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## *The Olmstead Challenge: Community Care for the Disabled*

The concept of promoting independence for people with disabilities by helping them move out of institutions and into the community is not new. Texas has established a network of community-based services and continues to adjust the funding mix between institutional and community care. In 1999, however, 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 (ADA).

In *Olmstead*, the Supreme 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 can reasonably accommodate it, taking into account the resources available to the state and the needs of other people with disabilities.

With about 48,000 people on waiting lists for community placement, Texas faces a significant challenge. While the state has not yet been a party to an *Olmstead*-related lawsuit, 13 other states are involved in or have settled such litigation. Some say it is a matter of time before Texas is challenged in court, and they encourage state lawmakers to consider a full spectrum of solutions, from preventing inappropriate institutionalization to increasing funds for Medicaid waiver slots, which allow individuals to "waive out" of institutional care and move to the community while retaining

Medicaid funding. State agencies have asked the 77th Legislature for an additional \$1.3 billion in all funds for programs to facilitate and support community placement in fiscal 2002-03. That would represent a 35 percent increase over current spending levels.

*A 1999 U.S. Supreme Court ruling challenges Texas and other states to move disabled people from institutions into the community at a faster pace.*

This report focuses on Texas' potential liability under the *Olmstead* ruling and the Legislature's options in addressing it. The report summarizes other states' experience with *Olmstead*-related litigation, reviews the state's initial policy response to the

ruling, and discusses the debate over expanding Medicaid waivers for Texans with disabilities.

### Long-term care in Texas

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. (See chart below.) 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 fiscal 2000-01, DHS will spend \$3.2 billion to serve about 66,500 clients in nursing homes, and MHMR will spend \$1.8 billion to serve about 15,300 people in state hospitals, state schools, and ICF-MRs.

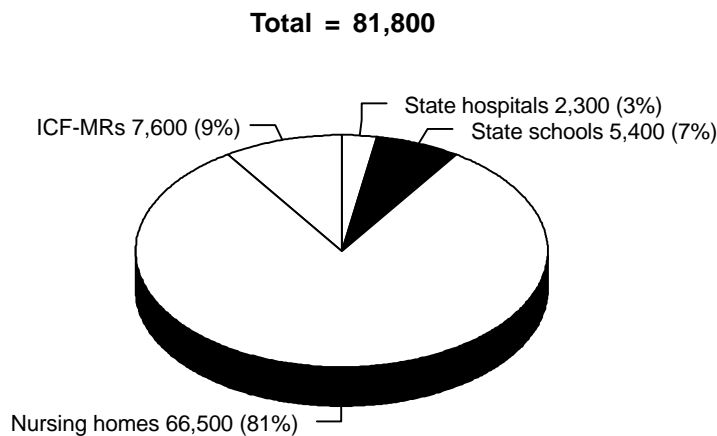
**State hospitals.** The state hospital system’s main function is to provide mental-health care for indigent people without third-party health insurance. The state pays for 2,600 inpatient beds on a per-bed basis through

local Mental Health Authorities (MHAs), joint ventures between MHMR and the community that provide local services to the priority population using federal, state, and private funds. In fiscal 2000-01, state hospitals will receive \$479 million in all funds for services and administration and provide services to more than 2,200 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 individuals who are considered ready leave a state hospital, but they may face other barriers. Often these individuals 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 population’s situation reflects a more general problem for MHAs: the need for expansion of appropriate community supports.

**State schools and ICF-MRs.** State schools provide specialized, campus-based long-term care for people with mental retardation. ICF-MRs, regulated and reimbursed by the state, provide training in independent living skills in a structured environment. A network of local Mental Retardation Authorities, similar to MHAs, administer community mental-retardation services. In fiscal 2000-01, MHMR will serve more than 5,000 people in state schools

Texas’ Institutional Population, Fiscal 2000



Source: Texas Health and Human Services Commission

at a cost of \$626 million for services and administration. MHMR will spend \$726 million for ICF-MRs, serving an average of 7,600 people per month. MHMR recommends community placement for 316 people living in state schools and 228 people in ICF-MRs.

