

2004 Texas Biennial Disability Report



Texas Council for Developmental Disabilities
Texas Council for Prevention of Developmental Disabilities

Texas

Biennial Disability Report

Year 2004

December 2004

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Texas Council for Developmental Disabilities

The Texas Council for Developmental Disabilities (TCDD) is a 29 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 who are unable to represent themselves. As of September 1, 2004, members also represent the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, the Department of Family and Protective Services, the Department of Housing and Community Affairs, the Department of State Health Services, the Health and Human Services Commission, the Texas Education Agency, and the Texas Workforce Commission. The state's protection and advocacy program (Advocacy, Inc.), the Texas Center for Disability Studies, 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.

Texas Office for Prevention of Developmental Disabilities Program

The Texas Office for the Prevention of Developmental Disabilities (TOPDD) coordinates activities among the many state and local agencies working to prevent developmental disabilities. The mission of the agency is to help minimize the human and economic losses in Texas caused by preventable disabilities. The executive committee consists of nine members appointed by the Governor, Lt. Governor, and the Speaker of the House and includes experts in medicine, academia, human services, substance abuse, developmental disabilities, and prevention. TOPDD is authorized to appoint task forces to address prevention.

- Texas Fetal Alcohol Spectrum Disorders Task Force includes state and local agency, family/consumer, and special population (Native American) representatives concerned with the health and social concerns associated with alcohol-exposed pregnancy and Fetal Alcohol Spectrum Disorders (FASD).
- Child Safety and Injury Prevention Task Force includes representatives from health and human services and policy institutions.

The TOPDD goals include:

- ❖ Increase public awareness and education about prevention of developmental disabilities thereby reducing costs and sparing individuals, families, and the state from the economic and personal burdens associated with preventable developmental disability.
- ❖ Enhance community-based resources to better respond to under-served populations by identifying and encouraging adoption of strategies that direct prevention activity toward high-risk populations.
- ❖ Create strategic partnerships with federal, state, and local organizations to introduce promising practices into existing systems of care.
- ❖ Advocate for public policy to improve public health through prevention.

The Governor and Texas Legislature created the agency to coordinate and facilitate activities that are aimed at primary prevention of disabilities that stem from substance abuse, teenage pregnancy, and accidents experienced by children and youth. No other state or local entity has this mandate. The agency works across the health and human service enterprise to accomplish the mission.

Biennial Report Background

This Biennial Disability Report, a joint report of TCDD and the TOPDD 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 that TCDD and TOPDD prepare biennial reports to the Legislature on the “state of services to persons with disabilities in Texas” and propose recommendations.

Additionally, TCDD entered into a Memorandum of Understanding with the Texas Department of Housing and Community Affairs (TDHCA) to collaborate on the development of a report that addresses the availability of integrated, affordable, and accessible housing for people with developmental disabilities. The recommendations in this report are a result of research and analysis of information provided by health and human service agencies and TDHCA, as well as information gained through statewide focus groups and one-on-one interviews.

Texas Government Code Title IV, Chapter 531.0235, directs the Texas Council for Developmental Disabilities (TCDD) and the Texas Office for Prevention of Developmental Disabilities (TOPDD) to outline present and future needs for consumer-friendly, appropriate, and individualized services and supports and to make recommendations related to those services. To do this, TCDD and TOPDD compiled statistical data and information about best practices, as well as information and personal stories from the people behind the statistics. The addition of the stories of people from across the state whose experiences illustrate the state of services makes objective data more complete. If Texas intends to provide individualized, consumer driven services and supports for people with disabilities, their voices must be heard.

