



*Working Towards a Better Future*

**2006 TEXAS BIENNIAL DISABILITY REPORT**

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TEXAS BIENNIAL  
DISABILITY REPORT**



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DEVELOPMENTAL  
DISABILITIES

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## EXECUTIVE SUMMARY

### BACKGROUND

The *Biennial Disability Report* regarding the state of services to individuals with disabilities was mandated by Senate Bill 374, passed by the 76th Texas Legislature in 1999. This legislation requires the Texas Council for Developmental Disabilities (TCDD) and the Texas Office for Prevention of Developmental Disabilities (TOPDD) to jointly prepare a biennial report to the Legislature on the "state of services to persons with disabilities in Texas," to outline present and future needs for consumer-friendly, appropriate, and individualized services and supports, and to make recommendations related to those services.

This report outlines specific recommendations in the following areas:

- People Receiving and/or Waiting for Community-Based Services
- Fiscal and Programmatic Barriers to Consumer Friendly Services
- Progress Toward Individualized Service Delivery Based on Functional Needs
- Progress in Development of Local Cross-Disability Access Structures
- Projection of Future Long-term Care Service Needs
- Consumer Satisfaction and Consumer Preferences
- Employment of Persons with Developmental Disabilities
- Transportation Related to Employment
- Aging with Developmental Disabilities
- Prevention of Fetal Alcohol Spectrum Disorders
- Prevention of Head and Spinal Cord Injury

## **TCCD RECOMMENDATIONS FOR COMMUNITY-BASED SERVICES AND SUPPORTS FOR PEOPLE WITH DISABILITIES**

### **PEOPLE RECEIVING AND/OR WAITING FOR COMMUNITY-BASED SERVICES**

- 1.** Ensure that individuals receiving and/or waiting for services have real options for home and community-based waiver services from which to choose.
- 2.** Reduce the number of children and young adults under age 22 who are living in large institutional settings and transfer any cost savings to quality community programs.
- 3.** Appropriate funding increases sufficient to eliminate waiting lists for Medicaid waiver programs within 10 years, including anticipated demographic growth in those programs.
- 4.** Reduce the time and number of people waiting for Medicaid waivers and other publicly funded services.
- 5.** Expand contracted relocation services to be available to individuals in ICFs/MR.
- 6.** Establish a statutory provision for "Money Follows the Person" in all programs to allow individuals who desire to move from an institutional setting into the community to take their long-term care dollars with them and be transferred to purchase community waiver services.
- 7.** Increase funding for Permanency Planning for Children Initiatives including efforts that support family decision making and kinship care initiatives, increase the recruitment of foster and adoptive parents, and strengthen supports available for adoption and post adoption.

### **FISCAL AND PROGRAMMATIC BARRIERS TO CONSUMER FRIENDLY SERVICES**

- 8.** Increase funding for all health and human services programs, including Medicaid and CHIP services, and modify eligibility criteria to allow greater access to needed services and supports.
- 9.** Allocate the requisite resources to support community living for people with disabilities.
- 10.** Increase funding for programs providing alternatives to guardianship.

**11.** Mandate that all state regulated health insurance policies provide coverage for mental and behavioral disorders in children and adults, equal to coverage provided for other medical conditions.

**12.** Require DADS to develop a plan to close and/or consolidate three state schools within the next six years and reallocate net savings to support individuals in the community.

**13.** Increase funding for Promoting Independence Initiatives, specifically the expansion of Rider 46 of HB 1 (79th Legislative Session) to ensure that individuals who desire to move from an institutional setting (ICFs/MR) into the community can take their long-term care dollars with them and be transferred to purchase community waiver services.

**14.** Remove barriers for institutional facilities to convert to Home and Community-based Services (HCS).

### **PROGRESS TOWARD INDIVIDUALIZED SERVICE DELIVERY BASED ON FUNCTIONAL NEEDS**

**15.** Review current policies and regulations to remove programmatic and regulatory barriers to self-determination and individual choice.

**16.** Promote self-determination principles in the service delivery system via increased utilization of consumer directed service options.

**17.** Expand Consumer Direction in Medicaid and non-Medicaid waivers to include a broader array of community-based services.

**18.** Design and implement comprehensive and systematic approaches to setting higher payment rates for directly-hired and agency-employed personal care workers to ensure the availability and stability of a high quality, direct care workforce.

**19.** Improve the system of long-term services and supports to provide for individualized service delivery based on functional needs by aligning similar administrative and programmatic aspects across home and community-based services wherever appropriate, while ensuring that the unique needs and choices of individuals are addressed.

**20.** Include Person Directed Planning in all programs.

## **PROGRESS IN DEVELOPMENT OF LOCAL CROSS-DISABILITY ACCESS STRUCTURE**

- 21.** Assure that long-term services and supports delivered through a Medicaid managed care program are delivered based on an independent living model that promotes choice and control.
- 22.** Ensure that individuals have the option for service coordination that is independent from service delivery and is provided by organizations that understand the principles of choice and control and have experience working with people with disabilities and older adults.
- 23.** Build cross-disability resource networks to provide information and assistance that is equally accessible to urban, suburban, and rural families through organizations they trust.
- 24.** Develop cross-disability information and assistance structures with information obtained through the Texas Aging and Disability Resource Center (ADRC) demonstration projects.

## **PROJECTION OF FUTURE LONG-TERM CARE SERVICE NEEDS**

- 25.** Authorize a formal study in Texas to gather data to accurately forecast future service and support needs of individuals aging with developmental disabilities.
- 26.** Require all agencies, with consumer, family member, and stakeholder involvement, to conduct ongoing collection, evaluation and reporting of data related to person-centered outcomes and quality of life for all individuals.
- 27.** Include performance standards in future managed care plans that evaluate clinical care management, long-term care services and supports, and community integration, to ensure that quality services are provided to the clients in the most cost-effective manner and in the most integrated setting appropriate to the needs of the consumer.

## **CONSUMER SATISFACTION AND CONSUMER PREFERENCES**

- 28.** Ensure individuals have access to and knowledge of services and supports to live and age in place in the setting of their informed choice, including assistance in preparing individual emergency plans.
- 29.** Use citizen monitoring as a method of quality control in determining whether individuals are receiving the services and supports they need in the setting of their choice.
- 30.** Ensure participation of people with disabilities and family members on state and local committees that make recommendations regarding policy, the development and implementation of service and support programs, and emergency preparedness planning.

## **TCDD RECOMMENDATIONS FOR IMPROVING THE LIVES OF PERSONS WITH DISABILITIES**

### **EMPLOYMENT FOR PERSONS WITH DISABILITIES**

- 31.** Direct the Texas Workforce Commission and other appropriate agencies to provide small and micro business loans and related business development training for individuals with disabilities who are interested in starting their own business/self-employment.
- 32.** Direct the Texas Workforce Commission and other appropriate agencies to fund Employment Navigators to assist persons with disabilities to find and maintain employment.
- 33.** Develop options for more appropriate employment, including a plan for the closure and/or consolidation of day programs and sheltered workshops that employ persons with disabilities.
- 34.** Increase funding for School-to-Work Transition Services.
- 35.** Develop customized employment programs that promote person-directed goals, individual choice and self-determination.

- 36.** Expand Benefits Counseling programs to ensure that persons with disabilities do not lose needed benefits as a result of employment.
- 37.** Develop programs that promote principles of individual career development and economic engagement.
- 38.** Increase funding for Supported Employment services and clarify availability of Supported Employment services in Medicaid home and community-based waivers.
- 39.** Promote tax incentives for employers who employ individuals with disabilities.
- 40.** Direct the Texas Workforce Commission to provide training and support to employers on employing persons with disabilities.

### **TRANSPORTATION RELATED TO EMPLOYMENT**

- 41.** Increase the availability and accessibility of special transit (para-transit) services in both urban and rural settings in Texas.
- 42.** Provide funding to create a transportation voucher program to allow greater flexibility to persons with disabilities who need to get to work.
- 43.** Engage in demonstration projects to explore innovations in transportation services that support obtaining and maintaining employment.
- 44.** Require HHSC and TxDOT, with consumer, family member, and stakeholder involvement, to collect data regarding the preferences of persons with disabilities who rely on transportation services to seek and maintain employment, as well as the number of persons with disabilities who are unable to work due to transportation barriers.

### **AGING WITH DEVELOPMENTAL DISABILITIES**

- 45.** Increase funding for respite services for aging caregivers of persons with developmental disabilities.
- 46.** Assist caregivers of individuals with developmental disabilities in planning for the future long-term care needs of their loved one.
- 47.** Assist individuals with developmental disabilities in planning for their future long-term care needs.
- 48.** Provide funding to develop cross-disability databases to ensure access to appropriate information and resources.
- 49.** Develop specialized services and supports to allow individuals with developmental disabilities to age in place following the loss of a family caregiver.
- 50.** Require health care providers in Texas to receive education and training on the unique needs of individuals who are aging with developmental disabilities.

## **TOPDD RECOMMENDATIONS FOR THE PREVENTION OF FETAL ALCOHOL SPECTRUM DISORDERS**

1. Increase professional knowledge and skill in assessing and intervening with women and children at risk.
2. Improve surveillance methods for identifying women and children at risk.
3. Improve system capacity to provide state-of-the-art services by incorporating recent scientific findings into current program practices.
4. Increase awareness among the general public about the harm caused by maternal alcohol consumption.

## **TOPDD RECOMMENDATIONS FOR THE PREVENTION OF HEAD AND SPINAL CORD INJURY**

1. Conduct an analysis to estimate the number of unreported bicycle-related injuries to better understand the extent of the problem in Texas.
2. Evaluate educational programs to discover what is effective and produces sustained behavior change.
3. Increase awareness and knowledge among the general public about the importance of helmet use in preventing death and disability.

## **BIENNIAL REPORT BACKGROUND**

The *Biennial Disability Report* regarding the state of services to individuals with disabilities was mandated by Senate Bill 374, passed by the 76th Texas Legislature in 1999. This legislation requires the Texas Council for Developmental Disabilities (TCDD) and the Texas Office for Prevention of Developmental Disabilities (TOPDD) to jointly prepare a biennial report to the Legislature on the "state of services to persons with disabilities in Texas," to outline present and future needs for consumer-friendly, appropriate, and individualized services and supports, and to make recommendations related to those services. Specifically, SB 374 directs TCDD and TOPDD to address the following categories:

- People Receiving and/or Waiting for Community-Based Services
- Fiscal and Programmatic Barriers to Consumer Friendly Services
- Progress Toward Individualized Service Delivery Based on Functional Needs
- Progress in Development of Local Cross-Disability Access Structures
- Projection of Future Long-term Care Service Needs
- Consumer Satisfaction and Consumer Preferences

## **TEXAS COUNCIL FOR DEVELOPMENTAL DISABILITIES**

The Texas Council for Developmental Disabilities (TCDD) is a 27-member board appointed by the Governor. At least 60 percent of the members are individuals with developmental disabilities, parents of young children with developmental disabilities or family members of people with developmental disabilities. As of September 1, 2006, members also represent the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, the Department of State Health Services, the Health and Human Services Commission, and the Texas Education Agency. Advocacy, Inc., the state's protection and

advocacy program; the Texas Center for Disability Studies at The University of Texas; the Center on Disability and Development at Texas A&M University, and other local organizations are also represented on the Council.

TCDD is established as a state agency by state and federal law to support and promote community inclusion and integration of people with developmental disabilities. The Council uses information about the service system, disability-related issues and people's needs to develop projects and activities that focus on gaps and barriers in services and supports that help Texans with disabilities live in, work in and contribute to their communities. These activities, designed to impact the entire state, are developed in close collaboration with consumers, parents, advocates, state agencies, service providers, and policymakers.