**Nursing homes.** Texas has about 1,250 certified nursing facilities with 125,900 beds. These facilities house 66,500 Texans, 81 percent of the state's institutional population. Although regulated by the state, the nursing-home industry is private. Disabled people who live in nursing homes are the most difficult institutionalized population to assess for community placement because they often have no case workers to evaluate their situation and to provide information about community placement.

**Community-based services.** The state has not established a comprehensive system of supports for people with mental disabilities who live in the community. Rather, supports for non-medical needs like transportation, food, and housing are supplied by a loose network of local and nonprofit organizations that provide varying levels of assistance. As a result, a significant funding disparity exists for DHS clients who live in the community. About 65 percent of DHS clients who receive medical assistance are served in community settings, yet only about 35 percent of DHS' expenditures are in the community.

Community-based services vary widely according to need. People with mental illness may need to participate in a program where a nurse administers medication twice a day to ensure that they take the appropriate amount. Other people may need access to case workers who manage their money. People who use wheelchairs may need personal attendants who can lift them from the bed in the morning. Because people with different types of disabilities have different needs, community-support services can range from help with basic living activities, such as eating and bathing, to more general case-worker services, such as money management or help finding a place to live.

Once in the community, people also may obtain some services through the Texas Rehabilitation Commission's (TRC) ten Independent Living Centers across the state. These centers offer counseling, work training, adult basic education, vehicle modification, and assistive devices. However, TRC's services are designed for those who need help to improve their ability to live independently rather than for those who need continuing assistance.

## Medicaid waiver programs

Over the past two decades, the number of people living in institutions has declined in Texas and nationwide as consumers, advocates, and the state have worked to provide less restrictive housing options for people with disabilities. Among the programs and funding streams developed to facilitate this transition, the main mechanism is the Medicaid waiver program.

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.

Under the Social Security Act, sec. 1915(c), states may 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. Budget neutrality ensures that waivers do not increase a state's Medicaid burden.

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 an individual into the community, such as rental deposits and furniture, leaving financial responsibility for these items with families or charitable organizations.

When a person with disabilities obtains a waiver slot, the person "owns" that slot. Unlike Medicaid in an institutional setting, which pays for a broad array of services at an aggregate daily rate, waiver funds pay for individual services specific to each person's needs. For example, a client may need help with bathing and preparing meals each day. If a person in a nursing home were unhappy with meals, this service could not be carved out of the total package of services. However, if that client

lived in the community, he or she could obtain any available meal service without affecting other services. This characteristic of waiver slots makes them more flexible for clients.

## ***Olmstead* and disability rights**

The federal Americans with Disabilities Act (ADA), enacted in 1990, provides comprehensive civil-rights protection for people with disabilities in the areas of employment, public accommodation, state and local government services, and telecommunications. It defines certain types of discrimination against disabled persons. These include physical barriers — for example, the absence of a ramp into a library could block access for people in wheelchairs, or the absence of Braille in an elevator might impair access for the blind — and policy barriers, institutional decisions such as funding and eligibility determinations that could hinder a disabled person. Title 2 of the ADA prohibits discrimination on the basis of disability in the services, programs, or activities of state and local governments.

In 1995, two Georgia women sued the state, alleging that it had violated their rights under the ADA by failing to provide community placement. The plaintiffs were women with mental and cognitive disabilities who lived in institutions. Both had been admitted voluntarily, and in both cases, their treatment professionals had determined that the women could receive appropriate care in a community-based program. The state placed the women on a waiting list that was stagnant because of a lack of funds. As a result, the women could not enter a community-based program and remained in the institutions.

The federal district court ruled that Georgia had violated Title 2 of the ADA in failing to place the plaintiffs in a community-based program once it had been determined that such placement was appropriate, and that unnecessary institutional segregation constitutes discrimination that cannot be justified by lack of funding. The 11th U.S. Circuit Court of Appeals affirmed the district court's ruling in favor of the plaintiffs but instructed the district court to consider whether the additional cost to the state of treating the plaintiffs in the community would be unreasonable given the constraints of the state's mental-health budget.