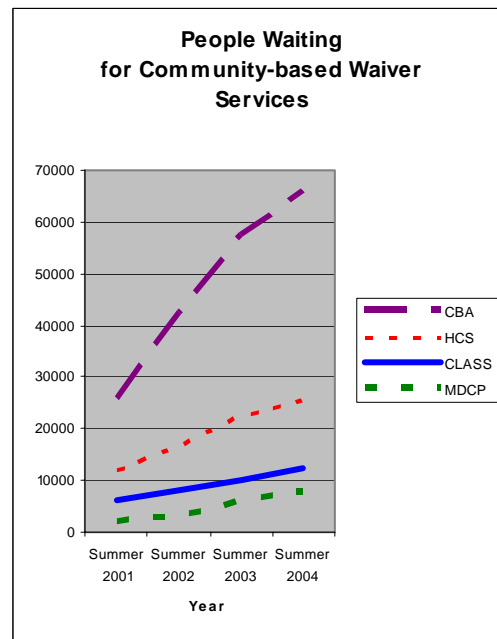
Section I: Introduction and Demographics

On June 22, 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.*¹ that placing and keeping people with disabilities in institutions unnecessarily is a form of discrimination prohibited by the Americans with Disabilities Act (ADA). In 2001, President George W. Bush signed an executive order creating the New Freedom Initiative, which directed multiple federal departments to work with states to implement the *Olmstead* decision; directed agencies to explore how to increase community-based services for people with disabilities; and directed the United States Attorney General and U.S. Department of Health and Human Services secretary to enforce the ADA and ensure that no one is unjustly institutionalized. In 2002, Texas Governor Rick Perry issued Executive Order RP-13, directing the Texas Health and Human Service Commission to review and amend state policies that make it difficult for people to move from institutions.

The Supreme Court and state and national leaders agree that people with disabilities must be able to live in their own communities and that states must expand community-based services. To ensure that Texans with disabilities can live independently, it is essential that an effective and efficient system of services and supports based on best practices be in place. To develop an adequate services system, people with disabilities and their family members must be involved in designing the types of services needed and how those services are provided. In addition, agencies must recognize that necessary services include the “generic” services that are available to all citizens – such as housing, employment, transportation, and education – as well as short- and long-term care services.

Unfortunately, many citizens with disabilities – without sufficient support – do not have the same resources that many other Texans have to be able to participate actively in policymaking. Being “willing and able” is not enough; transportation and financial issues frequently prevent travel. Fear of retribution prevents others from openly registering their dissatisfaction. Finally, many people with disabilities, particularly those whose disabilities affect their communication and/or thinking, report that they experience discrimination based on prejudicial attitudes. Agency leadership must ensure that these barriers to stakeholder involvement be replaced with consistent customer service with regard to all people. Only then will people who need services be able to fully participate in their communities as directed by the

Olmstead decision and the Executive Orders of both the President and the Governor. As seen below, the numbers of people waiting continues to grow.



Disability Trends in the United States

Currently, one in five Americans have some kind of disability, one in 10 have a severe disability,² and the number and percentage of people with disabilities can be expected to rise dramatically in the coming decades. Estimating the number of people with developmental disabilities is difficult as evidence suggests that some people may have disabilities that are not recognized as disabilities but are thought to be issues of “character.” Rather than receiving support, people may be accused of being intentionally “difficult” or “lazy.” For example, untreated clinical depression may cause a person to sleep more than is average, feel very little motivation to work or even to maintain their personal hygiene, and/or to interact with others very little or inappropriately. Individuals with a fetal alcohol spectrum disorder (FASD), in particular, are routinely under-identified by current assessment processes and therefore under-represented and under-served. These individuals can experience severe and permanent emotional, physical, and cognitive and/or behavioral difficulties that are often disregarded because testing may indicate average IQ or they may not have any readily identifiable physical or mobility-related disability.

Despite difficulty in obtaining consistently accurate data regarding the number of people with disabilities, general demographics and disability-related statistics indicate unequivocally that the percentage of people who have a disability is increasing dramatically and will continue to do so.

Percent of People with Disabilities by Age - Nationally		
Age Group	Any Disability	Severe Disability
65 years and over	52.5 %	33.4%
15 to 64 years	18.7%	8.7%
0 to 14 years	9.1%	1.1%

(Source: *Disabilities Affect One-Fifth of All Americans*, Census Brief/1997)

Rising disability rates among children

The prevalence of a disability increased 40% for boys and 33% for girls under age 18 between 1970 and 1990.³ Some of this increase may be due to better diagnosis and reporting, but other possible reasons for this include:

