SUBJECT: Requiring appropriate care settings for people with disabilities

COMMITTEE: Human Services — favorable, without amendment

VOTE: 7 ayes — Naishtat, Chavez, J. Davis, Ehrhardt, Noriega, Raymond, Villarreal

0 nays

2 absent — Telford, Wohlgemuth

SENATE VOTE: On final passage, May 7 — voice vote

WITNESSES: *(On House companion bill, HB 967:)*
For — Raul Acosta; Judy Allen, The ARC of Texas; Wendell Alley-Williard; Patty Anderson, United Cerebral Palsy of Texas; Karen Greebon; Aaryce Hayes and Jonas Schwartz, Advocacy, Inc.; William Herron; Norine Jaloway Gill; Bob Kafka, ADAPT of Texas; Susan Marshall, The ARC of Texas and The Disability Policy Consortium; Jennifer McPhail; Martha Moyer; Susan Murphree, Children's Long-Term Policy Consortium; John Sampson, Center for Independent Living; James Templeton; *Registered but did not testify:* Edward Alley-Williard; Dennis Borel, Coalition of Texans with Disabilities; Bruce Bower, Texas Senior Advocacy Coalition; Candice Carter; Ron Cranston; Leslie Hernandez, National Association of Social Workers; Roy Kelly; Diana Kern, NAMI-Texas; David Latimer, Texas Association of Homes and Services for the Aging; Spencer McClure, Community MHMR Centers of Texas and Texas Council of Community MHMRs; Kim McPherson, The Mental Health Association in Texas; Leigh Redmond, Texas Mental Health Consumers; Catherine Robles Cranston; Linda Rushing, Texas Catholic Conference; Heather Vasek, Texas Association for Home Care

Against — Evelyn Cherry; Charles Ferguson, Texans Supporting State Schools; Cindy Ferguson; Barbara Harris; Jim Miller; Fred Snyder; Ruth Snyder; Mike Stephens; Nancy Ward, Denton State School; *Registered but did not testify:* George Bradley; Glenda Cameron; Mitchell Cameron; Robert Peggram; Lloyd Seay; Jean Stephens; Joan Umfress-Seay; Sherry Williams

On — Ann Denton, Enterprise; Frank Genco, Texas Council for Developmental Disabilities, The ARC of Texas, and Advocacy, Inc.; *Registered but did not testify:* Sarah Anderson, Texas Department of Housing and Community Affairs

BACKGROUND: Texas has a network of community-based and institutional services for people with disabilities. Almost 82,000 people live in institutional long-term care facilities in Texas, including nursing homes, state schools, intermediate-care facilities for people with mental retardation (ICF-MRs), and state hospitals for people with mental illness. Those who are Medicaid-eligible have a federal entitlement to receive long-term care in an institutional setting. Two agencies administer most long-term care services in Texas: the Department of Human Services (DHS), which oversees the nursing-home industry and administers Medicaid, and the Department of Mental Health and Mental Retardation (MHMR), which manages nine state hospitals and 13 state schools and oversees ICF-MRs.

In 1999, the U.S. Supreme Court ruling in *Olmstead v. L.C.*, 527 U.S. 581, challenged states to accelerate placements into community care or else risk legal liability under the federal Americans with Disabilities Act of 1990 (ADA). In *Olmstead*, the court ruled that unjustified institutionalization constitutes discrimination under Title 2 of the ADA. States must place people with mental disabilities in a community setting within a reasonable amount of time if community placement is appropriate, the client does not oppose it, and the state reasonably can accommodate it, taking into account the resources available to the state and the needs of other people with disabilities.

Waivers. Under federal law, Medicaid, the federal-state health insurance program serving the poor, the elderly, and people with disabilities, can pay for long-term care services only in institutional settings unless the client obtains a waiver. Because the number of waivers is limited by availability of funds and the demand for waivers is greater than the supply, most states have created waiting lists for waiver programs.

States may obtain waivers to use Medicaid funds to provide services to people in their homes or in the community rather than in institutions. Waiver programs are apportioned into “slots” that target specific populations, such

as nursing-home residents or medically dependent children. To be eligible for a waiver slot, a person's new care plan must be budget-neutral — that is, the cost of caring for that person in the community must be no more than the cost in an institution.

