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# *Steps to Support for All*

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An association for the support of Texas citizens who are aging or have exceptional challenges

*Steps to Support for All* is a group of individuals working to move the State of Texas in a positive direction toward fully funding programs and facilities provided by the Department of Aging and Disability Services (DADS) as well as other Health & Human Services Commission (HHSC) systems which serve those Texans with disabilities or are aging senior citizens.

OUTCOME MISSION: To eradicate the waiting lists for Medicaid Waiver programs, which provide services to disabled Texans; to maintain adequate level of "aging well" services for seniors; and to insure adequate funding for a full continuum of home, community and institutional services.

## **Strategy for Success - Education**

- Provide accurate information about the needs of those having disabilities or who are aging to the citizens of Texas through community leaders and organizations.
- **Stress the importance of working together in the distribution and delivery of service. All services are necessary!** We do not place higher value on the needs of one segment over those of another segment.

Through a spirit of good will and education, *Steps to Support for All* formed to promote close and effective cooperation between groups advocating for certain populations of Texans with disabilities and those advocating for senior citizens. By doing so, the association will **provide a climate of fairness and compassion for all who need services** and foster an effective working relationship with legislators and the administrative organization of the Department of Aging and Disability Services. These efforts are extended to end the confusion created by factions and **redirect the focus onto the Texas citizens needing the services.**

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*Steps to Support for All* strives to assist the Department of Aging and Disabilities in their vision and mission statements outlined in the DADS 2005 Reference Guide as follows:

## **Vision**

Older Texans and persons with disabilities and mental retardation will be supported by a comprehensive and cost-effective service delivery system that promotes and enhances individual well-being, dignity, and choice.

## **Mission**

To provide a comprehensive array of aging, disability, and mental retardation services, supports, and opportunities that is easily accessed in local communities.

Our key responsibilities include:

- Working in partnership with consumers, caregivers, service providers, and other stakeholders;
- Developing and improving service options that are responsive to individual needs and preferences; and
- Ensuring and protecting self-determination, consumer rights, and safety.

<http://www.bms.dhs.state.tx.us/glance/Reference%20Guide%202005/2005RGCom.pdf>

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Members of *Steps to Support for All* recognize there is a need for many types of services. There is a need for community-based services and there is also a need for institutional services such as nursing facilities and state schools.

**Individuals from these agencies or groups worked with members of *Steps to Support for All* to produce this document. They checked for accuracy of facts and helped determine those needs that are most prominent. The document does not serve as a platform for any of the entities. The individuals serve only as resources for accurate information:**

- MHMR
- State schools
- Adult Protective Services
- Texas Silver Haired Legislature
- Texas Guardianship Association
- Texas universities
- Private service providers
- Families who have family members in state schools
- Families who have family members with disabilities living in the community
- Families who have family members with disabilities living in the family's home

## Services to be supported

1. Adequate housing and services for those having exceptional needs whom choose to stay in home-community settings.
2. Adequate housing and services for the elderly citizens of Texas who choose to stay in home-community settings. Protect the service programs for older Texans, such as Area Agencies on Aging, which are working well.
3. Community programs with a positive history. Maintain the local control that has produced these successful programs - do not allow restructuring (DADS) to sacrifice successful programs.
4. Continuity of effective community services. Allow counties to do individual planning in the restructuring so to continue to use effective community services and funding i.e. food banks, local Area Agencies on Aging, etc., plus the extensive contribution by volunteers.
5. Adequate housing and programs for those living in state schools.
6. Pay scale raises to equitable levels for those providing medical and direct care to persons with disabilities to ensure qualified and sufficient personnel.
7. Elimination of the waiting list for all Medicaid Waiver Programs through proper funding of needed services.
8. Redefining the customer as the person in need of services and therefore eliminate compartmentalizing and restrictions that hamper delivery of services.
9. Consistent services for the future of all with disabilities.
10. Letting the market place determine what support is required for each individual, i.e. state school, community placement, in home and family support. The market place should determine what people need in order to minimize waste and provide appropriate service to the individual.
11. Support programs to extend guardianship for 18-year-old foster children with mental retardation or developmental disabilities to age 22 to enable the young adults to receive support as they develop life skills training, establish work situations, or complete their educations. Upon reaching the age of 22, if the guardian is not a family member, then it would become necessary for the guardian to reapply to continue the guardianship if such care and protection are needed.
12. Support voluntary emergency placements in state schools for families in crises.

