preserve life.
- People we serve still experience discrimination and devaluation by the very hospitals and medical providers upon whose advice we rely to reach critical care decisions
- The quality-of-life considerations which people who have lived without disabilities use to make critical care decisions for themselves produce untenable results when applied to people we serve.

For these reasons, we feel it is essential to build some kind of independent oversight into our process for critical care decisions.

...And that's why we've asked you to be here.

(updated 5/05)