The Texas Council for Developmental Disabilities determined to include recommendations in the 2006 Biennial Disability Report on three specific areas that impact the lives of persons with developmental disabilities. The focus areas addressed in this report include:

- Employment of Persons with Developmental Disabilities;
- Transportation, Related to Employment; and
- Aging with Developmental Disabilities.

## **TCDD METHODOLOGY**

To develop its recommendations, TCDD obtained input from individuals, family members, and service providers through public forums held across the state. TCDD solicited general comments and suggestions related to services and supports through statewide surveys and public forums conducted as part of the TCDD five-year state planning process. Five additional forums were held specifically to gather input from self-advocates, family caregivers, and employers on the Council's specific focus areas for the 2006 Biennial Report-employment, transportation related to employment, and aging with developmental disabilities. TCDD Council members and disability advocacy

groups such as the Disability Policy Consortium, the Children's Policy Council, and The Arc of Texas provided information and feedback.

Recommendations were developed through the analysis of information provided by research entities, demographic reports, data from Texas health and human service agencies, and best practice models from other states (where available).

## **TEXAS OFFICE FOR PREVENTION OF DEVELOPMENTAL DISABILITIES**

The Office for Prevention of Developmental Disabilities was created by the Texas Legislature in 1989 to coordinate prevention activity among the state's health and human services enterprise. The governor and legislature directed the agency to address substance abuse, teen pregnancy, and childhood injury. The agency's mission is to help minimize the human and economic losses caused by preventable developmental disabilities.

A nine-member executive committee consisting of experts in medicine, business, academia, and mental health governs the agency and establishes policy directed toward its priorities: preventing fetal alcohol spectrum disorders (FASD) and head and spinal cord injury.

TOPDD authorized and appointed two state task forces to advise the agency on: 1) intervening with women to prevent alcohol-exposed pregnancy, the cause of FASD; and 2) educating parents and young children about using helmets and safety rules while riding bicycles.

## **TOPDD GOALS:**

- Increase public awareness about FASD and head and spinal cord injury.
- Improve workforce capacity to intervene with at risk populations.
- Implement public health strategies that emphasize prevention.
- Lead the Texas health and human services enterprise in transferring science-based knowledge to practice in prevention programs.

The term "developmental disability" is defined by the federal Developmental Disabilities and Assistance Act (the DD Act) as a severe, chronic mental or physical disability that occurs before age 22. (see Appendix B for the complete definition). Developmental Disabilities limit a person's participation in three or more major life activity areas and require assistance or intervention to assist the individual to fully participate in his/her community<sup>1</sup>. A few examples include intellectual disabilities, cerebral palsy, epilepsy, autism, severe learning disabilities, head injuries, and others that impact intellectual and/or physical capabilities. People with developmental disabilities may need assistance throughout life in work, housing, and social settings. This impacts an estimated 411,479<sup>2</sup> Texans who have a developmental disability.

## DISABILITY TRENDS IN THE UNITED STATES AND TEXAS

According to the U.S. Census Bureau, approximately 19.2%<sup>3</sup> of all Texans over age five who are not living in institutions have a disability. Trends further indicate that the rate of disability increases with age:

Age 5-15 years	Age 16-64 years	Age 65 years and older
5.3	18.6	41.9

*\* Number and Percent of Noninstitutionalized Population by Disability Status Totals and by Age Groups for the United States and States in the United States, 2000, Texas State Data Center*

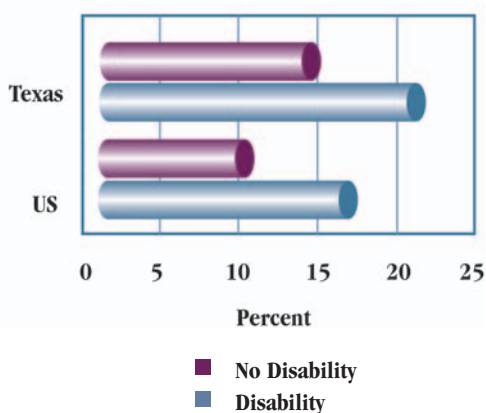
Texas' rate of population growth is expected to outpace the rest of the U.S. over coming decades. Areas near the border, along the Dallas/Fort Worth - San Antonio corridor, and around El Paso should grow by more than 25%; others more slowly. Texas also expects a dramatic change in the ethnic makeup. The Hispanic population will likely grow by 175%; the African American population by 35%; and the White population by only 3%<sup>4</sup> by 2030. Disability rates differ among minority groups, with African Americans (23.4%) and Native Americans (25.4%) having disproportionately higher rates of disabilities. Disability rates are expected to continue to rise among the general population due, in part, to advances in medicine that enable people to survive injuries or illnesses that might have once been fatal.

Overall projections suggest the Texas population will be more diverse, less educated, poorer, and older due to increased longevity, increased population growth in groups that tend to have less education, and the aging of the baby boomer population.

The 2000 Census reports more persons with disabilities live in poverty, compared with those who do not have a disability. In Texas, the rates are higher than the United States.

Texas has the 8th greatest income gap between rich and poor<sup>5</sup>. Over the next decade, the average household income is expected to drop by at least \$1,500. Future challenges include increased service needs coupled with decreased average education and wage earning ability.

**POVERTY RATES IN TEXAS AND UNITED STATES**



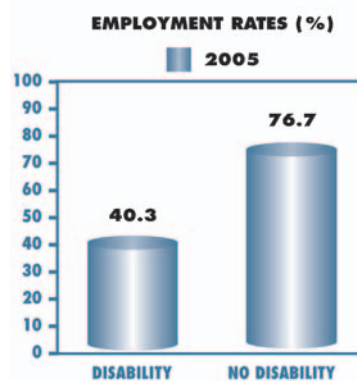
## **RISING DISABILITY RATES AMONG CHILDREN**

In the United States, developmental disabilities affect approximately 1.7% of children under 18 years of age, resulting in a lifetime of accumulated financial and social costs<sup>6</sup>. Poverty is a critical factor in the disability rates of children. Children and youth in families living below the poverty line have significantly higher rates of activity limitation than children in more wealthy families. Texas ranks fourth in the nation in total child population growth. Between 2004 and 2005, more than 50,000 children were born in or moved to Texas.

Since 1970, the disability rate has increased approximately 40% for boys and 33% for girls under age 18<sup>7</sup>. Some of the increased prevalence rates may be due to changes in eligibility in the federal and state programs in which children with disabilities are counted. Increasing numbers of children with disabilities may also be attributed to medical and technological advances that have reduced the number of premature births and have allowed children to survive injuries and live longer than in previous decades. Recent advances have also been made in our ability to detect and diagnose disabilities such as Autism Spectrum Disorders and Fetal Alcohol Syndrome. While it is not clear whether the reported increases represent growth in actual numbers, reduction in stigma in reporting, better identification and outreach, or some combination of the above, it is clear that there are significant increases in the prevalence of children with disabilities.

## **RISING DISABILITY RATES OF THE WORKING AGE POPULATION (18-64)**

Considerable differences in employment exist between people with disabilities and those without disabilities<sup>8</sup>.



Over the last two decades, the relative employment rate of individuals with a disability dramatically declined in most states. Thus, people with disabilities did not benefit from the strong economic expansion of the 1990s, as indicated by higher poverty

rate trends for households of adults with disabilities than those without disabilities. As a result of the decline in employment rate, a higher number of individuals with disabilities have turned to federal and state programs for assistance. Expenditures to support working age people with disabilities and their dependents under programs such as Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Medicare, and Medicaid have risen at twice the rate of other spending<sup>9</sup>.

One notable trend in employment for persons with disabilities is the rise in self-employment. The U.S. Census data found that individuals with disabilities were almost twice as likely to engage in self-employment (14.7%) as those without disabilities (8%). Similarly, researchers with the U.S. Department of Labor (DOL) found that women with disabilities were 1.5 times more likely to engage in self-employment than those without, and men with disabilities were 1.3 times more likely to engage in self-employment. Data from the DOL and U.S. Census Bureau shows the rate of self-employment is approximately 10.2 percent for individuals with disabilities.<sup>10</sup>

## **RISING PERCENTAGES OF PEOPLE WHO ARE OVER AGE 65**

Future population trends include a growing segment of people with developmental disabilities who are aging. The mean age at death for persons with intellectual disabilities or developmental disabilities rose from 19 years during the 1930s to 66 years in 1993, an increase of 247 percent<sup>11</sup>. Today, adults with developmental disabilities can experience similar life expectancies as the general population. While exact figures are not known, there were approximately 641,000 adults age 60 and older in the United States with intellectual disabilities and other developmental disabilities (e.g., cerebral palsy, autism, epilepsy) and the numbers continue to grow.<sup>12</sup> Expectations are that the 60 and over age group will increase three-fold in the next 20 years.<sup>13</sup>

Many people with developmental disabilities continue to rely on their families for care throughout life. The care is often provided by parents who will likely be aging beyond the capacity to provide care over the next 10 to 20 years. An estimated 1.9 million persons with developmental disabilities (60%) live at home or with a family caregiver, and approximately 25 percent of these caregivers are age 60 and older. Coupled with long waiting lists for home and community-based residential services, persons with developmental disabilities face significant challenges in the future when aging caregivers are no longer able to provide care.

## **FEDERAL TRENDS RELATED TO SERVICES**

The federal government has implemented several initiatives in recent years related to increasing flexibility in the provision of services for persons with disabilities. Notable initiatives include the Real Choice Systems Change Grants, the President's New Freedom Initiative, and policy changes outlined in the Deficit Reduction Act.

The Centers for Medicare and Medicaid Services (CMS) has awarded approximately \$188 million in Systems Change Grants for Community Living to 50 states, the District of Columbia, and two U.S. territories. These grants are intended to help states build the infrastructure that will result in effective improvements in community-integrated services and long-term support systems. The program is designed to enable individuals of all ages to live in the most integrated community setting suited to their needs, to have meaningful choices about their living arrangements, and to exercise more control over the services they receive. Since 2003, Texas has received more than \$3.3 million in funding for grant programs related to Community Integrated Personal Assistance Services and Support (C-PASS), Real Choice Systems Change, Community-Based Treatment Alternatives, Quality Assurance/Quality Improvement, and Money Follows the Person.

The New Freedom Initiative, established in 2001, is a comprehensive plan to build upon progress from the Americans with Disabilities Act (ADA) and remove barriers to community living for people with disabilities. The Initiative's goals are to increase access to assistive and universally designed technologies; expand educational opportunities; promote homeownership; integrate Americans with disabilities into the workforce; expand transportation options; and promote full access to community life. The initiative's specific proposals related to health and human services include: promoting full access to community life through swift implementation of the *Olmstead* Supreme Court decision; integrating Americans with disabilities into the workforce through swift implementation of

the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA); and the creation of the New Freedom Commission on Mental Health. This initiative has resulted in increased funding for research and the development of programs, policy and legislative changes, and demonstration programs for innovations in service delivery related to employment, technology, and transportation services<sup>14</sup>.

The fiscal year 2005 budget resolution called for changes to entitlement programs to reduce federal spending by almost \$35 billion over five years. This Deficit Reduction Act (DRA) includes a number of provisions affecting long-term services and supports. Section 6086, *Expanded Access to Home and Community-Based Services for the Elderly and Disabled* will become effective on January 1, 2007. Section 6086 establishes a new option for states to provide home and community-based services (HCBS) without states needing to use a waiver process; allows states to provide any of the services now covered under HCBS waivers; and requires states to establish stricter eligibility (level of care) criteria for institutional services than for community-based services.