- Medical and technological advances that sustain lives of children who in earlier years would not have survived premature births or critical injuries sustained in an accident.⁴ Survival rates for low birth-weight infants have increased 70-fold over the past 25 years, directly affecting the prevalence of developmental conditions and learning impairments.⁵
- Unexplained rises in certain disabilities. For example, the rate of diagnosis of Autism Spectrum Disorders has risen dramatically. The Centers for Disease Control estimates that approximately one in 250 people born have autism.⁶ The National Institute of Mental Health has found that between one in 1,000 to one in 166 Americans have Autism Spectrum Disorders and that some recent studies cite dramatic apparent increases in prevalence in certain locales.⁷ Conditions such as

autism, mental illness, and learning disorders appear to be growing in prevalence. While it is not clear whether the reported increases represent growth in actual numbers, greater awareness, the reduction of stigma in reporting, better identification and outreach, and/or some combination of the above, it is clear that there are significant increases in the number of reported incidences.⁸

- Increasing numbers of preventable disabilities due to environmental or lifestyle issues. In particular, alcohol-exposed pregnancies are a leading cause of disabilities. Centers for Disease Control surveys indicate that between 9% and 12% of pregnant women drink alcohol and 3% say they drink at levels that have been consistently associated with adverse fetal effects.⁹ Reports on drinking behaviors among Texas women of reproductive age (18-44) indicate 14% report binge or chronic alcohol consumption.¹⁰

Rising disability rates of the working age populations,18-64

The prevalence of a disability increased by 16% for people ages 18-64 between 1990-1994. As with children, all the reasons for the increase are not yet known, but medical and technological advances are now saving the lives of a larger percentage of people who suffer traumatic injuries. Survival rates for spinal cord and severe brain injury have dramatically increased in recent decades due to better trauma care. Injuries from these two traumas alone account for an estimated 80,000 people acquiring a disability each year, according to the National Institutes of Health. In addition, there has been a documented decrease in overall health and wellness of Americans, which can lead to higher incidence of disability from complications related to diseases, such as adult onset diabetes, as well as musculoskeletal problems.¹¹

Rising percentages of people who are over age 65

More people over 65 have a disability than any other age group with over half reporting some type of disabling condition. By 2030, 20% of the U.S. population will be over age 65, compared with 12% today.¹²

Recent Federal Trends Related to Services

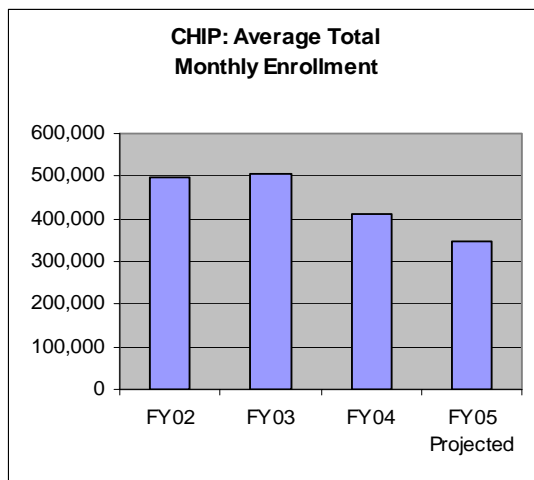
The U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), has launched several initiatives related to increasing flexibility in service provision, some of them more beneficial than others.

- In 2001, CMS awarded \$30 million in Real Choice Systems Change Grants to help states develop programs for people with disabilities or long-term illnesses. These Real Choice Systems Change Grants are aimed at building infrastructure that will result in effective and enduring improvements in community long-term support systems.
- The Independence Plus Waiver, announced on May 9, 2002, gives individuals more control over the selection of services that affect their health care or that of a family member. Independence Plus and other “Self-Directed” Waiver Programs in 10 states serve approximately 64,000 individuals who now have the option to self-direct their care.

