

- SUBJECT:** Pilot program for medically fragile children
- COMMITTEE:** Public Health — favorable, without amendments
- VOTE:** 5 ayes — Berlanga, Hirschi, Davila, Delisi, Glaze  
0 nays  
4 absent — Coleman, Janek, Maxey, Rodriguez
- WITNESSES:** For — Cynthia Baughn, Melissa Hawley, Keith Loftin, Debra Ortegon and Lory Warton, The House That Kerry Built; Sara Speights, Texas Association for Home Care; Mark Tuley; Robert Walsh  
Against — None  
On — Susan Penfield, Texas Department of Health
- DIGEST:** HB 2984 would require the board of health to establish a pilot program to study and research the unique health care, maintenance, education, social and related needs of medically fragile children and their families.
- “Medically fragile child” would be defined as a person younger than 21 years of age who was chronically ill or disabled and required indefinite skilled nursing care; temporarily ill or disabled because of premature birth, accident or trauma and required temporary skilled nursing care; suffering from uncontrollable seizures, diabetes, asthma or other chronic illness; or chronically dependent on medical devices to perform vital bodily functions.
- The pilot program study would have to include
- specialized case management involving 24-hours a day availability for family support;
  - parent mentor programs to educate and assist parents of medically fragile children;
  - support services for clients, siblings and parents, including individual, group and family therapy;
  - respite services emphasizing family involvement and support, including

- temporary supervisory services for healthy siblings;
- a resource library that included information in printed form and computer resources;
  - medically supervised day care that recognized the need to reduce or make more efficient the state's financial Medicaid support;
  - pediatric home nursing; and
  - other criteria the board found in the public interest.

The board would select a nonprofit private entity to operate the pilot program based on such considerations as the extent to which an entity demonstrated immediate ability to provide the services listed in a cost-efficient manner; was able to provide services on a regional basis, including in rural areas; and had a demonstrated record showing it could meet program study criteria. The selection would be effective for five years.

The board could provide the entity with up to \$400,000 during each fiscal year to cover program costs. It also could adopt all necessary rules to implement the pilot program.

The board would have to submit a report on the program to the Sunset Advisory Commission by September 1, 2000, and make recommendations to the Legislature by January 1, 2001, on whether the pilot should be extended or modified.

HB 2984 would also provide a statement of legislative intent recognizing the expanding demographics of chronically ill children in Texas and acknowledging that care in private regional and community settings is preferred and the significant state savings can be achieved through competent programs. The statement also would provide that because the issues surrounding care for medically fragile children are complex and varied, there is a general need to study and research these matters to develop rational legislative and executive branch responses.

HB 2984 would take effect September 1, 1997. The board would have to select the entity to run the pilot program by January 1, 1998.

SUPPORTERS  
SAY:

HB 2984 would be a first start toward a coordinated attempt to help medically fragile children and their families throughout the state. The pilot program would replicate a successful model for providing quality care at a reduced cost. Other programs based on this model could then be set up throughout the state, ultimately saving a significant amount of money in health care costs for medically fragile children.

The bill does not attempt to anticipate the rules for the pilot project, but would provide specific authority to the board of health to develop appropriate regulations. The board oversees numerous health-related projects; it is quite capable of tailoring rules to fit the specific needs of this pilot project.

The pilot program outlined in HB 2984 is modeled after The House That Kerry Built, a resource center in Abilene that provides day care, a respite program, and other services for medically fragile children and their families. By pooling resources, such as nursing care, respirators, feeding tubes, kidney dialysis and other measures required to care for these children, and providing group care for a number of medically fragile children, the program has been able to significantly reduce medical costs. Since the inception of The House That Kerry Built four years ago, medical costs for each of the children in the program have dropped 87 percent. Children using this facility in lieu of hospital services resulted in Medicaid savings of approximately \$600,000 over the past three years.

HB 2984 would provide the funding needed to double the size of the day care program, which currently serves up to 15 children, and to expand other services. The program currently receives no state or federal aid and is funded entirely through private donations, grants, and memorials. The program is pursuing other funding sources, including Medicaid, in addition to the funding that would be provided by HB 2984. HB 2984 would provide a way for the state to reach out to the families of medically fragile children, who need financial support to provide expensive health care services.

While the funding for HB 2984 has not been specifically appropriated for this program, the health department could transfer funds from other programs for medically fragile children to pay for this program. Because the

pilot program can care for several children at the cost the state is currently paying to provide for one child, it would offer a better use of state funds that could ultimately lead to savings in other programs for medically fragile children.

**OPPONENTS  
SAY:**

HB 2984 is drafted to provide up to \$400,000 per year in general revenue funds for one facility that cares for 15 of the state's estimated 5,000 medically fragile children. If the Legislature intends to provide financial aid to medically fragile children, it should distribute these funds more evenly over a larger population of children.

Funding for the pilot program mandated by HB 2984 has not been specifically appropriated for the upcoming biennium. In order to meet the requirements of HB 2984, the board of health would have to take money from other programs. The health department already has a number of important programs on its wish list that have yet to receive full funding. This pilot program should not be funded at the expense of equally worthy efforts that have been included the health department's appropriations request for fiscal 1998-99.

HB 2984 would make no provisions for the health department to follow its usual competitive bidding process for awarding funding for the pilot program. Thus, The House That Kerry Built could receive up to \$400,000 in funding over five years without having to compete for the contract. The bill is also vague about who would conduct the research, which methodology would be used, and how the information would be disseminated to other interested parties throughout the state. The bill would require the health department to monitor the program, meaning the department would have to divert resources from other programs for one project in Abilene.

Medicaid and other funding sources are available to help provide financial support for medically fragile children. For example, nurses who care for these children can bill for their services through Medicaid. Further, The House That Kerry Built is already successfully providing services to a number of medically fragile children in Abilene.

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OTHER  
OPPONENTS  
SAY:

HB 2984 would authorize but not require the board of health to provide a grant of up to \$400,000 per year to operate a pilot program for medically fragile children. In addition to requiring the board to establish the pilot program, HB 2984 should require the board to provide funding.