While many of these policies are consistent with individuals' preferences to live in the community, significant negative implications may also result from implementation of DRA options. For example, Section 6086 allows states to cap the number of people to be served under the new home and community services Medicaid option. Unlike Medicaid State Plan services, states are allowed under this new policy to provide these services in limited areas of the state and will explicitly allow states to maintain waiting lists for these services. Thus, the state's flexibility with respect to the delivery of services has the potential to hinder efforts to move people out of institutions in compliance with the U.S. Supreme Court's decision in *Olmstead*, which required that waiting lists move at a reasonable

pace. Individuals may have a more difficult time accessing community-based services if states also move to cap the number of beneficiaries and maintain waiting lists for services now covered under the state Medicaid plan such as personal care services and rehabilitation services, by moving them into the new home and community-based services option.

Other long-term services and supports sections of the budget reconciliation conference report establish a Money Follows the Person Demonstration to provide incentives for states to move people from institutions to community settings. They also establish a new option for self-directed personal assistance services. This federal legislation provides Texas with the opportunity to enhance the current system to create a more person-centered, community-based system of services and supports for persons with disabilities; however, Texas must choose to take advantage of such provisions offered through this legislation.

### MEDICAID WAIVER INTEREST LISTS

	CBA	CLASS	DBMD	MDCP	HCS
Current Interest List As of September 30, 2006	45,441	15,438	12	10,045	30,089
Average Number of Years Spent Waiting for Services	1.3	2.6	1.0	1.9	3.4
Percent Waiting for Services More Than 5 Years		10.1%			27.5%

Source: Department of Aging and Disability Services, Sept. 30, 2006

### NUMBER OF CHILDREN RESIDING IN LARGE INSTITUTIONAL SETTINGS<sup>16</sup>

<i>Setting</i>	Number of Children*
Nursing Facilities	174
DFPS Facilities	208
ICFs/MR; State Schools; HCS Waiver Supervised Home Living Programs	1,214
<i>Total</i>	1,596
Number of Children Recommended for Transition to Community Settings	1,400

Source: Health and Human Services Commission.

\*As of July 2006

## PEOPLE RECEIVING AND/OR WAITING FOR COMMUNITY-BASED SERVICES

National trends indicate movement away from large congregate settings and toward individualized, community living for individuals with disabilities. Segregation and institutionalization are no longer the preferred method of "care." Today the vast majority of persons with disabilities and their families are seeking services and supports to help them lead successful lives in the community.

In general, Texas' spending for institutional settings has decreased and spending for community-based services has increased. However, an institutional bias remains. Individuals and families continue to wait many years to obtain community waiver services. Every waiver has long waiting lists, some of which can take more than 10 years for services to become available. When community services and supports are not available, families sometimes have no choice but to seek assistance through institutional services offered as an entitlement even though it is not their preference. Some individuals and families will not consider the option of institutional living for their child. Texas was ranked 51st (including D.C.) in the number of community placements in 2000.

Texas is regarded as a national leader for its Promoting Independence initiative, and other states have used Texas as a model for developing their own Money Follows the Person (MFP) programs. Thus far, however, this opportunity has only been available to individuals residing in nursing facilities and not individuals residing in other long-term care facilities such as state schools or Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). Legislation attempting to expand the MFP initiative was introduced during the 79th Legislative Session, but did not pass.

## TCDD RECOMMENDATIONS:

- 1. Ensure that individuals receiving and/or waiting for services have real options for home and community-based waiver services from which to choose.** National trends indicate movement away from large congregate settings and toward individualized, community living for individuals with disabilities. Today the majority of persons with disabilities and their families seek services and supports to help them lead successful lives in the community. In September of 2006, more than 17,500 Texans residing in long-term care facilities said they wanted to leave to live in the community.
- 2. Reduce the number of children and young adults under age 22 who are living in large institutional settings and transfer any cost savings to quality community programs.** An institution includes an "ICF/MR, a Medicaid waiver group home under the authority of the Department of Aging and Disability Services (DADS), a foster group home or agency foster group home, a nursing facility, an institution for people with intellectual disabilities licensed by Department of Family and Protective Services (DFPS), and a residential arrangement (other than a foster home) that provides care to four or more children who are unrelated to each other"<sup>15</sup>. In Texas, there are almost 1,600 children residing in large institutional settings. A large majority of these children have been recommended for transition to community-based settings.
- 3. Appropriate funding increases sufficient to eliminate waiting lists for Medicaid waiver programs within 10 years, including anticipated demographic growth in those programs.** Funding was provided to reduce the statewide waiting list for community-based services and supports by 10% during the current biennium in addition to increased funding for demographic growth in those Medicaid waiver and other programs. This resulted in approximately 9,360 additional individuals receiving long-term services and supports during the current two years budget period (FY 2006-2007). Yet, many individuals are still waiting for services.

**4. Reduce the time and number of people waiting for Medicaid waivers and other publicly funded services.** There are more than 165,000 individuals in Texas on all community service waiting lists (including non-Medicaid and state funded programs). Some individuals spend an average of six to 10 years waiting for community-based services and supports. On August 4, 2006, a Settlement Agreement was reached in the *McCarthy v. Hawkins* waiting list lawsuit. The agreement includes a provision that the Health and Human Services Commission will include in its Legislative Appropriations Requests for the next three biennial legislative sessions a request for sufficient funding to offset the estimated increase in the number of persons waiting for HCS and CLASS waiver services during the preceding biennium and to achieve a five to 10 percent reduction in the number of persons waiting for HCS and CLASS waiver services each year.

**5. Expand contracted relocation services to be available to individuals in ICFs/MR.** Statewide Relocation Assistance is available to nursing facility residents from the Independent Living Centers (ILCs). DADS has contracted with four ILCs to assist in the transition of individuals from nursing facilities to the community. Resources are needed to provide similar Relocation Assistance to residents in ICF/MR programs.

**6. Establish a statutory provision for "Money Follows the Person" in all programs to allow individuals who desire to move from an institutional setting into the community to take their long-term care dollars with them and be transferred to purchase community waiver services.** Promoting Independence Initiatives provide funding to allow Money Follows the Person for nursing facility residents. Funding for persons in ICFs/MR who wish to live in the community is more limited. Recent legislation (Rider 46, HB 1; 79th Legislative Session) provided funding for a pilot of only 50 children to transfer from ICFs/MR to community services. In addition, DADS requested funding from the 79th legislature to provide HCS waiver services to 240 individuals to be used by residents of large ICFs/MR (those with more than 14 beds) to transition to the community. However, funding for only 96 individuals was appropriated to the department, and the net

number of ICF beds funded across the state remains unchanged since neither of these actions resulted in the decertification of ICF beds. Occupancy rates across the ICF/MR system vary and present a barrier to implementing MFP from ICFs/MR as long as the occupancy rates of large and small ICFs (those with less than 6 beds) are averaged together.

**7. Increase funding for Permanency Planning for Children Initiatives including efforts that support family decision making and kinship care initiatives, increase the recruitment of foster and adoptive parents, and strengthen supports available for adoption and post adoption.** Families seeking initial placement in an institutional living arrangement for a child under age 22 must participate in a process called "permanency planning" which is designed to assist families or legally authorized representatives (LARs) in considering all available resources and alternatives to prevent institutional placement. In the event that sufficient resources are not available and institutional placement is the only alternative, children may be temporarily placed in institutional care. The permanency planning process helps ensure that a child lives outside the family home for the shortest time possible.

## **FISCAL AND PROGRAMMATIC BARRIERS TO CONSUMER FRIENDLY SERVICES**

Spending on services and supports for people with disabilities in Texas still lags far behind that of most states. Texas ranks 45th nationally in per person spending for Public Health, 47th for Mental Health, and 46th for Public Welfare and Medicaid. A higher percentage of people in Texas than in any other state do not have private health insurance. In addition, Texas is 44th nationally in the percentage of people living in poverty who are covered by Medicaid. Changes to eligibility requirements for the Children's Health Insurance Program (CHIP) further decreased the number of children who are insured. In 2003, the 78th Legislature dramatically cut services and supports for people with disabilities to balance the budget. In 2005, the 79th Legislature restored some of the cuts and provided some funding to help reduce the waiting lists for community-based services.

## TCDD RECOMMENDATIONS:

**8. Increase funding for all health and human services programs, including Medicaid and CHIP services, and modify eligibility criteria to allow greater access to needed services and supports.** Texas has the highest rate of uninsured children in the nation, a problem exacerbated by recent declines in Medicaid and CHIP enrollment. More than half of the over 1.3 million uninsured Texas children qualify for Medicaid or CHIP coverage under current program rules. Funding limitations, increased restrictions on eligibility, and reductions in covered services continue to eliminate many from access to needed services and supports.

**9. Allocate the requisite resources to support community living for people with disabilities.** Institutional bias is rooted in regulatory provisions that define the Medicaid eligibility and benefits. States are required to provide nursing facility benefits to any individual who meets financial eligibility criteria and requires a nursing facility level of care. In contrast, Medicaid-funded community-based care, such as personal care and rehabilitation services, are provided at a state's option. A state that wants to provide more comprehensive community-based care for individuals who meet a nursing facility level of care must obtain a waiver of federal Medicaid program rules. However, waiver services also are optional, and states have authority to limit the number of people served in a waiver and to limit the array or amount of services or impose service caps that limit the quantity of services and supports provided. Texas should allocate the needed financial resources to provide services and supports for individuals who wish to reside in the community.

**10. Increase funding for programs providing alternatives to guardianship.** Guardianship is the legal removal of a person's basic civil and legal rights and is fraught with the potential for abuse and misuse. All people, no matter how severe their disability, have choices and preferences which may be expressed in non-traditional ways. Agencies and courts may develop

policies and innovative programs that provide needed assistance and support to individuals in the decision-making process without the imposition of a legal guardianship process which deprives individuals of their right to self-determination. Alternatives may include multi-party contracts, representative payees, powers of attorney, advance directives or surrogate decision-makers (under the Health and Safety Code).

**11. Mandate that all state regulated health insurance policies provide coverage for mental and behavioral disorders in children and adults, equal to coverage provided for other medical conditions.** Texans with mental disorders do not have equal access to health insurance. Many health plans discriminate by limiting mental health and substance abuse services. Texas has enacted laws that require insurance parity only for a small set of specified diagnoses (schizophrenia, bipolar disorder, and/or major depression). These laws discriminate against children and adults whose illnesses can be as disabling as those specified in the laws, but do not fit neatly within the statutes' current criteria.

**12. Require DADS to develop a plan to close and/or consolidate three state schools within the next six years and reallocate net savings to support individuals in the community.** A study of the feasibility of closing of a state school, commissioned by the 78th Legislature (2003) for the 2004-2005 biennium (Rider 55), found that it was "feasible" to close a state school or state hospital. The study revealed low barriers to closure and sufficient numbers of beds available for clients in other state facilities.

### PROGRAM COST COMPARISONS, State Fiscal Year 2005

Program	Number of Consumers	Average Annual Cost Per Person
State School	4,879	\$111,506
ICF/MR	6,771	\$50,895
HCS	9,286	\$42,453
TxHmL	1,871	\$8,807

Source: Rider 44 Cost Comparison Report  
Department of Aging and Disability Services, December 2006

**13. Increase funding for Promoting Independence Initiatives, specifically the expansion of Rider 46 of HB 1 (79th Legislative Session) to ensure that individuals who desire to move from an institutional setting (ICFs/MR) into the community can take their long-term care dollars with them and be transferred to purchase community waiver services.** In response to the directives of the Supreme Court ruling on the *Olmstead* decision, the Health and Human Services Commission (HHSC) implemented the Promoting Independence Initiative to help the state move toward more accessible community-based services for people with disabilities. The Promoting Independence Initiative allows "money to follow the person" for persons in nursing facilities to receive services in the community (HB 1867). Funding for persons in ICFs/MR who wish to live in the community is more limited. Recent legislation provided funding for a pilot for only 50 children to transfer from an ICF/MR to community services.