Community-care services funded through a waiver program are designed to provide the same level of care as in an institution but are tailored to meet the specific needs of people living in the community. These services include case management, home health aides, personal assistance, equipment adaptations, and home modifications. Medicaid does not cover non-medical costs associated with moving a person into the community, such as rental deposits and furniture.

Promoting Independence Plan. In September 1999, in response to the *Olmstead* decision, Gov. George W. Bush directed the Texas Health and Human Services Commission (HHSC) to conduct a comprehensive review of all services and support systems available to Texans with disabilities. The Promoting Independence Advisory Board, formed that fall, included representatives from provider, consumer, and advocacy organizations. The board's Promoting Independence Plan, published in January 2001, included recommendations for promoting independence for people with disabilities by preventing institutionalization, identifying and assessing people who live in institutions, financing community-based services, increasing the number of available community-care slots, and supporting transition by disabled people from institutions to the community.

For additional background information, see *The Olmstead Challenge: Community Care for the Disabled*, House Research Organization Focus Report Number 77-9, March 27, 2001.

DIGEST:

SB 367 would establish a framework for Texas' long-term care placement initiatives and a time line for implementation. It would direct health and human services (HHS) agencies to develop a working plan and a task force to provide guidance on community and institutional long-term care. It also would establish ways for people who need long-term care services to be assessed for the appropriateness of different settings and to receive assistance to move from one setting to another, as needed. The bill would establish a pilot program to develop systems of integrated community-based

support services. SB 367 would take effect September 1, 2001.

Working plan. The bill would direct HHSC and other appropriate agencies to implement a working plan that would include services and supports to foster independence and provide opportunities for people with disabilities to live in the most appropriate setting. Appropriateness would be determined considering the person's needs, the least restrictive setting possible, personal preferences, availability of state resources, and current state programs. Under the plan, state agencies would have to provide a person with a disability who lived in an institution, or that person's legally authorized representative, information about care and support options, including community-based services.

Agencies would have to facilitate a timely transfer to a community setting if the person chose to live in the community, the treating professionals agreed that this was appropriate, and the state's resources reasonably could accommodate the transfer. Agencies also would have to develop strategies to prevent unnecessary institutionalization of a person living in the community who might need to enter an institution because of a lack of adequate services in the community. Such people at risk for institutionalization would include people with mental illness who were hospitalized three or more times in a 180-day period.

Eligible people with disabilities could not be denied access to an institution or removed from one if they did not wish to move. People who did not wish to move could be removed from an institution only if the move were necessary to protect that person's health or safety.

Each HHS agency would have to implement the recommendations in the working plan subject to the availability of funds. HHSC would have to submit a report on the implementation of the plan to the governor and the Legislature not later than December 1 of each even-numbered year.

Task force. SB 367 would establish an interagency task force to develop recommendations for the working plan. Membership of the task force would have to include representatives from HHS agencies, related work groups, consumer and family advocacy groups, and service providers for people with disabilities. Task force members would serve and the task force would meet

at the will of the commissioner. Members would not receive compensation but could be compensated for travel expenses.

The task force would be charged with identifying appropriate components of the pilot program to integrate among agencies. It would have to consider:

- methods of assessing people for whom community placement was desired and appropriate;
- availability of community services;
- barriers to implementing the state's working plan; and
- funding options.

The task force would have to submit a report of its findings to HHSC not later than September 1 of each year. The commission would have to establish the task force not later than December 1, 2001.

Assessment. SB 367 would expand the requirements for HHS assessment. It would require that agencies give each client and at least one family member, if possible, information about all options for care, including community-based care, not later than March 1, 2002. It also would specify nursing homes, ICF-MRs, and institutions licensed or operated by the Department of Protective and Regulatory Services (DPRS) among the care settings where clients must receive such information upon admission.

The information would have to cover all long-term care settings and would have to be shared with the client's representative, caseworker, or foster parents. The agency that provided the information would have to help the client take advantage of the option the client chose, subject to availability of funds. If the selected option were unavailable, the agency would have to place the person on a waiting list. The HHS agencies would have to report to the Legislature, rather than to HHSC, on the number of placements each agency made.

Not later than March 1, 2002, MHMR would have to implement an information process on community living options for institutionalized people with mental retardation and their legally authorized representatives. This information would have to be provided at least annually or upon request, and the results would have to be documented in the person's records. If a person

or a legally authorized representative requested a move to a community setting following this information process, MHMR would have to refer the person to the local mental retardation authority, which then would have to place the person in an alternative community living option within 30 days or place the person on a waiting list, if the community living option was unavailable within that period.

