

SUBJECT: Decision-making advocate pilot program for the intellectually disabled

COMMITTEE: Human Services — favorable, without amendment

VOTE: 8 ayes — Rose, Herrero, Darby, Elkins, Hernandez, Legler, Naishtat,
Walle

0 nays

1 absent — Hughes

WITNESSES: For — Jeff Garrison-Tate, Community Now!; Norine Jaloway Gill, The Arc of Texas; Susan Murphree, Advocacy, Incorporated; (*Registered, but did not testify*: Dennis Borel, Coalition of Texans with Disabilities; Susanne Elrod, Texas Council of Community MHMR Centers; Melissa Fox; Linda Litzinger; Stephanie Thomas, ADAPT of Texas; Tanya Winters, Texas Advocates

Against — None

On — Colleen Horton, Texas Center for Disabilities Studies, University of Texas; (*Registered, but did not testify*: Angela Lello, Texas Council for Developmental Disabilities)

BACKGROUND: In Texas, guardianship and surrogate decision-making are the options available to individuals with intellectual, developmental, or other cognitive disabilities for making important life decisions.

Texas Probate Code, sec. 693 states that if a court finds individuals to be totally without capacity to care for themselves, operate a motor vehicle, or vote in a public election, then the court may appoint a guardian with full authority over the individual. A limited guardianship may be appointed by the court if the individual is found to meet some, but not all, of the criteria for full guardianship. Probate Code, sec. 602 requires that, in designing the guardianship, the court grant powers to the guardian only as necessary to promote and protect the well-being of the person and to maintain the maximum self-reliance and independence of the incapacitated person. The incapacitated person or "ward" retains all legal and civil rights and powers

except those specifically granted to the guardian by the court order. In 1993, the 73rd Legislature established a surrogate decision-making process with enactment of SB 1142 by Moncrief. Surrogate or substitute decision-making is a less intrusive and less restrictive type of support used to assist those who are unable to make decisions independently. Health and Safety Code, sec. 597.041 defines a surrogate decision-maker as an actively involved family member (spouse, parent, sibling) who, acting in good faith, consents on behalf of the individual regarding major medical or dental treatment decisions.

DIGEST:

HB 1454 would amend Government Code, ch. 531 to establish a volunteer-supported decision-making advocate pilot program. The bill would require the Health and Human Services Commission (HHSC) to create the pilot program to provide services to assist individuals with cognitive or developmental disabilities in making life decisions without impeding the self-determination of the individual.

HHSC would be required to implement the program in at least one rural area and one urban area, targeting persons living in community and institutional settings with at least one site serving state school residents — especially those who have no guardian and have expressed a desire to leave the state school. HHSC would have to convene a work group consisting of family members of, and advocates for, individuals with developmental or cognitive disabilities to develop the rules and structure of the program.

HHSC would contract with a non-profit entity, self-advocacy organization, local mental retardation authority, or some combination thereof to create and administer the pilot program and to recruit and train volunteer advocates to provide the supported decision-making services. The selected entity or collaboration of entities would have to meet certain requirements and expectations as set out by the bill.

Under HB 1454, the HHSC executive commissioner would be required to appoint individuals to the pilot program work group by January 1, 2010, and to establish criteria for evaluating the effectiveness of the pilot based upon the National Core Indicators. HHSC would, before each legislative session, publish a report including an evaluation of the pilot and recommendations to improve, continue, expand, or eliminate the program.

The pilot program would expire September 1, 2013.

The bill would take immediate effect if finally passed by a two-thirds record vote of the membership of each house. Otherwise, it would take effect September 1, 2009.

**SUPPORTERS
SAY:**

Under Texas law, guardianship and surrogate decision-making, which deal mainly with medical treatment decisions, are options for individuals who are not capable of making decisions on their own. Both involve someone else making decisions for the intellectually-disabled individual. No alternative exists for individuals who are intellectually, developmentally, or cognitively disabled but capable of making their own decisions with assistance. HB 1454 would create a pilot program to recruit and train volunteer advocates to provide support and guidance to intellectually disabled individuals and to assist them in the decision-making process.

Currently, when an intellectually disabled individual is capable of making decisions on his or her own behalf with support and guidance, but does not have a guardian, the decisions are made by the state. An interim study determined that more than 60 percent of individuals with intellectual and cognitive disabilities residing in state schools and centers do not have a guardian, nor do many community-based residents.

The supported decision-making process that would be established by HB 1454 would differ from surrogate decision-making in that individuals would retain the legal right to make decisions concerning certain choices in life such as where to live, who to live with, and what to do with leisure time. It is critical that people living in institutions as well as those living in the community learn to speak for themselves.

The pilot program also would address concerns about individuals in state schools who have expressed a desire to leave the system but have been denied the opportunity by the facilities' interdisciplinary teams. Conflicts of interest that exist in the current system would be eliminated with trained and supervised advocates ensuring that comprehensive information regarding the individual's choices was available to, and understood by, the individual.

The bill would create a system of support that would protect the civil rights of cognitively disabled individuals and would offer the support

needed to ensure each individual's preferences are respected, thus allowing an element of self-determination that currently does not exist.

The pilot program established by HB 1454 would not be mandatory. It simply would allow a less restrictive alternative for intellectually disabled individuals who want assistance and choose to participate. A family member who was not a legal guardian but was actively involved in the life of an intellectually disabled individual would be aware of the individual's participation in the program and would, therefore, be closely involved in the process and in no way supplanted by a volunteer advocate. In fact, the bill would require that family members be involved in shaping the structure of the pilot program.

HB 1454 would not change the existing authority of guardians or surrogate decision-makers. For example, should an individual choose to participate in the program when they have a legal guardian, the guardian still would have final decision-making authority.

**OPPONENTS
SAY:**

Under the pilot program established by HB 1454, a volunteer advocate potentially could supplant family members in the decision-making process involving their loved ones. Many intellectually disabled individuals have family members who are actively involved in their lives and in assisting the individuals in making life decisions. While these family members often are not legal guardians due to the high legal costs involved, individuals in state schools may, nevertheless, have the regular assistance of a family member, and a volunteer advocate should not take their place. Also, the bill would apply even when a legal guardian does exist, and problems could arise should an advocate and a guardian provide conflicting advice.

Some volunteer advocates may have their own agenda of seeking to depopulate the state schools regardless of whether it is in the best interest of an individual resident.

NOTES:

The companion bill, SB 1144 by Zaffirini, has been referred to the Senate Health and Human Services Committee.