**14. Remove barriers for institutional facilities to convert to Home and Community-based Services (HCS).** Some large residential facility-based providers have expressed an interest in moving to a community-based model and see business potential in responding to consumer preferences. However, many providers are hesitant to move forward due to the financial risks during the downsizing and transition. As a result, individuals remain in large facilities. Provider training and other program incentives to remove the barriers to these business transitions are needed.

## **PROGRESS TOWARD INDIVIDUALIZED SERVICE DELIVERY BASED ON FUNCTIONAL NEEDS**

Individual choice is a central element in recent federal policy initiatives (e.g. the President's New Freedom Initiative, Deficit Reduction Act). Texas supports the national trend of empowering individuals to play an increasing role in their selection of providers and types of services they receive. Texas' waiver services, which support community services and opportunities, are critical to the extent they are available. Access and availability is limited throughout the state,

and when they are available, there are long waiting lists or the services offered are not appropriately integrated into the community setting of their choice. The capacity of the service delivery system to provide community-based supports according to the preferences and desires of individuals must be addressed.

## **TCDD RECOMMENDATIONS:**

**15. Review current policies and regulations to remove programmatic and regulatory barriers to self-determination and individual choice.** In other states, as regulatory barriers (e.g., individual authority to allocate funds) to individual choice are removed and information to individuals about service options increases, those individuals play a much more active role in determining the services and supports that they receive. This can create a more efficient system by forcing providers to improve their service delivery or risk having individuals choose a competitor. Ultimately, more consumer choice will compel providers to deliver services and supports that produce more self-directed outcomes.

**16. Promote self-determination principles in the service delivery system via increased utilization of consumer directed service options.** The Consumer Directed Services (CDS) service delivery option, implemented in July 2002 in multiple Medicaid home and community-based waiver programs, allows consumers (or guardians/designated representatives) to be legal "employers of record" for their service providers. Under CDS, consumers have greater control and responsibility for their own care. The utilization rate of CDS varies widely across programs, with a high of 35.2% in Community Living Assistance and Support Services (CLASS) to a low of less than 1% in Primary Home Care (PHC) and Community Based Alternatives (CBA).

**17. Expand Consumer Direction in Medicaid and non-Medicaid waivers to include a broader array of community-based services.** Until recently, personal assistance services and respite care were the only services available under CDS. The CDS option has recently been added to the HCS and Texas Home Living (TxHmL) waiver programs. Individuals can use the CDS service

delivery option for all services in the TxHmL program. Similar efforts are needed to allow consumer direction of other services, such as physical, occupational and speech therapies and specialized therapies under the CDS option in all Medicaid and non-Medicaid community long-term care services.

**18. Design and implement comprehensive and systematic approaches to setting higher payment rates for directly-hired and agency-employed personal care workers to ensure the availability and stability of a high quality, direct care workforce.** Wages can play a critical role in determining workforce adequacy and care quality. Personal care and home care workers earn wages that place them in the category of low-wage work. These workers typically lack access to affordable benefits; receive minimal training; do not have paid holidays, sick leave or vacation time; and are often employed on unstable, part-time schedules. These factors can result in shortages of direct-care workers, high turnover rates, lack of qualified staff, and difficulty retaining workers.

**19. Improve the system of long-term services and supports to provide for individualized service delivery based on functional needs by aligning similar administrative and programmatic aspects across home and community-based services wherever appropriate, while ensuring that the unique needs and choices of individuals are addressed.** Texas currently has eight Medicaid home and community-based waivers (including STAR+PLUS, which operates under a 1915(b) and (c) waiver) providing long-term care services and supports to individuals with disabilities. The majority of these waivers were developed over time to address needs of specific populations. As a result, while the waivers are similar in services they provide, they are vastly different in administration, reimbursement rates, caps, and service coordination, etc. The outcome is a fragmented system that results in services provided based on diagnosis rather than functional needs. Thus, individuals often have difficulty in obtaining the appropriate services they need.

**20. Include Person Directed Planning in all programs.** Person directed planning is a process of communication and planning

with individuals and families to help identify options and develop services and supports based on the goals of the individual. Person directed planning is currently promoted in some waiver programs (e.g., HCS), but should be expanded to increase individual choice across all service programs.

## **PROGRESS IN DEVELOPMENT OF LOCAL CROSS-DISABILITY ACCESS STRUCTURE**

The 78th Texas Legislature (2003) passed HB 2292 requiring HHSC to streamline the process through which health and human service agencies conduct business and maximize efficiency and effectiveness. Twelve health and human services agencies were consolidated into one umbrella agency and four departments; the executive commissioner of HHSC became responsible for all policy development and rulemaking authority for health and human service programs; and HHSC investigated whether using call centers to conduct eligibility determinations would be more cost effective. HB 2292 was intended to create cost savings by centralizing administrative functions and to decrease the fragmentation of services across agencies. This consolidation also offers the opportunity to better streamline services and supports across programs and to create systems that cross disability, functional status, and age.

## **TCDD RECOMMENDATIONS:**

**21. Assure that long-term services and supports delivered through a Medicaid managed care program are delivered based on an independent living model that promotes choice and control.** The 79th Legislature (2005) passed HB 1771 to coordinate acute and long-term services and supports within Medicaid using a managed care approach. Contracts between HHSC and Administrative Services Organization (ASO) providers to deliver long-term care services through Medicaid managed care is currently under development. This system should be designed to allow individuals from all disability groups to have choice and control in accessing long-term care services and supports.

**22. Ensure that individuals have the option for service coordination that is independent from service delivery and is provided by organizations that understand the principles of choice and control and have experience working with people with disabilities and older adults.** Coordination of benefits and information at the time of intake is a critical step in ensuring that individuals have a complete array of services from which to choose. Ideally, this includes the full array of state, local, community, not-for-profit, for profit, faith-based organizations, and others. It is the responsibility of the service coordinator to: 1) advocate on behalf of the individual; 2) help the individual become empowered to act on his or her own behalf; and 3) support the right of that individual to make decisions and to take risks based on informed choice and individual goals and values. Service coordinators must be knowledgeable about resources available and understand the process for referral to services within both the aging and disability networks in order to best meet the needs of the individual.

**23. Build cross-disability resource networks to provide information and assistance that is equally accessible to urban, suburban, and rural families through organizations they trust.** A growing number of service providers must assist individuals across disability programs (e.g., developmental disabilities, aging, mental health). To improve individual entry into the service delivery system, resources must be dedicated to better coordinate information on services in a consistent, integrated manner across networks in all geographic areas. Building such networks may include increasing provider awareness across disability programs (cross-training) and knowledge of the point at which an individual should be referred to another entity (cross-referral). The development of shared resource databases across disability networks is a best practice model for building cross-disability networks as demonstrated in other states through the Aging and Disability Resource Center (ADRC) projects.

**24. Develop cross-disability information and assistance structures with information obtained through the Texas Aging and Disability Resource Center (ADRC) demonstration projects.**

In August 2005, the Department of Aging and Disability Services (DADS) was awarded a three-year grant to create a unified source of information and assistance for families about long-term care services in their communities. This demonstration grant was awarded jointly by the Centers for Medicare and Medicaid Services (CMS) and federal Administration on Aging to help overcome barriers to community living for people who are elderly or have disabilities. Other states have been successful in demonstrating and evaluating innovative information and assistance models. DADS announced on October 2, 2006, that it is approving contracting with Tarrant County and Central Texas Council of Governments for local ADRC demonstration projects, in addition to the initial pilot site in Bexar County. Together, these three project sites will pilot various different integrated information and access strategies across aging and disability services. Future cross-disability networks in Texas should build on what is learned from these demonstrations.

## **PROJECTION OF FUTURE LONG-TERM CARE SERVICE NEEDS**

Overall projections suggest the disability population will become older, more diverse in race/ethnicity and income, and less educated. The number of individuals with disabilities is growing, while the first of the baby boomers are turning 60, and the numbers of persons who are aging with developmental disabilities are increasing substantially. Further declines in employment status among persons with disabilities will result in reduced income and a greater reliance on federal and state programs for needed support. The most pressing need in accurately projecting long-term care needs is the collection, evaluation, and reporting of meaningful data to track critical population trends and appropriately plan in order to make informed decisions about our future.

## **TCDD RECOMMENDATIONS:**

**25. Authorize a formal study in Texas to gather data to accurately forecast future service and support needs of individuals aging with developmental disabilities.** Expectations

are that the population of persons with developmental disabilities age 60 and older will increase three-fold in the next 20 years. An estimated 60% of persons with developmental disabilities live with family caregivers, and 25% of these caregivers age are 60 and older. Many caregivers will age beyond their capacity to provide care in the next 10 to 20 years. These demographic forces are stretching state service-delivery systems well beyond their capacities to meet current and projected demands for residential, vocational, and family support services for individuals with developmental disabilities. The specific impact of these demographic shifts in Texas should be adequately evaluated.

**26. Require all agencies with consumer, family member, and stakeholder involvement to conduct ongoing collection, evaluation and reporting of data related to person-centered outcomes and quality of life for all individuals.** Adequate planning for the future long-term care needs of individuals with disabilities cannot be conducted without specific information on person-centered outcomes and quality of life, such as the extent to which the services and supports provided are individual focused, ensure quality of care, and assist the individual in meeting his/her personal goals. The service delivery system should incorporate outcome measures that capture the extent to which the services and supports result in meaningful outcomes for the person served. This data is needed to plan for future long-term care services based on consumer preferences.

**27. Include performance standards in future managed care plans that evaluate clinical care management, long-term care services and supports, and community integration, to ensure that quality services are provided to the clients in the most cost-effective manner and in the most integrated setting appropriate to the needs of the consumer.** Federal and state changes to the Medicaid program include greater emphasis on a managed care approach. As new Medicaid managed care plans are implemented in Texas (e.g., Integrated Care Management, STAR+PLUS expansion), contracted entities (ASOs) should be required to develop performance standards to ensure that all individuals receive quality care in the setting of their choice.

## **CONSUMER SATISFACTION AND CONSUMER PREFERENCES**

Quality of life, as perceived by the consumer, is an essential part of the quality of long-term care. Quality of life includes outcomes such as choice and autonomy, dignity, individuality, comfort, meaningful activity, meaningful relationships, and a sense of security. Long-term-care providers cannot be responsible in total for quality of life outcomes which are also a function of health and disability status, family relationships, and personality; however, the delivery of services and settings does play a significant role. The current regulatory system was not designed with quality of life factors as outcomes. Researchers have had success in developing consumer self-report measures of quality of life, including persons with considerable cognitive impairment<sup>17</sup>.

Consumer-centered care can be seen on a continuum of various levels. Consumer-centered care allows the consumer (or his or her representative) to be involved to the extent desired and practical in all goal-setting and planning for care, and to have input into the evaluation of care. True consumer-driven care recognizes that the consumer's view of quality may sometimes involve conditions and circumstances that professionals view as a threat to health or safety. However, when promoting quality of life as the goal of long-term care, the system must allow consumers to assume some risks in order to maximize the benefits they view as important.

## **TCDD RECOMMENDATIONS:**

**28. Ensure individuals have access to and knowledge of services and supports to live and age in place in the setting of their informed choice, including assistance in preparing individual emergency plans.** Individuals repeatedly cite their preference to remain in their homes -- not having to move from their chosen residence in order to secure necessary support services in response to changing needs. As needs change or in the event of an emergency, individuals with disabilities and their families should continue to receive information on the full array of support services (e.g., state, local, public, private) in order to remain in the setting of their choice.