- State and Federal expenditures for home and community based services have increased. Between 2001 and 2004, a total of \$68.7 billion was allocated to support home and community-based waivers nationally. Over the same period, care expenditures for related state plan services supporting community living grew as well, from \$5.25 billion to \$7.95 billion. Texas received more than \$1.3 million in federal funds to provide assistance in promoting full community participation for people with disabilities as part of the President’s New Freedom Initiative.
- The President’s fiscal year (FY) 2005 budget proposes the Living with Independence, Freedom, and Equality (LIFE) Account Savings Program. Under this proposal, Medicaid-eligible individuals with disabilities who self-direct all of their Medicaid, community-based, long-term supports will have the opportunity to place up to 50% of the savings from their self-directed Medicaid community-based service budget into a LIFE Account at the end of the year. Earnings from employment and limited contributions from other sources may be used in the LIFE Accounts to align the amount in the fund with the level of need. Income and resources in the LIFE accounts will not be considered when making a determination for a state’s Medicaid program or any federal assistance program or in establishing benefit levels under those programs for either the account holder or for any members of the account holder’s immediate family. However, the plan will both cap and reduce available funding for participating individuals, which could significantly limit the overall array of services and supports provided.

Disability Trends in Texas

State trends in Texas regarding rates of disability are generally consistent with federal trends regarding prevalence of disability. According to sample data taken from the 2000 Census, about 20 percent of Texans reported having one or more disabling conditions. Among younger adults ages 18 through 39, 17 percent reported a disability. Among those ages 65 and over, however, about 47 percent reported having one or more disabling conditions. Among persons age 85 and over, about 77 percent reported having one or more disabling conditions.¹³



Spending on services for people with disabilities in Texas, however, has lagged behind that of most states. As of the summer of 2003, Texas ranked 45th nationally in per person spending for Public Health, 47th for Mental Health, and 46th for Public Welfare and Medicaid.¹⁴ 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. Recent changes to eligibility requirements for the Children’s Health Insurance Program (CHIP) have further decreased the number of children who are insured.

Texas has instituted some policy changes and initiated efforts to assist people with disabilities to be able to live in the community. The 77th Texas Legislature supported the Promoting Independence Initiative that responds to the U.S. Supreme Court's Olmstead decision. The Promoting Independence Initiative addresses all long-term care services and supports and endeavors to ensure that the state's community-based programs effectively foster independence and acceptance of people with disabilities and provide opportunities for people to live productive lives in their home communities. The 77th Texas Legislature directed the Health and Human Services Commission (HHSC), through SB 368, to monitor the efforts of other agencies to ensure that permanency plans are developed for children at risk of placement in an institution and to develop and implement a pilot program to assure that children under the age of 18 who currently reside in institutions can transition to live in a family-based alternative.

Texas health and human service agencies have made some progress in addressing the needs of children with disabilities and their families. Some of the positive actions follow.

- HHSC developed the Family-Based Alternatives initiative to promote family-based options to institutional care for children. The project assists children living in institutions in selected areas of the state to return home to their birth families with support. When a return to the birth family is not possible, the project recruits alternate "Support Families" who are carefully matched with children and their birth families to care for that child for a long-term period.
- The Health and Human Services Commission used authority under Appropriations Rider 13(c), approved by the 78th Texas Legislature, to transfer a portion of fiscal year 2004 funding to support certain key initiatives, including family-based alternatives and promoting independence activities.
- The 78th Texas Legislature approved Appropriations Rider 28 authorizing the Department of Human Services to allow funding to follow children and adults moving from nursing facilities to community programs.
- The legacy agency Department of Human Services (DHS), now the Department of Aging and Disability Services (DADS), used federal funds to assist individuals to transition from nursing homes to the community through the Money Follows the Person grant from the federal U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS).
- The Texas Department of Mental Health and Mental Retardation (TDMHMR) (now the Department of Aging and Disability Services) used existing resources to provide additional Home and Community-based Services (HCS) waiver services.
- "Family support services" were added as a service option in the Community Living Assistance and Support Services (CLASS) waiver program.
- TDMHMR (now DADS) initiated the Texas Home Living Waiver, which provides a limited level of services to people of all ages living with their families or on their own if they qualify for ICF/MR care and meet the Supplemental Security Income (SSI) income limit.
- Child Protective Services (CPS) added a foster family option for children at intensive levels of service need and added 11 developmental disability specialists, one for each region, to find and coordinate services for the children.