Transitional assistance. SB 367 would direct HHSC to coordinate with DHS, MHMR, and the Texas Department of Housing and Community Affairs (TDHCA) to help people move from institutions to community settings, subject to availability of funds. The agencies would have to establish eligibility criteria, duration of assistance, types of expenses to be covered, and locations where the program would be operated. DHS would administer the program and would coordinate with TDHCA in obtaining funding from the U.S. Department of Housing and Urban Development.

Pilot program. MHMR and DPRS would have to establish a pilot program, subject to availability of funds, to develop a system of supports and services that would enable people with disabilities to live in the community. The pilot program would have to include three sites, one urban, one rural, and one mixed. In choosing the sites, the agencies would have to give preference to those with the longest waiting lists for community-based services. The program would have to use presumptive eligibility for community-based services and would have to be implemented by December 1, 2002.

The pilot program would have to include policies to prevent inappropriate institutionalization, including pre-admission screening with the patient's hospital discharge staff and physician and a cost-benefit and feasibility study of placing that person in the community. It would create a program to educate physicians and hospital discharge staff about community-based alternatives to institutionalization and would require those professionals to inform patients with disabilities about all options for long-term care.

Community-based organizations would be eligible to receive grants to provide transition case managers who would help people make the transition from institution to community, coordinate with the local mental health or mental retardation authority, and perform outreach to people inappropriately placed in institutions.

Not later than September 1, 2002, MHMR and DPRS would have to adopt a memorandum of understanding that would define each agency's responsibilities in the pilot program and ensure interagency coordination. Each component of the pilot program would require sufficient appropriation of funds before it could be implemented, and MHMR and DPRS would not have to implement any component for which insufficient funds were appropriated. Not later than January 15, 2005, the agencies would have to submit a report evaluating the program and make a recommendation about its continuation or expansion to the governor and Legislature. Each year, both agencies would have to review and update the memorandum of understanding.

SUPPORTERS SAY:

SB 367 would create the infrastructure for Texas' response to the *Olmstead* decision. The Promoting Independence Advisory Board assessed the state's current situation and made recommendations about the initial steps that it needed to take to address the issues raised by the Olmstead decision. This bill would put into place the recommendations that the state can implement now and would establish ongoing monitoring and advisory roles to continue this work in the future.

The bill would reduce Texas' liability under the *Olmstead* decision, under which states must place people with disabilities in community settings within a reasonable amount of time if community placement is appropriate, the client does not oppose it, and the state reasonably can accommodate it. Without appropriate services in the community, the state cannot establish long-term community placement. SB 367 would lay the groundwork for increased community placement, reducing the state's potential liability under the *Olmstead* decision.

This bill would create a community-first policy that would ensure emphasis on community placement. In the past, people with disabilities were placed in institutions because it was believed that that was the only appropriate care for them. Today, many families, advocates, people with disabilities, and other groups understand that community care can be superior to institutional care for some people. The state's policies should reflect that.

SB 367 would create a time line for implementing the recommendations of the Promoting Independence Advisory Board. The time line would call for

implementing projects in stages over the coming years, ensuring that the state would make incremental progress in these areas.

The agencies would have to implement these programs only if the state provided sufficient funding. Waiver slots, a significant portion of the state's community-based care initiatives, are set by legislative appropriations. Thus, the Legislature would have direct control over all aspects of these initiatives and would consider non-waiver services and programs in light of the state's commitment to fund waiver slots.

SB 367 would require the development of assessment tools to ensure that all people for whom community placement is appropriate would be identified and informed about their options. The waiting list of people who have expressed interest in community placement may not reflect the total population of people for whom community placement may be appropriate. Some people with disabilities who have lived in institutions for many years may hesitate to sign up for a waiver slot because they fear the potential challenges of living in the community. It is important to overcome the bias of self-selection and to determine the whole population for whom community care may be appropriate, rather than waiting for people in institutions to place themselves on a waiting list.