**29. Use citizen monitoring as a method of quality control in determining whether individuals are receiving the services and supports they need in the setting of their choice.** The use of citizen monitors who are independent of the service delivery system (functioning similar to an ombudsman) is one approach to improve the quality of care received. The Regulatory Services workgroup of the DADS Service Delivery Redesign process recommended that individual monitors serve as a quality assurance mechanism. Pennsylvania has used citizen monitoring as a key component of its system for more than five years.

**30. Ensure participation of people with disabilities and family members on state and local committees that make recommendations regarding policy, the development and implementation of service and support programs, and emergency preparedness planning.** Individuals receiving services must be more involved in the decision making process regarding the services and supports they receive. Appropriate funding must be provided within service programs (e.g., long-term care, employment, transportation, etc.) to allow individuals with disabilities to attend task force and committee meetings and participate in the planning process. The need has been identified most recently in state and local emergency planning efforts in which the perspectives of persons with disabilities were glaringly omitted. Even Texas state agencies that have relationships with people with disabilities have not always formally engaged them in planning to meet the agency's disaster responsibilities. Various recommendations have been made in recent months to address this issue. Additional resources may include the U.S. Department of Justice's ADA Emergency Preparedness Guide for Local Governments.

## Tala Shoghi, 21

Tala has been working as a clerk at Target for a little over a year. A high-school student, Tala is part of the To-Go Project, which is a transition program for students who have completed their special education program and are in the process of transitioning to adult life in the community. Through her transition program, she learned the job skills necessary to interview and apply for the job and maintain good work performance. Currently her parents provide her transportation to and from work, but she plans on learning to use the city bus once she moves into her own apartment. A major goal for Tala is to live independently, in her own place and make enough money to pay the bills. A good job is definitely a key part of accomplishing her future goals of living on her own, and eventually starting her own family.

One of the major issues Tala has at her current job is the attitude of some of her co-workers. Because she has a developmental disability, some of her co-workers assume that she can't do her job. Often, they watch her while she's performing her job tasks to make sure she's doing it right.

*“Right now, both my parents take me to work and pick me up. When I live on my own, I’m going to take the city bus, so I’m going to learn how to do that now. It’s important for me to learn how to use the bus on my own so then I’ll know how to use my own transportation. It’s important to find a job close to where I live because it would be easier to walk or take the bus. I want to get a good job so that I have enough money to pay my own electricity and live on my own. As I’m getting older, I have to move on with my life and graduate from my Goodwill program. I have so many plans for my future. First, I’ll graduate from Goodwill, and then move into an apartment of my own and eventually have my own home and family. Next I want to get married and have kids. My parents worry about me moving on because I’m the baby of the family, but I tell them not to worry about me because I’ll have people to take care of me like my job coach, friends, and my support network.”*

*“I hate my co-workers looking over my shoulder to watch to see if I’m doing something right. It makes me feel irritated. I think that they want to make me happy, but I just hate it. I know they know I can do my job on my own, and they know I have other jobs I like to do.”*



## Nora Zamaripa, 43

Nora receives social security benefits and when she decided to go to work, she needed to make sure she didn't earn so much money that she would lose her benefits. Understanding the complicated rules of the Social Security Administration was difficult for Nora, and she also had trouble understanding the letters that SSA would mail to her about her and her children's benefits. To help navigate the SSA programs and rules, she contacted a Benefits Planning Assistance and Outreach (BPAO) specialist who has been providing ongoing assistance.

*"I've been working with people to help me make sure I don't work too many hours and lose my benefits. There's a lot of paperwork, and Valerie has helped me when problems came up, like if they want to cut back my check. She's helped me from getting too much of the money taken away. Sometimes they do things with my check that I don't understand, so Valerie calls to find out what's going on and then explains it to me."*



## EMPLOYMENT FOR PERSONS WITH DISABILITIES

Employment is the economic engine of our nation, our communities and our families. For people with disabilities, employment and personal income promotes greater independence and productive, fulfilling lives. National studies continue to indicate that people with disabilities have higher levels of unemployment than people without disabilities.

According to a National Organization of Disabilities/Harris 2000 Survey of Americans with Disabilities, people with disabilities aged 18-64 are much less likely to be employed (either full-time or part-time) than people without disabilities<sup>18</sup>. Even when people with disabilities who reported that they were not able to work for health reasons were taken out of the equation, there was still a significant gap in employment between people with disabilities and people without disabilities (57% versus 81%)<sup>19</sup>. Despite progress made as the result of the ADA, the unemployment rate of people with severe disabilities remains high. Title I of the Americans with Disabilities Act of 1990 (ADA) prohibits private and state and local government entities that employ 15 or more employees from discriminating against qualified individuals with disabilities with respect to recruitment, the application process, hiring, advancement, and other terms, conditions, and privileges of employment. Employers covered by Title I of the ADA must also make reasonable accommodations so that qualified individuals with disabilities may participate in the application process, perform the essential duties of a job, and enjoy the benefits and privileges of employment available to all employees.

Texas employers in a TCDD focus group expressed concern about providing accommodations to workers with disabilities, yet many reported making numerous accommodations--often without even realizing it. Several employers described job modifications, site alterations and other accommodations that allowed workers to stay on the job or join the company that were done naturally, stemming from a business need.<sup>20</sup> A similar survey of employers indicated that the average cost of accommodations was \$500 or less, and that approximately 73% of employees with disabilities did not require accommodations<sup>21</sup>.

Traditionally, the goal of employment programs for persons with disabilities has been job and position focused, not career focused. Recent trends in employment for persons with disabilities indicate a shift away from traditional employment "services" for persons with disabilities to focus more on developing the relationship between the employer and the employee. The principles of economic engagement require the creation and maintenance of an interactive relationship with the employee and the employer, allowing the employer to recognize the unique skills and contributions of the employee, and providing an opportunity for the employee to be recognized and rewarded in the form of raises, promotions, and career advancement.

Self-employment or small business ownership is one method of career development that serves to reduce unemployment for people with disabilities. According to the U.S. Department of Commerce, people with disabilities are almost twice as likely to start a business as people without disabilities. Commerce Department data indicates that 14% of people with disabilities who are employed are self-employed compared to eight percent of people without disabilities. However, starting a small business can be difficult for people who do not have the capital or the borrowing power to start their own business. Microenterprises are a relatively new form of self-employment that has been gaining popularity with individuals with disabilities and others because of its relative organizational simplicity and low start-up cost.

### TCDD RECOMMENDATIONS:

**31. Direct the Texas Workforce Commission and other appropriate agencies to provide small and micro business loans and related business development training for individuals with disabilities who are interested in starting their own business/self-employment.** According to the U.S. Department of Commerce, people with disabilities are almost twice as likely to start a business as people without disabilities. Microenterprise development organizations exist to offer business training, technical assistance and financing options for these small and

previously underserved ventures. One demonstration is the Brooklyn Economic Development Corporation, a New York-based microenterprise organization that markets their LAUNCH Program to individuals with mental health disabilities and offers basic business development classes as a means to accessing small loans for business start-up. In Colorado, the MicroBusiness Development Corporation targets promising entrepreneurs with disabilities, along with other low income populations, and offers an accessible computer lab, access to capital and asset building through their Individual Development Account program. In Oregon, Lane MicroBusiness has been successful leveraging equity grants from The Abilities Fund for their entrepreneurs with disabilities after feasibility assessment and business planning take place.

**32. Direct the Texas Workforce Commission and other appropriate agencies to fund Employment Navigators to assist persons with disabilities to find and maintain employment.**

System-wide Employment Navigators serve to provide customized employment services to persons with disabilities in order to reduce common barriers to finding and maintaining work. Services provided by Employment Navigators include but are not limited to locating employment opportunities, resume building, developing interviewing skills, job training, and job coaching.

**33. Develop options for more appropriate employment, including a plan for the closure and/or consolidation of day programs and sheltered workshops that employ persons with disabilities.** Significant numbers of people with developmental disabilities continue to work in sheltered workshops and day activity programs, especially people with moderate and severe intellectual disabilities. As greater numbers of individuals with disabilities are attending school and receiving appropriate education and training, they are obtaining greater opportunities in the general workforce, thus reducing the need for programs of this type. In efforts to promote more options for appropriate and integrated employment opportunities for persons with disabilities, some states (e.g., Washington) have implemented statutes requiring that a person who hasn't previously been in a sheltered workshop request an exception to

state policy to enter such programs. Cognizant state agencies should jointly develop plans to facilitate the transition of individuals from segregated day programs and sheltered workshops to integrated competitive employment with necessary supports and the closure or consolidation of those segregated programs as individuals move.

**34. Increase funding for School-to-Work Transition Services.**

Recent federal and state efforts to increase school-to-work transition have demonstrated effectiveness in increasing employment following graduation. DARS has recently added 100 Transition Specialists to coordinate with local schools concerning transitioning to adult employment services and supports. Additional funding is needed to adequately prepare students with disabilities for employment. Programs that allow students to obtain work experience prior to graduation serve to increase marketability when looking for work.

**35. Develop customized employment programs that promote person-directed goals, individual choice and self-determination.**

Individuals with disabilities report that employment makes them feel proud and happy while providing them with financial resources to maintain independent living. Individuals with disabilities cite frustration in the types of job opportunities that are made available to them. Employment programs should allow for greater self-direction and strive to more effectively match the array of jobs in the workforce with the unique employment preferences of each individual. Experimentation involving individual budgets, self-directed services, and asset development has taken place on only a limited scale.

**36. Expand Benefits Counseling programs to ensure that persons with disabilities do not lose needed benefits as a result of employment.** People with disabilities who are eligible for and depend on either SSI or SSDI with related medical coverage are cautious about pursuing any employment situation that would lead to earning a wage that would make them ineligible for services. Benefits counseling can provide potential employees with needed information to understand the complexities of work

incentive programs, Medicaid Buy-In, and how to obtain employment while maintaining needed services and supports. Benefits counseling services are available to SSA beneficiaries through the Benefits Planning, Assistance and Outreach (BPAO) authorized by the Ticket to Work and Work Incentives Improvement Act of 1999 and the Social Security Administration (SSA), and are also offered through independent living centers. These planning and assistance services should be expanded to ensure that all persons with disabilities have access to information about benefits so they can make informed decisions about employment.

**37. Develop programs that promote principles of individual career development and economic engagement.**

The development of training programs for low-demand occupations will not advance the employment of persons with disabilities. Like other professionals, individuals with disabilities have personal career goals (e.g., owning lawn equipment company, driving delivery trucks<sup>22</sup>) yet are unable to gain entry into these chosen employment fields. Career development and economic engagement require a strong and interactive relationship between the employer and the employee so that employee skills are recognized and rewarded (e.g., promotions, earnings, benefits), and employers can use workforce skills to advance business goals.

**38. Increase funding for Supported Employment services and clarify availability of Supported Employment services in Medicaid home and community-based waivers.**

Many individuals with significant disabilities are successfully working in gainful employment with various assistance and support such as supported employment. Supported employment usually includes a job coach to help the individual learn the necessary skills on the jobsite to work independently or with co-worker supports. The Department of Assistive and Rehabilitative Services is responsible to provide employment and supported employment services for adults with disabilities. However, revisions in Medicaid home and community-based waivers services and billing methods could also provide opportunities for individuals to receive supported employment services in other instances.

## Tenisha Dewberry, 22

Tenisha has been participating in a school-to-work transition project that helped her get her current job as a silverware roller at the Kerby Lane restaurant in Austin. She is very career oriented and would like to one day become a Braille teacher.