The length of time people spend waiting for services that are needed to keep their families together and stay in their own homes as well as the large number of people waiting for services and supports in Texas demonstrate that much work remains to be done. The Texas Council for Developmental Disabilities (TCDD) has worked collaboratively with various partners to demonstrate how supporting individuals with disabilities can be done in a way that benefits all members of a community.

TCDD efforts include:

- Providing training to people with disabilities and their families to be advocates for themselves;
- Offering funding to support people with disabilities to serve as public members of health and human services agency advisory boards where appropriate;
- Providing funding for the design and initial development of the state's 211 Information and Referral network;
- Demonstrating best practices to assist people to move from institutions into their own homes in the community and demonstrating an array of best practices in providing the services and supports needed for people to live in the community such as transportation, housing, personal assistance, medical care and support, education, recreation, and employment initiatives;
- Providing funding support and technical assistance for the development of the Family-Based Alternatives Project; and
- Participating on numerous advisory and policy boards, such as the Children's Policy Council, the Texas Correctional Office on Offenders with Medical or Mental Impairments Advisory Committee, the Traumatic Brain Injury Advisory Committee, the Quality Assurance and Quality Improvement Task Force for the Real Choice Systems Change Grant, and the Promoting Independence Advisory Committee.

Federal Medicaid Waivers

The Health and Human Services Secretary can waive particular Federal requirements to allow states to adopt special programs known generally as "waiver programs." The three primary types of Medicaid Waivers are:

1115 - Demonstration Waivers to allow states to implement demonstration projects which are "likely to assist in promoting the objectives" of the Medicaid statute.

1915(b) – Freedom of Choice Waivers typically waive requirements for statewide, comparability of services among groups of beneficiaries and free choice of provider. Typically uses prepaid, risk-based managed care programs and/or primary care case management programs, which pay participating providers a monthly case management fee per enrollee.

1915(c) – Home and Community Based Services Waivers, which allow states to provide a broader array of community-based support services that are available under the Medicaid State Plan for individuals who qualify for institutional care.

According to federal rules 1915(c) waivers cannot cost any more than institutional care would have cost for the group served by the waiver. In addition, there may be a "cost cap" for the services any one individual may receive.

Section II: The Findings and Recommendations

People with Disabilities Receiving and/or Waiting for Community-Based Services

Despite the 1999 Supreme Court Olmstead Decision and the finding that an overwhelming majority of people with disabilities would prefer to live in their own home in a neighborhood of their choosing, more than 7,300 Texans with disabilities are currently living in public and private institutional settings with more than 15 other people. This living arrangement most commonly exists because individuals are unable to find the services and supports they need to live at home, even when community-based services and supports would be less costly than providing services in an institution.

Texans with Mental Retardation and/or Severe Disabilities Living in Institutions	
Type of Facility	Number of People
All public and private facilities of all sizes <i>Source: HHS Strategic Plan, 2004</i>	20,042
Large, state-operated facilities serving people with mental retardation <i>Source: HHS Strategic Plan, 2004</i>	4,978
Nursing Homes <i>Source: Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002 (June 2003)</i>	2,415

The Children’s Policy Council (CPC) Report to the Legislature and HHSC Executive Commissioner states, “The fundamental flaw in the system of long-term supports and services for children in Texas is that institutional services are provided on demand (known as entitlement), yet community-based, family support services are provided on an ‘as available’ basis. In recent years, ‘as available’ often means not available.”

Families of children with disabilities sometimes feel forced to place their children in institutions – sometimes giving up custody – because they find no other option. A ward of the state will receive the medical and/or mental health care that may not be available to the child otherwise. Medicaid will fund services provided in a nursing home immediately, but families often must wait six to seven years or more before receiving any services in their homes through a Medicaid waiver program.