In June 1999, the U.S. Supreme Court affirmed the lower courts' view that unjustified isolation of the mentally disabled constitutes discrimination based on disability

under Title 2 of the ADA. However, the court also recognized that, once the state provides community-based treatment to qualified people with disabilities, its responsibility is not boundless and the state need not make modifications that would alter its programs fundamentally. In evaluating a state's assertion that ordering community-based services would alter the nature of its programs fundamentally, lower courts must consider, in view of the resources available to the state, not only the cost of providing community-based care, but also the range of services that the state provides to others with mental disabilities and the state's obligation to administer services even-handedly.

*Olmstead*-related lawsuits challenging the practice of putting clients on waiting lists for community-based services have been filed in 13 states thus far. The common elements in these cases are long waiting lists or otherwise restricted access to community services. Four states — Florida, Hawaii, Massachusetts, and Pennsylvania — have settled or suspended *Olmstead*-related litigation. In all four cases, the state agreed to provide additional Medicaid waiver slots. These cases have established that creating more Medicaid waiver slots is an adequate first response to an *Olmstead*-related legal challenge.

**Florida.** Filed in March 1998, *Prado-Steiman v. Bush* sought to improve services and supports for people with developmental disabilities. As part of the settlement agreement, Florida agreed to provide services to all people who were waiting for services as of July 1, 1999. Since this case was filed, Florida has expanded its Medicaid waiver program significantly by appropriating about \$100 million in additional funds each year. This largely has eliminated Florida's waiting list for services for people with developmental disabilities.

**Hawaii.** A class-action complaint, *Makin v. State of Hawaii*, was filed in December 1998 on behalf of people on waiting lists for community-care waivers. In April 2000, the state settled the lawsuit by agreeing to increase the number of people served by the home- and community-based waiver program by 70 percent over a three-year period. Hawaii's legislature approved \$4.3 million in additional funding during its most recent legislative session to fund the first phase of this expansion.

**Massachusetts.** *Boulet v. Cellucci*, filed in March 1999, alleged that the state was not acting with "reasonable promptness" but was wait-listing people indefinitely. When the lawsuit was filed, about 3,000 people were on

waiting lists for community-care services. In a settlement reached in December 2000, Massachusetts agreed to provide residential services to an additional 300 people during the current fiscal year and to seek funding for 1,975 people over the next five years. The state also will provide interim services to people on waiting lists.

A separate case, *Rolland v. Cellucci*, was filed in October 1998 on behalf of a group of people with developmental disabilities who lived in nursing facilities. The plaintiffs demanded that the state provide residential services to people for whom community placement was appropriate. In October 1999, the state agreed to pay for community placement for such people. Massachusetts has committed to spending \$356 million over the next five years and to increasing funding from current levels to \$114 million per year by 2006.

**Pennsylvania.** A class-action suit filed in July 1999, *Gross v. Houston*, alleged that Pennsylvania had violated Medicaid law by failing to provide ICF-MRs or equivalent residential services. Gov. Tom Ridge's commitment to provide \$850 million in funding over five years caused activity to be suspended in this case.

## Texas' response: promoting independence

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 people with disabilities in Texas. The Promoting Independence Advisory Board, formed that fall, included representatives from provider, consumer, and advocacy organizations. The board's Promoting Independence Plan (PIP), published in January 2001, described how the *Olmstead* decision might affect Texas and the steps the state could take to move toward full compliance with the ADA.

The board assessed Texas' long-term care system and identified barriers to meeting the demands of the *Olmstead* ruling. Although Texas has developed effective community-based alternatives to institutional services, the board found that lengthy waiting lists slow people's access to services. Furthermore, the system for obtaining services is fragmented and confusing and often results in people entering institutions when they could be served better by community-based services.

The board developed a series of 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 the disabled from institutions to the community.

In addition to increased funding for Medicaid waiver programs, PIP recommendations include:

**Identification and assessment.** State schools and ICF-MRs use the Living Options Instrument to determine the appropriateness of community placement through input from clients, families, treatment professionals, and others involved in client care. All new clients are evaluated, and the evaluation is repeated for continuing clients during their annual review. The PIP recommends that MHMR continue to expand use of the Living Options Instrument through these periodic evaluations. Because DHS does not have the infrastructure in place to implement a similar assessment program, the PIP recommends that DHS train long-term care staff to promote community awareness. It also recommends that DHS inform all nursing-facility residents and all new applicants of long-term care options and that DHS intensify permanency planning — the process of determining a permanent home — for children living in institutions.