*“Thinking about careers makes me think about moving on with my life, like going to Grad school and growing up. Some of my co-workers think it’s pretty amazing that I’m working. I think it’s amazing myself, but everybody - all of my family and myself - have always thought that I’d be working. But I would like to make more money. I am getting ready to go to ACC to study to be a Braille teacher, so I can teach people how to read Braille and work with people who are blind like me. I’ve been everywhere else except for college. I’ve seen people teach once before, and it interested me.”*



## Robbie Hearne

Robbie has wanted a job ever since he graduated high school (years ago). For the last several years, Robbie has been working with his mom and his job coach to find a job that was just right for him. Earlier this year, Robbie was eating lunch with his mom and his job coach at the KFC near his group home and noticed a "now-hiring sign." He pointed it out to his mom and job coach and went to the counter for an application. With assistance from his mom and job coach, he filled out the application, got an interview and was offered a job at the restaurant. He was really excited about getting the job because it paid \$8.50 an hour, which was much more than many of the other jobs Robbie has tried. One major reason Robbie decided to apply at this KFC is that he could walk to the restaurant from his house. He didn't want to deal with the hassle of finding rides to get to work and he can walk because it is so close.

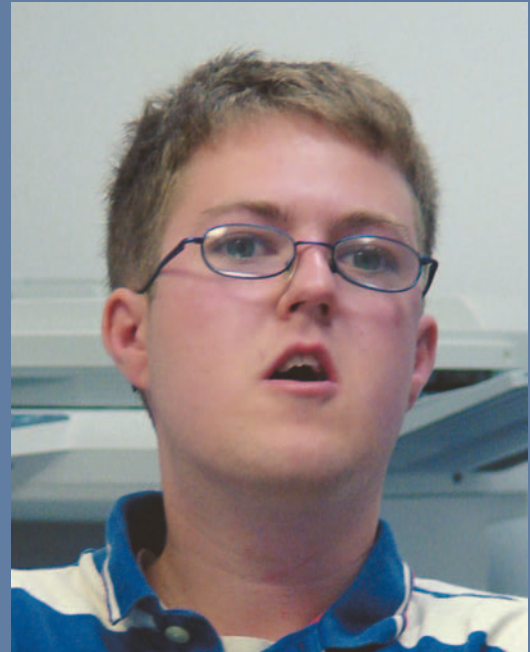
*“When I first started, my job coach went with me. He was there while I learned the job, for like six or so hours. Then my training was done, and he doesn't come to my job anymore. If I need any assistance, I will probably ask the assistant manager if I don't know what to do or how to do something or can't get help from anybody else.”*



## Gregory Smith, 22

**39. Promote tax incentives for employers who employ individuals with disabilities.** Tax incentives are currently available under the ADA to assist employers in making necessary accommodations for persons with disabilities<sup>23</sup>. Two tax incentives are available to businesses to help cover the cost of making access improvements. The first is a tax credit that can be used for architectural adaptations, equipment acquisitions, and services such as sign language interpreters. The second is a tax deduction that can be used for architectural or transportation adaptations.

**40. Direct the Texas Workforce Commission to provide training and support to employers on employing persons with disabilities.** Employers have expressed concerns over having to accommodate workers with disabilities, yet further exploration reveals that many employers have made numerous accommodations (e.g., job scope, site alterations, etc.) that have allowed workers to stay on the job or accomplish needed business goals. Thus, there seems to be a disconnect between employer expectations and general practices. Employers also cite lack of awareness of resources to assist them 1) in hiring employees with disabilities; or 2) in finding agencies that support employees with disabilities. Ongoing training for employers is needed.



*“The people at work just let me do my job (in a bookstore), and they know that I’m not really fast. They’re really flexible with schedules because if there’s a problem, my manager’s always good at accommodating that. I would like to work the cash registers, but it will take a lot of work and I’ll have to do it at a fast pace, which is hard work for me. But I don’t think I’ll be working the cash registers, but I do answer the phones from time to time. I would need supervision and a slower pace to do the cash register. A customer turned in a comment card to my manager thanking me for my good work and thanking me for being on board.”*

## TRANSPORTATION RELATED TO EMPLOYMENT

Transportation is a key component to ensuring an individual's access to employment training and jobs. Without a reliable means of traveling to and from work and other work-related destinations (e.g., childcare, benefits offices, training), individuals find employment and self-sufficiency unattainable. The Community Transportation Association of America (CTAA) reports that more than 100 million low-income individuals, older Americans and people with disabilities are at risk of being unable to provide or afford their own transportation and are more likely to be dependent upon others for their mobility. CTAA also notes that almost 40 percent of rural counties throughout the U.S. have no public transportation<sup>24</sup>.

The Americans with Disabilities Act of 1990 (ADA) requires that, where public transportation is provided, it must be made physically accessible for people with disabilities. Yet, in many rural and suburban areas, it is likely that no transportation exists at all for people with disabilities. As a result, people with disabilities are still at a significant disadvantage compared with the general public. Approximately 30% of Americans with disabilities have a problem with inadequate transportation, compared to only 10% of those without disabilities<sup>25</sup>. While physical access to public transportation has improved significantly since implementation of the ADA transportation provisions, the ADA did not create the comprehensive system and additional services and programs that people with disabilities need.

Almost one-third of individuals with a disability who report difficulty in looking for work cite lack of transportation as the reason. Barriers to transportation supports and services for people with disabilities generally fall into two major categories: 1) a lack of available transportation options due to shortages of public transportation in rural and suburban areas; and 2) a lack of access to existing transportation services due to physical inaccessibility, limited or no travel training for individuals with cognitive disabilities, or poor coordination among transportation providers in providing timely and convenient services.

## TCDD RECOMMENDATIONS:

### **41. Increase the availability and accessibility of special transit (para-transit) services in both urban and rural settings in Texas.**

Para-transit services are provided to individuals who need assistance in accessing regular public transportation systems. Approximately 12% of non-workers report a need for assistance with public transportation. However, para-transit systems are often more limited in the number of routes, hours of operation, and allowable trips, making this service less conducive to supporting employment, especially for those living in rural settings. Only 5% of non-workers with disabilities use special transit systems. Funding is needed to increase the availability and accessibility of para-transit services to be consistent with the work schedules of persons with disabilities in both urban and rural settings.

### **42. Provide funding to create a transportation voucher program to allow greater flexibility to persons with disabilities who need to get to work.**

The most frequently cited reason for the low use of public transportation services is that the services currently offered are limited in their ability to meet the unique mobility needs of each individual. Funding in the form of a transportation voucher (e.g., payment to family members, friends, taxi services, etc.) would allow greater flexibility for the individual to pay for transportation services that are most desirable and accessible, based on personal preferences and unique employment needs.

### **43. Engage in demonstration projects to explore innovations in transportation services that support obtaining and maintaining employment.**

Transportation services designed to assist the individual with a disability in getting to and from a work location on a regular basis are often cited as a primary barrier in maintaining employment. Similarly, one-third of persons who report difficulty looking for work (e.g., interviews, meeting with potential employers) report lack of transportation as the problem. Demonstration projects are needed to develop transportation alternatives to better meet the needs and preferences of persons with disabilities who are working as well as those who are looking for work.

## Angela Park, 18

Angela has been participating in a transition program through a local Goodwill and her school district. Right now, she's learning job skills at a Goodwill retail store, and she wants to find a paying job soon. Although she enjoys what she spends her time doing at Goodwill and meeting new people, her most important goal right now is to start earning money from a job. Even if that means finding a different job, Angela is ready to try.

A major obstacle Angela has faced while trying to find a paying job is the limited public transportation options in her area. Even though she lives in a major metropolitan area, her house is outside the city limits so she doesn't have access to city bus lines or the para-transit service. There is a much more limited rural transit service that comes out to her house, but the availability is restricted to certain days during the week at certain times which do not correspond to her work schedule. So for the time being, the school bus takes her to her Goodwill.



*“The school bus through the school takes me back and forth to work. If the school bus didn’t take me, I don’t know how I’d get to and from work, probably the rural bus. It’s a little harder living outside of the city because the city bus doesn’t go to where I live. It only stops out by a store a long ways from my house, but the rural bus will go into Pflugerville a couple times a week, and you still have to call in advance. I don’t know how I’ll get back and forth to my job once the school stops taking me.”*

## Joe Nolasco, 41

Joe Nolasco has been working at a local Applebee's restaurant. With the assistance of a job coach, Joe was able to find this job and get acclimated quite well to the point where he doesn't need any assistance with his daily tasks. When he first started working there, he had quite a lot of transportation problems getting to and from work. He was relying on the local para-transit service, but with the service's limited responsiveness, he was frequently dropped off and picked up late from the restaurant. The problems with the transit service continued to the point that they were negatively affecting his job; Joe realized he had to do something about it. Although his local para-transit service is pretty good compared to other cities, the timeframes just were not working for Joe. To resolve these issues, Joe called the operator for a resolution. But when that didn't work, he began filing official complaints each time his ride threw off his schedule. Eventually, the problems were resolved with the transit service, but only because of Joe's perseverance. Joe says that he'd like to work as long as he can, right up until he can retire because it gives him something to do.



*“I used to have a lot of transportation problems getting to and from work because of scheduling problems. They would show up late, get me to work late, or pick me up early from a shift. When they show up, you have to go with them because they are your ride. I kept calling and filing complaints over several months and my persistence paid off because now I don't have those problems.”*

## Ricky Broussard

*I have resided in institutions for 30 years, since I was eight. After moving to an ICF-MR house with five other individuals owned by the local Arc, I began to learn to dream and make friends who were in and of the community. Several years ago I called together a circle of friends to help me achieve my dream of a job and "a life." My dream was to have an accessible transportation system that could respond to others who wanted to participate in regular things in the community. After many meetings and much planning with my trusted allies, I decided that I needed to begin by earning money that I could use to acquire my own transportation and table forming a Transportation Company until later.*

*My circle included business people, an attorney, a CPA, the local Arc executive director, the area director for my ICF provider and other people from the community who had become my friends. My desire to "Get a Life" led to my telling others about my dream and that led to a business in public speaking. I named it "Get a Life in Texas." All the people in my circle helped with some part of getting my business off the ground. The Arc provides me with my office space. That is important because someone there can help me with things I cannot do myself. I no longer go to the workshop but come to work every day.*

*I do not need my van to get back and forth from the group home to work. My office is only eight blocks from my house and I am dropped off and picked up by my group home people in their van. I could not get to my speaking engagements without my own accessible transportation. A member of my circle got me a van donated that has a lift. I use the van in my business to get to local area presentations and to the airport when I have to fly to make my presentations. The van is old and not dependable enough to take on long trips, but it gets me to Toastmasters every week where I am honing my skills in speaking. My office is in a bank building, and they let me park in their lot, since there is not room where I live. I use my income to pay a driver and attendant, and I also employ a secretary.*

*Sometimes my community friends come by and get the keys and the van so that we can go to the Friday night fish fry or go to hear my friend and his band, or to a ball game or meeting. This does not cost me because they want me to be there so they drive for me. I could not do my job and increase my job skills without transportation. I am going to get HCS after the first of the year sometime. Then I will be able to have my own place, get to decide who touches my body, and have my own dependable transportation. Then I will truly "have a life."*



*“I wanted to work at Wal-Mart retrieving carts because they pay pretty good. But I couldn’t get there because I couldn’t work on Sundays or past 7 p.m. during the week or on holidays because I didn’t have a way to get there.” (MD)<sup>26</sup>*

**44. Require HHSC and TxDOT, with consumer, family member, and stakeholder involvement, to collect data regarding the preferences of persons with disabilities who rely on transportation services to seek and maintain employment, as well as the number of persons with disabilities who are unable to work due to transportation barriers.** Two-thirds of adults with disabilities say they have public transportation available and are not limited in using it by health problems or impairments. However, less than 20% of persons with disabilities use public transportation systems. The low usage rate of public transit services could mean that barriers exist to using these systems in general or specifically for getting to work, or that the current services offered do not meet the personal preferences and needs of the individual. Further research and evaluation of the specific barriers related to transportation and employment are warranted.