Children with Disabilities Living in Institutions <i>Health and Human Services Commission, August 2004</i>	
Type of Facility	Number of Children
Nursing Facilities	216
Intermediate Care Facilities for the Mentally Retarded (ICFs/MR)	871
Group Homes (Home and Community-based Services/HCS and Department of Family and Protective Services group homes)	423
Institutions for the Mentally Retarded licensed by DFPS	79
Total	1,589

Many more people have expressed interest in living in community-based homes than in institutions, and organizations such as Centers for Independent Living (CILs) provide services to people with disabilities and their families that can enable them to maintain independent lives in the community. DADS has renewed and extended contracts with four CILs to assist in the transition of individuals from facilities to the community. Additional assistance is available to nursing facility residents from the local Area Agencies on Aging (AAAs) that provide information about community-based services and support to help individuals and their families make decisions during the planning phase as well as during the actual relocation. Community Mental Health and Mental Retardation Centers have also provided information and assistance to individuals leaving institutions. However, Texas still has not provided sufficient resources in community services to address the stated preferences of individuals waiting for community services. Instead, Texas spends enormous resources on unwanted and unneeded services. Waiting lists and “interest lists” have grown steadily over the years. In June of 2001, there were 12,000 people waiting for home and community based services; on July 31, 2004, there were 25,543 waiting.

The numbers of Texans waiting for services through the Community Living Assistance and Supports and Services (CLASS), Medically Dependent Children Program (MDCP), and the Community-Based Alternatives (CBA) waivers have doubled in the last three years. Only the waiting lists for the Deaf-Blind-Multiple Disability (DBMD) waiver program and the Children with Special Health Care Needs (CSHCN) program have decreased during this time.

At the same time it is difficult to use waiting lists and interest lists as an accurate measure of need as some people may be on multiple lists and not all individuals on each list are actually eligible. Additionally, lengthy waiting lists discourage many people from applying for services (“Why bother?”), and some programs are not yet statewide and as such do not reflect the needs of individuals in areas of the state not yet served. The legacy agency Texas Department of Human Services indicated that historically 40-70% of those on the MDCP, CBA, DBMD and CLASS interest lists are determined eligible.

The Texas Department of Mental Health Mental Retardation estimated approximately 99% of those on the HCS waiting list are usually determined to be eligible. And as highlighted in the box above, nearly 15,000 people in nursing homes are waiting for community services.

The Minimum Data Set (MDS)

is part of a federally mandated process that requires the completion of a comprehensive assessment of each and every certified nursing home’s resident’s functional abilities on admission to the facility and then on a periodic basis. MDS information from the State databases is captured into the national MDS database at CMS.

The data gathered by CMS for the third quarter of FY 2003 reveals that 16.6% of the residents in Texas nursing homes – 14,830 people – indicated a desire to move into the community and out of nursing homes.

For more information:

www.cms.hhs.gov/states/mdsreports)

People with Disabilities Waiting for Community-Based Services		
<i>Health and Human Services Commission/Texas Department of Health, July 31, 2004</i>		
Program	Total on Interest or Waiting List	Number of Children on Interest or Waiting List
Home and Community-based Services (HCS) Waiver	25,543	9,112
Community Living Assistance and Support and Services (CLASS)	12,495	10,287
Medically Dependent Children Program (MDCP)	7,763	7,733
Community Based Alternatives (CBA)	66,210	465
Children with Special Health Care Needs (CSHCN)	280	280
In-Home and Family Support Services (IHFS)	19,777	732
Total	132,068	28,609

The Texas Home Living Waiver

Texas received federal approval for a new Medicaid waiver program, the Texas Home Living (TxHmL) waiver, submitted by TDMHMR during 2004. TxHmL was created to use state general revenue funded community programs as match for federal Medicaid waiver funds to provide community services for people waiting for the Home and Community-based Services (HCS) waiver. The TxHmL waiver program provides minimal, essential, community-based supports to individuals, unlike other waivers that provide more comprehensive services. Individuals can choose a support/service provider from a variety of qualified providers including their local MHMR Center, in most cases, and private providers, many of whom also provide HCS services. Individuals enrolled in the TxHmL waiver will continue to receive Service Coordination through the MHMR Center just as in the past.

Not all individuals who were receiving community-based mental retardation supports from a Community MHMR Center can be transitioned into the new TxHmL waiver. To be eligible, individuals must:

- currently receive Medicaid supports or be Medicaid-eligible;
- meet the ICF/MR Level of Care 1 or qualify for HCS Level of Need 1, 5, 6 or 8 (Level of Need 9 is excluded);
- live in their own home or family home and seek community-based supports only; and
- use state funded supports that cost between \$3,000 and \$10,000 each year. Individuals whose supports costs exceed the \$10,000 cap are not eligible for this new waiver program.