DHS' legislative appropriations request (LAR) for fiscal 2002-03 sought \$24.5 million in all funds and 280 additional staff to increase community awareness and provide assessment services to people in nursing homes. This program would seek to define in more detail the population living in nursing homes for whom community care might be appropriate.

**Access to information.** The PIP recommends that HHSC complement the type of training that DHS would provide in nursing homes by coordinating training across agencies to provide information about community options. HHSC also would create a system of access to services that could include the development of a "211" telephone service for information and referral and deployment of case-management specialists who would work with families and clients. The PIP also recommends that HHSC address technological infrastructure issues that prevent agencies from sharing information. HHSC's LAR included an exceptional item request of \$7.1 million to implement a 211 telephone system to improve access to information about community alternatives and supports.

**Supporting transition.** Making the transition from an institution to the community can involve one-time costs involved in establishing a home. These costs may include paying a deposit on an apartment, converting a bathroom to accommodate a wheelchair, or acquiring pots and pans for cooking. Housing for low-income disabled people is subsidized at the federal level through the Department of Housing and Urban Development's Section 8 Rental Certificate Program. This program pays the difference between the rent and what the person can afford, but it can take a few months to process the application and begin receiving a check for rent.

The PIP recommends expanding affordable housing options for people moving into the community. Initiatives that address these issues include developing temporary rent subsidies and transition funding and dedicating part of the state's Housing Trust Fund to help people with special needs, including those with disabilities, through loans, grants, or other forms of housing assistance. DHS has sought authorization for a grant program that would provide a stipend of up to \$2,500 each for people moving into the community. These funds could be used to convert a space to support the needs of a disabled person or to buy necessary household goods.

**Preventing institutionalization.** The PIP also recommends structural changes that could help prevent institutionalization, such as giving people more information about community services before they enter institutions. For example, a mid-range waiver that offers a narrower range of services could make it unnecessary to institutionalize certain people. On a broader scale, the PIP recommends the ongoing development and expansion of community-based services to keep people in the community.

The PIP recognizes the availability of non-medical transportation as an essential element to preventing institutionalization. Buses, vans, or other types of transportation ensure that people can buy food, work, or participate in the community. The availability of non-medical transportation is of particular concern for rural areas that may not have a well-established public transportation system.

## Waiver proposals

While the PIP provides a framework for the state's approach to community placement, the most immediate strategy being recommended by state agencies regarding

the state's potential liability under *Olmstead* is to increase the number of Medicaid waiver slots.

About 48,000 Texans are now on waiting lists for Medicaid waivers to pay for community-based services. More than 98 percent are waiting for a spot with one of the five programs shown in the table on page 7.

Depending on a person's level of need, he or she may wait in an institution for many years before a waiver slot opens up to support a move into the community. Because Medicaid is an entitlement, once a person qualifies for the waiting list, he or she is considered to have the same level of need as any other Medicaid-eligible person on the waiting list. Therefore, when a slot becomes available, it is allocated on a first-come, first-served basis.

Other states' experience has shown that increasing the number of waiver slots accelerates the placement of people in community care. Because of the budget-neutrality provision, more slots should not require additional funds. In practice, however, additional slots do require new funds. Because institutional care is a Medicaid entitlement, as people vacate beds in long-term care institutions, those beds must stand ready for others who may need them. Pent-up demand for some services, mostly ICF-MR, also keeps occupancy levels high even as people move into the community. These factors prevent the cost of a vacated bed from immediately transferring to community services.