SB 367 would address the needs of mentally ill people. While state hospitals logged more than 15,000 admissions last year, only about 350 people lived in a state hospital continuously for 12 months. Of those, about 30 to 50 people at any given time are considered ready for community placement. Generally, funding is available for people who are considered ready leave a state hospital, but they may face other barriers. Often these people have failed placement in a community setting in the past, and it may be difficult to obtain placement in a more specialized setting, such as a halfway house or small group home. This bill would include people with a mental illness who had been hospitalized more than three times in a 180-day period in the population that agencies would look at to develop strategies to prevent unnecessary institutionalization.

The bill would protect a mentally retarded person's right to remain in an institution. Community placement is not appropriate for everyone, and people who do not wish to live in the community should not be forced to

move. The bill would remove state schools from the pilot program, ensuring that people with mental retardation who might not have the cognitive ability to interpret where they want to live would not be burdened unduly with these activities. The bill also would prohibit agencies from denying institutional care for any person with a disability who desired it and for whom it was appropriate.

OPPONENTS SAY:

SB 367 would duplicate much of what the state already has done to implement the *Olmstead* decision. The state should dedicate its resources to implementing the recommendations of the Promoting Independence Advisory Board, not to creating another advisory board and pilot project. Texans with disabilities who are placed in institutions inappropriately need ways to move into the community, not more information about the current situation.

The bill would not direct state agencies to act with reasonable promptness in placing people in the community, and it would not protect Texas from *Olmstead*-related litigation. One of the core points in *Olmstead* is the state's responsibility to act with reasonable promptness. This bill would not move people out of institutions more quickly. The only way to do that is to increase the number of waiver slots, which is an issue of legislative appropriation. Texas already has the tools it needs to place people in the community and should seek funding to do that before it develops ancillary services.

Texas does not need more assessment tools, but rather more Medicaid waiver slots. The state already is aware of thousands of people who want to live in the community: those who are on waiting lists. Finding more through new assessment tools would not solve the core issue of too few slots to satisfy the demand. It would be cruel to spend scarce resources on assessing and informing people about community-based alternatives, only to place them on a waiting list for years.

This bill would do nothing for people with mental illness who are in a revolving door of institutionalization. Even though it would include people with mental illness who had been hospitalized more than three times in a 180-day period, it only would direct agencies to develop strategies to prevent institutionalization. This population's situation reflects the need to expand appropriate community supports. That would require additional funding,

which SB 367 would not provide.

OTHER OPPONENTS SAY:

Texas should not have a community-first policy. Community transition places a higher burden on institutions, raising their costs per bed per day over time. Because of the many fixed costs in institutional settings, the movement of funds to community-based services would reduce the quality of life in institutions and ultimately could lead to the closure of many facilities. Some family members oppose moving their relatives into the community at any cost, on the grounds that the quality of community care cannot compare favorably to that in an institution.

A program to inform all consumers of community options would be misguided because community living is not appropriate for all people living in institutions, and publicizing an array of options could create confusion for consumers. Institutionalized people who cannot make decisions for themselves should not be coerced and confused by the state or by advocacy groups into using community-based services.

Grants for transitional case workers and pre-admission screening in the pilot program are unnecessary and would result in unfair community bias. People with disabilities already have interdisciplinary teams of health professionals to assess their needs and options. Their care is evaluated often, particularly during transitions such as from an institution to the community. They do not need another case worker at that time. The bill's provisions for transitional case workers and pre-admission screening are designed to force people in institutions to be seen by those who are community-biased. Not all people with disabilities should have to go through these hoops to be in an institution.

The programs that SB 367 would authorize would cost the state $87 million in the first biennium and almost $200 million in the following biennium. Neither the House nor the Senate included funding for the pilot program or for elements other than waivers in their versions of SB 1 by Ellis, the fiscal 2002-03 general appropriations bill. They included waivers only in Article 11.

NOTES:

The bill's fiscal note estimates that the proposed programs would cost the state almost $87 million in fiscal 2002-03 and almost $200 million in fiscal 2004-05. Most of these costs would be associated with waiver slots for

mentally retarded people, but costs also would include funding for a mid-range waiver that would provide a limited range of services for mentally ill people with fewer needs, increased costs at MHMR, additional staff at DHS to provide assessment and information, one-time transitional assistance grants through DHS, and costs at DHS and DPRS associated with the pilot program. The cost of moving people from nursing homes into the community is estimated to be budget-neutral and to require only shifting funds among strategies.