## Current deterrents to services

1. Current political environment in Austin does not match the concerns of the general public. The general public, even those Texans who have no family members needing services at the current time, are appalled when they learn about the lack of funding for programs in place. Texas citizens want to care for those in need. Their compassion is greater than their greed. Texas taxpayers care about how their money is used, but they do not want to save pennies at the expense of providing for the care of those citizens in most need.
2. The current focus of HHSC and DADS is on *cost cutting* rather than *service providing* as outlined in the 2005 Reference Guide provided by DADS.
3. Generally, families who have been caring for their disabled family member in their homes, are keeping the cost of services needed from the state at a minimum, but in so doing often lack the additional time and capital necessary to push for programs in Austin. They have not had the opportunity to develop political contacts nor political savvy to work effectively with the legislative bodies or the policy makers of DADS. They have no paid lobbyists.
4. Substandard wages for persons working in community-based services and state schools make it is very difficult to attract the needed staff members, including medical personnel.

## Current available pathways to move up on the long waiting lists:

Individuals coming out of state schools or state hospitals go to the top of the current waiting lists for community-based services and placements. There are two avenues to follow:

1. The guardian of a person with disabilities currently living in the community could begin the application procedure to have that individual with disabilities placed in a state school. Then after placement, request that the person be placed in the community again.
2. Allow persons with disabilities who take medications that enable them to remain functional and happy in the community, to go off medications. Many would be eligible in a short period of time for entrance into a state hospital facility. Once in the state hospital, the individual would go back on effective medications and be ready to re-enter the community, but would now be at the top of the waiting list.

Using the state schools for state hospitals for emergency placement is certainly an acceptable placement for those in crisis or for those who have no other alternatives, but using the system when a genuine placement is not wanted is not acceptable. Never actually wanting a bed, just wanting to pass through the bedroom is abusing the system. These **unacceptable methods** to gain access to community-based services (HHSC funding) are the only alternatives currently provided by the State of Texas to those who are on the waiting lists for 10+ years. **Neither of the alternative choices are positive or sensible choices, but are currently valid options. These options would severely overload the state schools and hospitals and create an even bigger crisis.**

# DID YOU KNOW?

- That under the current provisions made by the Social Security Act a **family may not save money to provide for the basic need of their family member with disabilities** when the disabled person becomes elderly. A family may establish and put money into a Supplemental Special Needs Trust but the trust funds may not be used to pay for food or housing. If funds are used from the trust to supplement their SSI benefit (which is below the poverty level and is expected to pay for food and housing) the person with disabilities will lose not only their monthly SSI check but with it, they also lose their Medicaid benefits. It is imperative that those with disabilities remain on the list for Medicaid. They could have medical needs that would completely eradicate any savings their families might have made for their futures as elderly citizens.
- If the waiting lists continue to be massively under-funded, as they are today, **many individuals will be waiting at least a decade before receiving the benefits** they need. This is a daunting impediment for young adults today who have worked to gain the skills to live as independently as possible and who choose to be active and vital in their communities. These individuals want to care for themselves to the greatest degree possible, but because of their disabilities their independence can only be maintained with proper community-based services. <http://www.mkdowney.com/waitcsp.htm>
- The **special needs population is living longer** than ever before and developing additional health care needs. "Regular" assisted living centers will not have the knowledge to care for a person with cognitive delays as well as aging disorders. Some of those who are choosing to live in community-based housing today may one day need the more specialized care that residential programs may provide. Their **needs will change** just as surely as everyone's needs change through their life time.
- According to a study prepared in August 2004 Texas ranked **51st** among the states in the rate at which it furnished **community-based waiver services**. (<http://www.mkdowney.com/Texas%20Report%208-15-2004.pdf> page 6)
- In 2003, Texas ranked **47th** among the states in the rate at which it furnished **Medicaid long term services** (the combination of HCBS waiver and ICF/MR services). (<http://www.mkdowney.com/Texas%20Report%208-15-2004.pdf> pages 2 and 6)
- In 2003, Texas ranked 40<sup>th</sup> out of 42 states on the average resident daily expenditures in large state residential facilities. Only Arkansas and Mississippi spent less per day. Texas spent \$106 per day per resident less than the national average. <http://rtc.umn.edu/risp03>
- We're heading into an **even greater crisis** as this population ages.

