Promoting Independence: A Plan to Expand Opportunities for Texans with Disabilities

Introduction

In Executive Order GWB 99-2, dated September 28, 1999, Governor George W. Bush affirmed the value of community-based supports for persons with disabilities. Pursuant to his order, the Health and Human Services Commission (HHSC) is directed to enlist the participation of families, consumers, advocates, providers and relevant agency representatives in a comprehensive review of all services and support systems available to persons with disabilities. A report is due to be presented to the Governor, the Lieutenant Governor, and the Speaker of the House no later than January 9, 2001. HHSC is further directed to pursue opportunities for improvements to the current system of services and supports for Texans with disabilities, within its statutory authority.

The following plan of action, the Promoting Independence Initiative, is intended to assure that the state moves deliberately and decisively toward a system of services and supports that fosters independence and productivity and provides meaningful opportunities for people with disabilities to live in their home communities. It will recognize the importance of a continuum of care and the role of client and family choice in the system of services and supports for Texans with disabilities.

Background

For almost two decades, Texas has focused on increasing community-based care options for the elderly and individuals with disabilities, especially in the Medicaid program. This emphasis has resulted in a population decline within institutional settings. Most striking is the 45% reduction of the average daily census in state mental hospitals. In 1986, the average daily census in these facilities was 4,500 compared with 2,400 (and approximately 13,000 admissions) in 1999. Similarly, for the same time period, state schools for the mentally retarded saw a census drop from 8,700 to 5,400, representing a 40% decrease. Although the average nursing facility census has increased 21%, the number of nursing home residents has remained fairly constant for the past six years. The resulting decline in the rate of institutionalization has translated into a 211% increase in persons receiving community services through DHS aged and disabled programs. Some 112,000 Texans are now receiving community services through these programs as opposed to the 53,000 thirteen years ago.

State agency budgets also reflect the shift from institution to community. Approximately 65% of the budget for the Texas Department of Mental Health and Mental Retardation (TDMHMR) was expended on institutional services in fiscal year 1989; community services accounted for the remainder. Ten years later, the balance has shifted, with 69% of the budget spent on home and/or

community services with institutional services representing only 31%. The trend continues with the Department of Human Services' (DHS) long-term care budget.

For the same ten-year period, DHS saw community programs escalate from 25% to 32% of the budget for long-term care services. DHS's total budget for both institutional and community care has also grown. Since 1989, DHS community programs have experienced a 300% increase from approximately $750 million to currently just over $2.4 billion. However, access to community supports can be extremely challenging. Community waiver programs are operated by four different agencies and lack common programmatic and administrative direction.

Establishing the Value Base for People with Disabilities

The Governor's Executive Order recognizes the need to provide community-based alternatives to institutional services. The Order also acknowledges that community based programs effectively foster independence and acceptance of people with disabilities. As we begin the comprehensive review of services and supports for Texans with disabilities, we must begin with the articulation of a value base that will serve as the framework for system improvements for the future. This value base should communicate our collective vision for people with disabilities.

- People should be well informed about their program options, including community based programs, and allowed the opportunity to make choices among affordable services and supports;
- Families' desire to care for their children with disabilities at home should be recognized and encouraged by the state;
- Services and supports should be built around a shared responsibility among families, state and local government, the private sector, and community based organizations, including faith-based organizations;
- Programs should be flexible, designed to encourage and facilitate integration into the community, accommodating the needs of individuals;
- Programs should foster hope, dignity, respect and independence for the individual.

Addressing the Wait for Community Care for those in Institutional Settings

In ruling on the *Olmstead* case, the United States Supreme Court decided that the states have an obligation to allow access into existing community programs for people in institutional settings if:

1. the state's treatment professional determines that community services are appropriate for the individual; and
2. the individual or legally authorized representative chooses to leave that institutional setting in favor of community alternatives; and

3. the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other persons with mental disabilities.

However, the state is not obligated to provide such services if doing so would be a fundamental alteration to the state's programs.

As of September 1, 1999, there are approximately 98,000 people living in institutional settings in Texas. This includes 66,500 people living in nursing homes, 3,100 living in large ICF-MR settings and 5,400 in state schools for the mentally retarded, and 2,400 receiving inpatient services in state hospitals for the mentally ill. There is an indication of the need for increased community alternatives to accommodate people currently living in some institutional settings as defined by established waiting lists for community services. This is, however, an imprecise measure of need, as there has been no uniform means of identifying those for whom community services are appropriate, who prefer to be served in a community setting, and for whom affordable and effective supports can be provided. This is especially true for people with disabilities who live in nursing homes. A comprehensive process of identifying affected populations must be developed and implemented in the early stages of the Promoting Independence initiative. The identification process should validate the waiting list data that exist for those living in state schools and other large ICF-MR facilities and assure that all people living in institutional settings have access to a process that identifies their desire for community services and supports and assesses the appropriateness of such services.

State Schools

As of September 1, 1999, there are approximately 409 individuals residing in the 11 state schools and El Paso and Rio Grande State Centers who have been recommended for and have expressed an interest in community placement. It must be recognized that this is not a static number. Additionally, efforts are underway at TDMHMR to establish uniform guidelines among the 11 state schools and 2 state centers for determining which individuals may appropriately be referred for a community placement. These guidelines will be evaluated in the context of the Promoting Independence Initiative and will likely influence the number of individuals recommended for community placement from state schools.

