



1016 LaPosada, Suite 145, AUSTIN TEXAS 78752 • 512 371-1783 •

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Byron Hughes  
REP. BYRON HUGHES  
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HB 1094

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### Letter to the 80<sup>th</sup> Texas Legislature

The Disability Policy Consortium is a group of 25 statewide disability advocacy organizations advocating for positive public policy that improves the quality of life for, and protects the rights of, people with disabilities. The Disability Policy Consortium strongly believes that the current discussion on advanced directives **is a disability issue**. People with disabilities have a long history of the quality of their lives being de-valued by the medical community, evidenced by the frequent recommendations for DNRs, termination of treatment, institutionalization, and more.

Current law is dangerous for people with disabilities as it creates an extreme imbalance of power where doctors and hospitals have significant protection and control while individuals have few protections and rights. Under current law, an arbitrary group of hospital representatives, who have a significant financial conflict-of-interest, can end the life of an individual against their will, the will of their surrogate, or preferences stipulated in an advanced directive. These ethics committees are unregulated and are comprised only of individuals the hospital invites. **There is no oversight and no accountability for ethics committee decisions or actions.** Individuals and families are often left powerless and are portrayed as emotional, irrational, and unable to make a reasonable decision – unless they agree with the hospital. Individuals and families have only 48 hours notice of the ethics committee meeting, are limited in their participation, and have only ten days to transition to another facility if the committee decides to end life-sustaining treatment. Under current law, individuals and families have no legal recourse to appeal the decision of an ethics committee to end treatment.

Under current law, people with disabilities die against their will and the will of their families. Under current law, an individual's advanced directive can be ignored and overruled by the hospital ethics committee.

**HB 1094 (Hughes) provides individuals and families with protection.** It ensures that life sustaining treatment will continue until a transfer to an alternate facility can be arranged. **This is the only way to ensure that the hospital has the incentive to assist a family by helping to facilitate a transfer rather than impeding the transfer which has been the case for a number of individuals.**

**HB 3474 (Delisi) changes current law, but in several ways puts people with disabilities at a higher risk of death against their will.** The addition of the newly introduced terminology of "pre-terminal" would give hospitals the ability to stop treatment and end the lives of individuals both "terminal" and "pre-terminal" Under the proposed definition, many individuals with disabilities could be considered "pre-terminal" and would have to live with the fear that doctors and hospitals could end their lives. Why would the state even consider allowing anyone to end the life of an individual who is not terminal? This law does little to improve protections for individuals and families while providing additional unchecked, unmonitored authority for life and death decisions to a committee that is formed by and operates on behalf of the hospital.

Rationing of health care resources should not be accomplished by allowing hospital ethics committees to decide who lives and who dies. The citizens of Texas deserve more protection. The default should be life, not death.

Respectfully,

  
Jeff Garrison-Tate, Chair

*promoting progressive public policy for Texans with disabilities.*