*“You have to go the unemployment office in Pasadena. Got to a doctor for a certificate (of disability) in Baytown. A letter from an old landlord in Conroe. A letter from lawyers filing for your Social Security. Do it all by next Tuesday and he can get me into a program for job retraining. I can’t get that even if I start walking now.”*  
—56 year old woman from Harris County<sup>27</sup>

*“I might be qualified for other jobs, but I don’t want to be a nuisance when I have to explain how I can’t work at this time, before that time, past this time, or on this day. . . and once you go through that whole thing they usually don’t want to hire you anyway.” (BB)<sup>28</sup>*

## **AGING WITH DEVELOPMENTAL DISABILITIES**

Texas has the fourth largest population of older adults (2.7 million), behind California, Florida and New York. With continued medical advances, improved public health, better nutrition, and wellness-oriented lifestyles, as well as the large number of Baby Boomers (those born between 1946 and 1964) growing older, Texas will continue to see growth in the 60-plus population. In 2000, the 60-plus population comprised 13 percent of the Texas population, but by 2040, older adults will comprise almost one quarter (23%) of the total Texas population. Texans 60-plus are projected to total 8.1 million by 2040 -- a 193 percent increase from the year 2000.

As recently as the 1960s, the life expectancy of people with developmental disabilities was 35-40 years.<sup>29</sup> Today, adults with developmental disabilities can experience similar life expectancies as the general population. Currently about 75 percent of all older adults with intellectual disabilities are in the 40-60 age group. Aging persons with developmental disabilities have the same concerns as other older adults, such as housing, health, finances, access to support services and information, employment, and a desire to live independent, productive lives. Yet, they differ in that they may have had limited social and employment experiences, need alternative housing, need help accessing medical and social resources or specialty disability services, and may face the loss of their family home with the aging of their caregivers.

An estimated 1.9 million persons with developmental disabilities live at home or with a family caregiver, 25 percent of whom are age 60 and older<sup>30</sup>. Thus, a significant portion of in-home supports are being provided by family caregivers who will likely be aging beyond the capacity to provide care over the next 10 to 20 years.<sup>31</sup> Coupled with long waiting lists for home and community-based residential services, persons with developmental disabilities face significant challenges in the future when aging caregivers are no longer able to provide care.<sup>32</sup>

## David Alex, 27

*"I'm kind of getting worried about my parents because they're getting closer to seventy and I think my parents worry more about me as I get older because they think I can't take care of myself and they have to take care of me. I think they're worrying because if they pass away, they won't be there to take care of me, but I reassure them that I can take care of myself. My mom is always trying to make me independent but my dad always baby-sits me and I'm trying to show them how independent I can be and take care of myself."*



The growth in both the number of older adults with a developmental disability and the number of their caregivers who are aging has led to an increased interest in this subgroup of the population. On April 1, 2005, Texas Governor Rick Perry issued an Executive Order (RP42) directing the Texas Department of Aging and Disability Services to review and/or comment on state policies for current critical trends that include *"improving the provision of services and supports to persons with developmental disabilities and mental retardation who are aging."*

### TCDD RECOMMENDATIONS:

**45. Increase funding for respite services for aging caregivers of persons with developmental disabilities.** Respite is short term, temporary care provided to people with disabilities to allow their families to take a break from the daily routine and demands of caregiving. Approximately 46% of state agencies on aging nationwide identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities.

**46. Assist caregivers of individuals with developmental disabilities in planning for the future long-term care needs of their loved one.** Staff training on future planning needs of older families was cited by state agencies on aging as one of the greatest unmet needs. An estimated 1.9 million persons with developmental disabilities live at home or with a family caregiver, with approximately 25% living with caregivers age 60 and older. Older families cite the need for assistance in planning for the future when they may no longer be able to provide care.

**47. Assist individuals with developmental disabilities in planning for their future long-term care needs.** The average age of an adult with a developmental disability living with parents age 60 and older is 38 years. Aging persons with developmental disabilities have the same concerns as other older adults such as housing, health, finances, access to support services and information, employment, and a desire to live independent, productive lives. Yet, they differ in that they may have had

## Gregory Smith, 22

Gregory has had to rely on his father to get to work, because the nearest bus stop is a significant distance from the bookstore. If Gregory were to take the city bus, that would mean he would have to get off at an unfamiliar stop and walk to the store. He understands that as his father gets older, he will be less able to give Gregory rides to work. When faced with this prospect, Gregory says that it might mean he has to quit his job, given that he won't have transportation, but he may also need to stay home to take care of his aging father. The prospect of aging brings practical concerns for Gregory, because it means not only caring for his parent, but also learning new or adapting existing life skills to fit a different role.

*“As my dad gets older I might have to stay home to take care of him and that means I'd have to leave work. I have to learn how to cook because I only know how to cook frozen dinners. I guess I can find a place where I can take cooking classes that will fit with my work schedules.”*



limited social and employment experiences, need alternative housing, need help accessing medical and social resources or specialty disability services, and may face the loss of their family home with the aging of their caregivers. Thus, persons who are aging with developmental disabilities have unique long-term care planning needs.

### **48. Provide funding to develop cross-disability databases to ensure access to appropriate information and resources.**

Other states have demonstrated the efficacy of developing cross-disability information and assistance databases to increase communication between aging networks and developmental disability systems. This approach serves to streamline access to information and resources in accordance with "no wrong door" principles.

**49. Develop specialized services and supports to allow individuals with developmental disabilities to age in place following the loss of a family caregiver.** Many family caregivers will age beyond the capacity to provide care in the next 10 to 20 years. Long waiting lists for home and community-based residential services make it difficult for persons with developmental disabilities who lose their family caregiver to maintain their independence and be active members of their communities. Resources are needed to ensure that these individuals are able to remain in their homes and age in place.

**50. Require health care providers in Texas to receive education and training on the unique needs of individuals who are aging with developmental disabilities.** Health issues pose a unique challenge in that pre-existing physical and cognitive conditions present in persons with developmental disabilities serve to compound the experiences of normal aging. Specific groups of persons with intellectual disabilities such as those with Down syndrome or other significant lifelong physical disabilities may experience unique age-related health conditions. For example, those persons with long histories of medication use (e.g., psychotropic, antiseizure) are at higher risk of developing secondary conditions. Those persons with lifelong physical disabilities may develop chronic pain, osteoarthritis, or osteoporosis.

## Mary Louise Ferguson, 78, and Clare Begbie, 71

Mary Louise and Clare grew up in "private schools" for people with learning disabilities during the 1930s. Mary Louise recalls this time as particularly hard for her and remembers learning different skills and eventually moving to a community residence. Most recently, Clare and Mary Louise lived in an apartment which was operated by a large company that also operated a treatment center. They had lived together in this apartment for many years until the company that operated it went out of business, and Clare and Mary Louise had to find a new place to live. They decided that the best option was an assisted living facility apartment, which they are both very happy with.

One of the reasons they are so happy with their new place is that they are able to continue doing their volunteer work. Mary Louise and Clare devote their time and energy volunteering at many community organizations and have even won volunteer awards from their local Mayor's Committee for People with Disabilities. Mary Louise says she likes to volunteer with children who have disabilities because she has one too, and she can teach them different things and she can also learn from them. Their newest volunteer endeavor is helping the activity director design and publish the newsletter for the assisted living facility residents.

As they get older, Mary Louise is reminded of the hard times she had growing up. Clare is happy with the new apartment and does not ever want to go back to living in a group home, not to mention a nursing home.



*"Getting older is when you achieve the work that you do and to try to act your age. I think about my early days being in places that I've been like the private schools my parents sent me to when I was just a little girl and how they taught me how to act. Back in the thirties, I had a very hard life because I was very sick and had lots of work that I had to do, but now I'm better. My biggest concern when I get older is to get out and enjoy the scenery that I didn't have when I was just a teenager and to get to know people and to tell them that I am here to enjoy life."*

*"We both have a better life now."*

The Office for Prevention of Developmental Disabilities was created by the Texas Legislature in 1989 to coordinate prevention activity among the state's health and human services enterprise. The governor and legislature directed the agency to address substance abuse, teen pregnancy, and childhood injury. The agency's mission is to help minimize the human and economic losses caused by preventable developmental disabilities.

A nine-member, executive committee consisting of experts in medicine, business, academia, and mental health governs the agency and establishes policy directed toward its priorities: preventing fetal alcohol spectrum disorders (FASD) and head and spinal cord injury.

TOPDD authorized and appointed two state task forces to advise the agency on: 1) intervening with women to prevent alcohol-exposed pregnancy, the cause of FASD; and 2) educating parents and young children about using helmets and safety rules while riding bicycles.

### **Agency Goals:**

- Increase public awareness about FASD and head and spinal cord injury.
- Improve workforce capacity to intervene with at risk populations.
- Implement public health strategies that emphasize prevention.
- Lead the Texas health and human services enterprise in transferring science-based knowledge to practice in prevention programs.

### **PREVENTION OF FETAL ALCOHOL SPECTRUM DISORDERS**

During the past biennium, TOPDD implemented a state plan to address FASD prevention. The agency's executive committee appointed the FASD Prevention Task Force consisting of 14 experts in medicine, academia, substance abuse treatment, policy, and program development. The Honorable Kay Bailey Hutchison serves as the group's honorary chairperson.

Texas has recognized that FASD poses a serious public health threat to women and children. FASD is a term that describes the

range of effects that can occur in an individual whose mother drank alcohol while pregnant. The effects may include physical, mental, behavioral, and learning disabilities with possible lifelong implications. Experts advise women who are pregnant or might become pregnant to abstain from alcohol. There is no safe time or amount or type of alcohol to drink while pregnant.

Persons with FASD may experience various types and magnitudes of secondary disabilities including:

- Mental health problems (94%)
- Dependence for meeting daily needs (80%)
- Employment problems (80%)
- Expulsion from or dropping out of school (60%)
- Trouble with the law (60%)
- Inappropriate sexual behavior (50%)
- Mental health confinement or incarceration for legal reasons (50%)
- Alcohol or drug problems (30%)

These secondary disabilities arise because the needs of children with FASD go unmet. One study<sup>33</sup> found that individuals who experienced preventive factors in their lives had better outcomes. Some of these preventive factors include:

- Living in a stable and nurturing home
- Receiving an accurate diagnosis early in life
- Receiving disability support services
- Having one's basic needs met

Individuals with FASD and their families often experience a serious disconnect with education and support services because of a lack of awareness and knowledge about the disorders. Children who are not accurately diagnosed are labeled or misclassified in the health and education systems, which results in their receiving inadequate or inappropriate services. Children and adults with FASD experience a significant difference in their chronological age and developmental skill level. These individuals may have severe central nervous system (brain) damage due to alcohol exposure. This damage results in significant disability.

Texas surveys reveal there is a great risk for children to be born affected by FASD. The rate of binge and chronic<sup>1</sup> drinking among women of childbearing age (18-44) is 14 percent. About six percent of pregnant women in the state report using alcohol. The national estimate is that one in 100 live births is affected by this disorder. Based on that estimate, Texas women could deliver more than 3,700 infants affected by FASD each year. Many of these children will need significant support services throughout their lifetimes and the cost per individual for needed services can range between \$1-2 million.