Children or young adults who are in the foster care system or are transitioning out of the foster care system and do not to exceed the Level II level of need are also eligible.

The program rolled out on June 1, 2004, and initially served an estimated 1,262 individuals who were previously receiving General Revenue-funded supports and services. The roll-out of the TxHmL waiver program for 1,589 individuals currently on the HCS waiver waiting list began in September 2004. People on the Home and Community-Based Services waiting list who will be served through the TxHmL waiver will remain on (and keep their place on) the HCS waiting list and will be able to transfer to the HCS program if and when HCS funding becomes available to them.

Fiscal and Programmatic Barriers to Consumer Friendly Services

The 2002 Biennial Disability Report highlighted multiple fiscal and programmatic barriers that continue to exist. The most obvious of these is the need for adequate funding for waiver services that allow people to live (and work) in their communities rather than remain isolated in nursing homes and other institutions. In addition, the 2002 Report revealed how insufficient funding of personal attendant services, specifically the low pay and lack of benefits, has contributed to an attendant care crisis. The issues and possible solutions related to community access and personal attendants remain relevant in 2004. In addition, funding and programmatic changes to existing services were authorized by the 78th Texas Legislature in an effort to manage an unusually large budget deficit. Many of these changes caused people with disabilities to lose community services.

Children's Health Insurance Program (CHIP)

CHIP is a health insurance program for children:

- Under 19 years of age
- Have family incomes less than 200% of Federal Poverty Level (FPL)
- Are not eligible for Medicaid
- Are uninsured
- Are U.S. citizens or legal Permanent Residents.

The federal funds pay 72.15% of CHIP medical care; each \$1.00 of state funds draws \$2.57 in federal funds.

Funding Cuts and Program Changes

The changes that have received the largest amount of publicity are the multiple changes to eligibility, benefits and provider rates in the Children's Health Insurance Program (CHIP). As of May 2004, 141,528 fewer children were enrolled in CHIP than were enrolled September 2003. According to the Children's Policy Council, "Children with disabilities or special health care needs typically comprise between 6 to 8% of the CHIP population. Many of the children who have lost coverage due to the policy changes will not be able to obtain other coverage and will remain uninsured or underinsured." This would suggest that between 8,491 and 11,322 children with disabilities and/or special health care needs who had health care insurance through CHIP no longer have that coverage.

Insurance coverage (through CHIP or similar medical insurance plans) enables adults and children to receive appropriate medical intervention when needed and also encourages regular preventive care which can avert the need for costly hospitalizations and/or expensive, intrusive treatments.

Enrollment: CHIP, Children's Medicaid, and Total Medicaid			
	CHIP	Children's Medicaid	Total Medicaid
August 2003	506,068	1,643,284	2,474,557
August 2004	359,734	1,778,603	(not available)
Sept 2004	355,528	(not available)	2,626,469

Adults and children complex needs frequently require not only the types of basic coverage that insurance offers, but also assistance with accessing and coordinating services which may be supplied and/or paid for by different agencies or funding streams. Most frequently this is done by a case manager or case managers. In the ideal situation, each individual is served by one primary case manager who avoids any conflicts of interest by being independent of the service provider(s) and who can offer the level of assistance that specific individual or family needs. Community Resource Coordination Groups (CRCGs) are local groups, one in each of Texas' 254 counties, that consist of several different service providers who are willing to come together to try to ensure that the needs of individuals (adults and children) who need multiple types of services are met. A few CRCGs have successfully secured funding for a part-time or full-time CRCG Coordinator, enabling them to provide better follow-up and accountability. A third approach that has met with success is that of the Texas Integrated Funding Initiative (TIFI). TIFI, working with the CRCGs, demonstrated the effectiveness and cost-efficiency of using "Systems of Care" to support the families of children with severe emotional disturbances who may be at danger of being incarcerated, hospitalized, or institutionalized. The Systems of Care approach organizes a comprehensive system of mental health and other necessary services into a coordinated network to meet the needs of children and their families and requires that those services and supports be "wrapped around" that person and their family, provided in a way that is family focused, culturally competent, and community based. TIFI was also able to use flexible funds – money that was contributed by each participating agency to be used to pay for any identified needs, not just those allowable under the funding streams traditionally used.