- Individuals living in state schools are often in need of exceptional medical care requiring daily treatment, or need close supervision due to behavioral issues. In addition to caring for individuals with very limited cognitive capacity, state schools currently care for those having cognitive delays who need long term medical care, or those having significant behavioral disorders in need of long-term placements with very close supervision. Many of these individuals with mental retardation needing long-term care are placed in state schools after leaving a state hospital or are sent by the courts if they are deemed to be of danger to themselves or others. **There will always be a need for facilities that care for individuals with significant needs.**
- Texans pay the least amount of taxes in the United States, and consequently provide the least amount of services to those in need. In the past, families and special interest groups thought the only way they could get the much needed funds for their programs was to take funds from other special needs programs. **It is imperative that we do not move funding from programs that serve the elderly into ones that serve those with disabilities. It is time we acknowledge that ALL of our programs need adequate funding.**
- Whether the community is using state dollars or county dollars, **they all come from the taxpayers' pockets.** In order that Texas taxpayers get the greatest benefits from their dollars, matching federal dollars should be used whenever possible.
- The mission of **The Department of Aging and Disability Services** is defined by their name. They are **first and foremost to provide services.** They are not to replace the Legislative Budget Board, the Senate Finance committee or the House Appropriation committee as money managers, but rather to provide support for those Texas citizens who need aging and disability services.

## Appendices

### Miscellaneous Documentation

- Waiting Lists for Community Service and Institutional Programs August 31, 2004 - Texas Dept of Aging and Disability Services <http://www.mkdowney.com/waitcsp.htm>
- THE STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES [http://www.cu.edu/ColemanInstitute/stateofthestates/summary\\_2004.pdf](http://www.cu.edu/ColemanInstitute/stateofthestates/summary_2004.pdf)

### Budgets

- HHSC Legislative Appropriations Request (LAR) FY 2006-2007 [http://www.hhsc.state.tx.us/about\\_hhsc/finance/FY06-07\\_LAR/LAR\\_TOC.html](http://www.hhsc.state.tx.us/about_hhsc/finance/FY06-07_LAR/LAR_TOC.html)
  - D.A.D.S. LAR FY 2006-2007 [http://www.bms.dhs.state.tx.us/2006\\_07\\_lar.html](http://www.bms.dhs.state.tx.us/2006_07_lar.html)
  - State MR Facilities Performance Indicators <http://www.dads.state.tx.us/services/stateschools/PerformanceIndicators.html>
  - National Residential Information Systems Project (RISP) <http://rtc.umn.edu/risp03>
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To learn more about how you can participate in the mission *Steps to Support for All*, please visit: <http://www.mkdowney.com/ef.html>

To print copies of this handout or the most current version, please visit: <http://www.mkdowney.com/ef.html> The link is at the top of the web page "*Steps to Support for All* handout".

Contributions to the association of *Steps to Support for All* or to individual members of *Steps to Support for All* to cover travel expenses, etc. are welcomed, but cannot be deducted as expense for business or charity. *Steps to Support for All* is an association of individuals, does not raise money nor have 501c3 status. **It is important that members have the freedom to speak without fear of retribution related to employment or loss of financial support.**