Planning efforts have begun at TDMHMR to provide placement options for the 409 individuals who are currently on waiting lists for community placement. The agency has committed to making community placement options available to each of these 409 individuals by August 31, 2001, provided that they are determined to meet the conditions in *Olmstead*. Interim benchmarks will be established as part of the Promoting Independence Initiative to assure the successful and timely community reintegration of these individuals.

To accommodate the needs of state school residents who meet the *Olmstead* conditions after August 31, 2001, the agency commits to provide opportunities for community alternatives within 180 days of the recommendation and request for placement.

Large ICF-MR Facilities

There are 216 persons currently living in ICF-MR facilities of more than 14 beds who are identified on the waiting list for the Home and Community Services (HCS) waiver program. Unlike persons in state schools, these individuals may have not yet been determined by a state-authorized treatment professional to be appropriate for HCS.

The appropriateness of HCS will be assessed for each of these individuals beginning in December 2000. For those determined to be appropriately served in an HCS setting, options will be made available not later than August 31, 2002, unless it is determined that HCS alternatives will require a fundamental program alteration and, therefore, cannot be offered by the state. An effective process will be developed to inform this population of potential HCS alternatives. TDMHMR will continue thereafter to monitor the waiting list for HCS placement from large ICF-MR facilities and offer opportunities for HCS for people to select within 12 months after the appropriateness of HCS has been established.

State Hospitals

There are approximately 2,400 beds (and approximately 13,000 admissions per year) in state hospitals. For the most part, inpatient psychiatric care is a relatively brief intervention, lasting no more than a few weeks. However, for those individuals whose treatment needs are the most severe, longer lengths of stay may be indicated. As of October 1, 1999, there are 54 individuals who have been in state hospitals for longer than 12 months and are also ready for discharge into a community-based living arrangement. There are additional persons who have been in state hospitals longer than 12 months, but are not recommended for discharge by treatment professionals and continue to meet commitment criteria for in-patient hospitalization under the Mental Health Code. Timeframes for addressing the needs of this population will be considered based on the evaluation of the data.

Nursing Homes

Effective October 29, 1999, a new DHS rule grants an exemption to the first-come, first-served rule in the Community Based Alternatives (CBA) program. Individuals who have resided in a nursing home within the last six months will automatically move to the top of the CBA interest list for a determination of CBA eligibility. It is clear, however, that not all individuals with disabilities who live in nursing homes have knowledge of and access to this new provision. Individuals who entered the nursing home prior to the date of the policy and those who entered the nursing home without DHS's assistance may have had

no opportunity to know about community-based alternatives. There must be an identification process developed in which people in nursing homes can be informed as to the options for community support and evaluated for reintegration once there is an expression of interest in leaving the nursing home setting. This process must be developed with concern and sensitivity to the needs of all nursing home residents. Timelines for community placement will be established based on data generated through the identification process. Efforts to effect community placement for people with disabilities who live in nursing homes, and for whom affordable supports can be provided, will move forward independent of the efforts to offer community alternatives to other institutional settings.

Evaluating and Refining the System of Services and Supports - Implementation of the Promoting Independence Initiative

In implementing the Promoting Independence Initiative, the steps that are taken must be consistent with the value base articulated in this plan and supported by the Governor. Consequently, a systematic process must be developed whereby the program design and application for all long-term care services and supports are matched against the value base. Inconsistencies must be identified and remedied. Given the breadth of these services and support programs, this value-based evaluation will take a considerable effort, both in terms of time and resources. The course of the evaluation should begin with a prioritization of programs for review. This prioritization should reflect the interests and concerns of people with disabilities and their families. Program and policy changes that are within the authority of the agency and/or HHSC should be made as necessary to adhere to the value base. In addition to directing the steps outlined above regarding each institutional setting, HHSC is: 1) creating a partnership to provide oversight and guidance; and 2) committing the resources to organize and deploy the initiative.

Creating the Partnership

A twelve-member advisory board will be appointed by and report to the HHSC Commissioner. The advisory board will be comprised of seven consumer/family representatives, three representatives of service providers to be selected by the Commissioner, and two agency board members, representing TDMHMR and DHS. Agency representatives will serve as ex-officio members of the advisory panel and will be appointed by the HHSC Commissioner. The advisory board will provide recommendations to the Promoting Independence implementation process, including guidance with respect to all aspects of evaluating and planning for system enhancements. The advisory board will meet monthly, or as deemed necessary, with the HHSC Commissioner and designated staff.

Committing the Resources

To assure that adequate staff resources are available for this initiative, a dedicated unit will be established by HHSC to organize and deploy the Promoting Independence Initiative. The unit will be made up of full-time staff assigned from existing resources at HHSC and among the various agencies.

Funding for the expansion of community-based alternatives will begin with the use of available funds appropriated by the 76th Legislature. As the movement from institutional to community services creates a sustained reduction in the demand for institutional services, HHSC will look for opportunities with the agencies, the Governor's Budget Office, and the Legislative Budget Board to fund additional community placements. HHSC will work with the agencies to identify and present further appropriations needs to the 77th Legislative session.

Reporting the Status

As directed by the Governor, a status report will be prepared and submitted to the Governor and legislative leadership before the start of the 77th legislative session. The report will detail the findings and corrective action taken, as well as any changes that may require legislative attention.

Conclusion

The Health and Human Services Commission believes that the Promoting Independence Initiative will further enhance the ability of individuals with disabilities to live and receive services in their communities. HHSC welcomes the opportunity to work with consumers, advocates, and providers to improve the system of services and supports for Texans with disabilities. Together, we can and will make a difference.

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