For fiscal 2002-03, DHS has requested \$380 million in all funds (\$170 million in general revenue) to decrease long-term care waiting lists, and MHMR has requested \$42 million in all funds (\$17.5 million in general revenue) to decrease the waiting list for Home- and Community-Based Services (HCS). MHMR also has requested \$6.4 million to create a new Medicaid waiver to develop a less costly alternative to HCS services. This program would provide services and support for individuals who already live in their own homes, rather than for people moving out of institutions. It would provide up to \$25,000 per client per year and could reduce the HCS waiting list by about 200 people during the biennium.

Even if the Legislature fully funded agencies' requests for additional waiver slots, a waiting list still would exist for community-based services. DHS and MHMR requests were based on the assumption that the number of waiver slots would increase each year as part of an increasing focus by the agencies on community-based services.

### Major Medicaid Waiver Programs

Program	Operating agency	Population served	Average caseload, fiscal 2000	Waiting list
Medically Dependent Children's Program	TDH	Children under 21 who qualify for nursing-facility care	958	1,701
Community Living Assistance and Support Services	DHS	People with developmental disabilities who qualify for ICF-MR care	1,146	5,196
Home and Community-Based Services	MHMR	People with mental retardation who qualify for ICF-MR care	4,186	13,726
Community-Based Alternatives	DHS	Adults age 21 and over who qualify for nursing-facility care	23,693	20,964
In-home and Family Support	DHS	People with physical disabilities (without a diagnosis of mental disability) living in the community	2,844*	5,854

\*Average caseload for fiscal 1998.

Sources: Texas Health and Human Services Commission and Texas Department of Human Services

Although *Olmstead* only addresses community placement for individuals who want to move into the community and for whom community placement is appropriate, the ruling also concerns advocacy groups associated with health and human services. Some families of people who live in institutions are concerned that the state will coerce their relatives into moving into a less than ideal situation in the community because care is less expensive there. They worry that even if their relatives remain in institutions, *Olmstead*-related initiatives will remove state support for institutions and care will deteriorate.

Others are wary of the price tag associated with increasing the number of waiver slots or funding other PIP recommendations. As the Legislature makes choices with limited state dollars, lawmakers will have little flexibility in paying for the rising costs of entitlement programs and in meeting other pressing needs.

The debate over specific issues involved in increasing funding for Medicaid waiver programs is summarized below.

#### Identification and assessment for waiting lists.

While many people agree that community placement would be the best outcome for some people who now live in institutions, deciding who qualifies for community placement can be contentious. Some supporters of community placement believe that 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. Supporters of enhanced identification and assessment efforts say 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.

Some family members and representatives of people living in institutions balk at increased identification and assessment efforts. They believe that a program to inform all consumers of community options is misguided because community living is not appropriate for all people living in institutions, and publicizing an array of options may create confusion for consumers. They say that 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.

**Money follows the client.** A proposed rider to DHS' appropriation for fiscal 2002-03 would require that as people moved out of institutions, the money associated with those clients would move with them into the community. HB 966 by Naishtat would require HHSC to study ways to implement this provision. Supporters say this provision is important for DHS to implement the PIP recommendations because it would allow the agency to redirect funds from nursing homes, where there is less

pent-up demand, to community services, thus balancing funding with program priorities.

Opponents say that the premise of “money follows the client” can have significant adverse implications for institutions. 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, advocates for people who will remain in institutions fear that 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.

**Community supports.** Although waivers are the primary funding mechanism for moving people into the community, Medicaid still leaves many needs unmet. These include expenses that would not be incurred in an institution, such as obtaining furniture, cookware, and cleaning supplies, as well as non-medical living

arrangements and expenses, such as rental deposits and transportation. The PIP recommends establishing and funding community supports such as information centers, non-medical items and services, and case workers to address these needs. Supporters of increasing the number of waiver slots also generally support the establishment of community supports, but their top priority in the short term is to fund more waivers to move people into the community. Given state budget constraints, supporters say that these other transitional needs must continue to be met through other means, such as private charities.

Opponents of increasing the number of waiver slots without increasing the funding for community-based services argue that the lack of established community supports could subvert the purpose of additional waivers. They say that expanding waiver programs without transportation support or the small items needed to look after a home could result in people returning to institutions. They also say the array of services provided by charitable or community organizations is fragmented and too difficult for consumers to rely on.

— by **Kelli Donges**

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