### **TOPDD FASD PREVENTION PROJECT**

TOPDD collaborates with state and local government and not-for-profit organizations to accomplish these prevention outcomes:

- Provide standardized diagnosis for individuals with FASD
- Increase awareness about the danger of maternal alcohol consumption
- Improve system capacity to competently serve women and children at risk
- Identify, evaluate, and promote adoption of promising practices
- Develop culturally appropriate practices for populations at risk
- Seek accurate estimates of the prevalence of alcohol-exposed pregnancy and FASD

TOPDD and The University of Texas School of Social Work began to collaborate on research and program development in 2004. The partners developed three interventions and used a fourth, existing intervention in order to identify, assess, and intervene with women at risk for an alcohol-exposed pregnancy. The four interventions are designed as prevention strategies to increase awareness and educate women and ultimately reduce the number of alcohol-exposed pregnancies in Texas.

Pilot sites in Dallas and Tarrant counties, where women of childbearing age receive prenatal or gynecologic care or substance abuse treatment services, are involved in the FASD Prevention Project. The interventions employed are:

- **(1) Screening and (2) Brief Intervention:** Each participant completes a questionnaire about her alcohol consumption and family planning practices. If her score indicates she is at risk for an alcohol-exposed pregnancy, or if she is pregnant and drinking alcohol, a brief educational intervention is administered on the spot. Women identified as high risk are referred to substance abuse treatment.
- **(3) Enhanced FASD Intervention:** Women who are already enrolled in substance abuse treatment receive group sessions on FASD, healthy relationships, and family planning.
- **(4) Parent Child Assistance Program:** Some women identified as high risk are enrolled in a 36-month case management program to assist them in seeking or maintaining abstinence from drugs and alcohol, building a network to aid in developing and maintaining self-sufficiency, and creating a stable home environment for their family.

### **FASD PREVENTION PROJECT EVALUATION RESULTS**

The evaluation results for screening and brief intervention and FASD intervention are positive. The fourth intervention awaits final evaluation. More than 550 women of varying races and ethnicities receiving care in medical clinics were screened and about a quarter of those received a short counseling intervention about FASD. The evaluation measures increased awareness of the potential harm to the fetus caused by alcohol consumption while pregnant. After the intervention, women said it was not safe to drink any alcoholic beverages if not using effective family planning (95%) and reported that no alcohol beverages are safe to consume when a woman is pregnant (94%).

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<sup>1</sup> Binge drinking is consuming four or more drinks in a single setting; chronic or frequent drinking is one drink a day.

Similar results were obtained for 90 women engaged in substance abuse treatment and receiving the FASD intervention. Measuring the woman's knowledge prior to intervention and after intervention yielded significant improvements in understanding the consequences of drinking alcohol while pregnant. It is important to remember that this group consisted of women presumed to be at a higher risk than women screened in health clinics.

Based on fiscal year 2006 implementation results, TOPDD identified prospective sites to expand the screening and brief intervention and the FASD intervention components. They include public health clinics serving women who are pregnant or who may become pregnant as well as substance abuse treatment facilities in Bexar County.

### **TOPDD RECOMMENDATIONS FOR POLICY AND PROGRAMS RELATED TO PREVENTION OF FASD:**

- 1. Increase professional knowledge and skill in assessing and intervening with women and children at risk.**
- 2. Improve surveillance methods for identifying women and children at risk.**
- 3. Improve system capacity to provide state-of-the-art services by incorporating recent scientific findings into current program practices.**
- 4. Increase awareness among the general public about the harm caused by maternal alcohol consumption.**

### **PREVENTION OF HEAD AND SPINAL CORD INJURY**

TOPDD appointed the Child Safety Injury Prevention Task Force, which consists of experts in public health and education, to provide strategic direction in this important endeavor. The task force has worked for many years to raise awareness about how to prevent head injury and traumatic brain injury among children. The focus is on having bicycle riders use helmets and follow rules of the road.

The Centers for Disease Control and Prevention research findings show that bicycle helmets reduce the risk of serious head injury by as much as 85 percent and the risk of brain injury by as much as 88 percent. Household surveys reveal that only about a quarter of children below 15 years of age report regularly wearing a protective helmet when bicycle-riding.

Surviving a traumatic brain injury (TBI) can be fraught with problems for the individual and his/her family. These injuries are permanent, and the secondary disabilities associated with this are difficult to manage. Individuals with TBI experience barriers in receiving appropriate and adequate support services. Support services that are tailored to an individual's needs are called for but often an individual must attempt to fit into an existing service model that may not adequately meet the person's needs. The cost for care during a person's lifetime for head injury is estimated at \$2-4 million.

### **Texas Child Safety Model**

In 2000, a national action plan for bicycle safety created by the National Highway Traffic Safety Administration (NHTSA), the Federal Highway Administration, and the Pedestrian and Bicycle Information Center addressed five practical issues. These are:

- Road sharing
- Enhanced bicycle safety education
- Increased use of bicycle helmets
- Enhanced law enforcement to promote bicycle safety
- Bicycle facilities and community planning for bicycle safety

TOPDD's Child Safety Injury Prevention Task Force implemented a model that emphasizes bicycle safety education and increasing the use of helmets. This program has tools and materials that are easily adoptable by community groups. The task force is active in policy and serves as an example for communities by implementing the annual Child Safety Day event. The program includes helmet giveaways and educational interventions.

The 79th Texas Legislature passed a resolution proclaiming April as Child Safety Month. This led to further promotional activity in the state to involve other community groups in sponsoring child safety events during April or at other times during the year. These efforts help increase awareness and educate parents and children about safety while riding a bicycle.

### **TOPDD RECOMMENDATIONS FOR POLICY AND PROGRAM ON PREVENTION OF HEAD INJURY:**

- 1. Conduct an analysis to estimate the number of unreported bicycle-related injuries to better understand the extent of the problem in Texas.**
- 2. Evaluate educational programs to discover what is effective and produces sustained behavior change.**
- 3. Increase awareness and knowledge among the general public about the importance of helmet use in preventing death and disability.**

### **TOPDD Summary**

The State of Texas is making progress on preventing FASD and Head and Spinal Cord Injury -- two preventable, disabling conditions that affect thousands of Texas children each year. TOPDD is encouraged by the support and interest of the Texas Legislature on FASD and head injury.

Additional information about the State of Texas activity to prevent FASD and Head and Spinal Cord Injury and recommendations will be submitted to the 80th Texas Legislature in a separate report to be issued by TOPDD in early 2007.



**GOVERNMENT CODE**  
**Title IV, Chapter 531**  
**Section 531.0235. BIENNIAL DISABILITY REPORTS**

Sec. 531.0235. BIENNIAL DISABILITY REPORTS.

(a) The commissioner shall direct and require the Texas Planning Council for Developmental Disabilities and the Office for the Prevention of Developmental Disabilities to prepare a joint biennial report on the state of services to persons with disabilities in this state. The Texas Planning Council for Developmental Disabilities will serve as the lead agency in convening working meetings, coordinating and completing the report. Not later than December 1 of each even-numbered year, the agencies shall submit the report to the commissioner, governor, lieutenant governor, and speaker of the house of representatives.

(b) The report will include recommendations addressing the following:

- (1) fiscal and program barriers to consumer friendly services;
- (2) progress toward a service delivery system individualized to each consumer based on functional needs;
- (3) progress on the development of local cross-disability access structures;
- (4) projections of future long-term care service needs and availability; and
- (5) consumer satisfaction, consumer preferences and desired outcomes.

(c) The commission, Texas Department of Human Services, and other health and human services agencies shall cooperate with the agencies required to prepare the report under Subsection (a).

*As enacted by SB 374, 76th Texas Legislature in 1999. The 76th Legislature also changed the name of the Texas Planning Council for Developmental Disabilities to the Texas Council for Developmental Disabilities (HB 1610).*



**The Developmental Disabilities Assistance and Bill of Rights Act of 2000  
Public Law 106-402--October 30, 2000, 114 STAT. 1677**

**SUBTITLE A--GENERAL PROVISIONS; 42 USC 15001 SEC. 101.  
FINDINGS, PURPOSES, AND POLICY.**

42 USC 15002 SEC. 102. DEFINITIONS.

**DEVELOPMENTAL DISABILITY**

(A) IN GENERAL. The term "developmental disability" means a severe, chronic disability of an individual that -

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - a. Self-care
  - b. Receptive and expressive language
  - c. Learning.
  - d. Mobility.
  - e. Self-direction.
  - f. Capacity for independent living.
  - g. Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN. An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.



- <sup>1</sup> The Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 USC 15001 Public Law 106-402--October 30, 2000. 114 STAT. 1677
- <sup>2</sup> Administration on Developmental Disabilities and U.S. Census Bureau, Population Finder for Texas at <http://www.census.gov/>.
- <sup>3</sup> Texas State Data Center, Number and Percent of Noninstitutionalized Population by Disability Status Totals and by Age Groups for the United States and States in the United States, 2000 (Accessed <http://txsdc.utsa.edu> October 2006)
- <sup>4</sup> Texas State Data Center, (Accessed <http://txsdc.utsa.edu> October 2006)
- <sup>5</sup> United States Department of Commerce, Bureau of the Census, Current Population Reports, 2000, (Accessed <http://www.census.gov>)
- <sup>6</sup> Centers for Disease Control and Prevention, Prevalence of Four Developmental Disabilities Among Children Aged 8 Years -- Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000, Morbidity Mortality Weekly Report, January 27, 2006
- <sup>7</sup> Wenger, B., Kaye, S., LaPlante, M. U.S. Department of Education, National Institute on Disability and Rehabilitation Research, Disabilities Among Children, Disabilities Abstract No 15, March 1996.
- <sup>8</sup> Houtenville, Andrew J. 2006. "Disability Statistics in the United States." Ithaca, NY: Cornell University Rehabilitation Research and Training Center, [www.disabilitystatistics.org](http://www.disabilitystatistics.org). Posted May 15, 2003. Accessed October 2006.
- <sup>9</sup> David C. Stapleton, Richard V Burkhauser, Andrew J. Houtenville. Has the Employment Rate of People with Disabilities Declined? Policy Brief, Employment and Disability Institute, Cornell University Year 2004
- <sup>10</sup> United States Department of Commerce, Bureau of the Census, Current Population Reports, 2000, (Accessed <http://www.census.gov>)
- <sup>11</sup> Janicki, M.P., Dalton, A.J., Henderson, C.M., & Davidson, P.W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21, 284-294.
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- <sup>13</sup> Center on Intellectual Disabilities, University at Albany, New York (October 28, 2004)
- <sup>14</sup> The President's New Freedom Initiative for People with Disabilities: The 2004 Progress Report
- <sup>15</sup> SB 368 Legislative Report on Permanency Planning, Texas Health and Human Services Commission, July 2006
- <sup>16</sup> SB 368 Legislative Report on Permanency Planning, Texas Health and Human Services Commission, July 2006
- <sup>17</sup> Noelker L.S. and Harel, Z. (eds). *Quality of Life and Quality of Care in Long-Term Care*. New York: Springer Publishing Company, 2000.
- <sup>18</sup> National Organization on Disability & L. Harris & Associates (2000). Survey of Americans with Disabilities. Washington, DC: National Organization on Disability. <http://www.nod.org>
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- <sup>20</sup> Texas Council for Developmental Disabilities, Discussion group with employers at Texas Business Conference, Fall 2006.
- <sup>21</sup> Dixon, K.A., Kruse, D., & Van Horn, C.E. (2003). *Restricted access: a survey of employers about people with disabilities and lowering barriers to work*. Piscataway: The State University of New Jersey, John J. Heldrich Center for Workforce Development, Rutgers.
- <sup>22</sup> Texas Council for Developmental Disabilities, Discussion group with self-advocates on employment at Texas Self-Advocate Conference, July 2005.

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