House Bill (HB) 2292, Section 2.166 of the 78th Legislature required each local CRCG that serves children and youth to assess the local provision of systems of care services for children with severe emotional disturbances and to make related recommendations. The Health and Human Services Commission (HHSC), in conjunction with the State Texas Integrated Funding Initiative (TIFI) Consortium, created a summary report based on this information from the local CRCGs, including recommendations for policy and statutory changes for each involved agency. CRCGs indicated that the most difficult barriers included: insufficient quantity of service or lack of services/staff; geographic challenges; misunderstandings related to cultural differences; limited funding or lack of funding; and, to a lesser extent, inflexible funding sources.

Other cuts to services on which people with disabilities depend may not have received as much attentions those to CHIP, but had significant impact on the state of services in Texas for children and adults. Some of the most drastic funding cuts and/or program changes and the effects of those changes are described below.

Community, In-Home and Family Support Services	
<i>Truth and Consequences: The State Budget for 2004-2005 and Its Impact on Texans. The Center for Public Policy Priorities, July 2004</i>	
Program/Funding Changes	Effects of Program/Funding Changes As of September 1, 2003
Elimination of the Mental Health In-Home and Family Support Program	Approximately 3,000 people with severe mental illness do not receive services
<p>Community Mental Health funding was frozen at 2002-2003 client service levels, and funds were not allocated for population growth or inflation.</p> <p>Funding for adult mental health community services is 5.5% below levels requested to maintain 2003 service levels, and 1.8% below the current services request for children's mental health community services.</p> <p>The priority population for mental health services was revised to include only persons with schizophrenia, bipolar disorder, and/or major depression.</p>	<p>Medicaid adult clients with other psychiatric diagnoses such as psychosis, non-suicidal depression, anxiety, autism, or personality disorders are now excluded from access to community mental health services through MHMR centers.</p> <p>According to the Mental Health Association in Texas, these diagnoses accounted for only 12 percent of community mental health services in 2002, or services for approximately 6,890 persons of approximately 139,000 individuals that were served.</p>
61% reduction in the legacy agency Department of Human Services' In-Home and Family Support Program serving individuals with mental retardation and 55% reduction in their In-Home and Family Support Program serving individuals with related conditions.	Approximately 3,090 people with mental retardation will not receive services. For those receiving services, annual allowances dropped from \$3,600 to an amount between \$1,200 and \$2,400.
11% reduction in funding for community mental retardation services.	Approximately 2,570 people with mental retardation do not receive services.

Services for Adult Medicaid Enrollees

Truth and Consequences: The State Budget for 2004-2005 and Its Impact on Texans.

The Center for Public Policy Priorities, July 2004

Program/Funding Changes	Effects of Program/Funding Changes
Termination of certain benefits for Adult Medicaid Enrollees: As of September 1, 2003, services of licensed professional counselors, social workers, psychologists, licensed marriage and family therapists, podiatrists, and chiropractors are not covered, nor are eyeglasses or hearing aids.	About 843,400 adults were covered by Medicaid in March 2004, and three-fourths of these were people who are aging or have disabilities. These people will no longer have access to the services named. HHSC has estimated the cost to restore the benefits coverage for fiscal years 2005-2006 to be \$42.8 million in General Revenue funds.
Medicaid Community and Long-term Care Waiver freezes.	These frozen Medicaid waiver programs were designed to help Texans who are aging and/or have disabilities to remain in their homes. Now only people wishing to leave an institution are allowed to place their name on a waiting list until enrollment drops down to a lower level.
Reduction, through attrition, of the number of Community Based Alternative (CBA) Medicaid waiver enrollees to a specified cap, reducing the number of persons served by at least 3,100.	Enrollment in CBA was 30,336 in 2003; the 2004-05 budget reduces that level to 27,211 by 2005 (a 10 percent drop). The waiting (or interest) list for CBA waivers is expected to grow to more than 67,300 people in 2004, up from 39,200 in 2002.

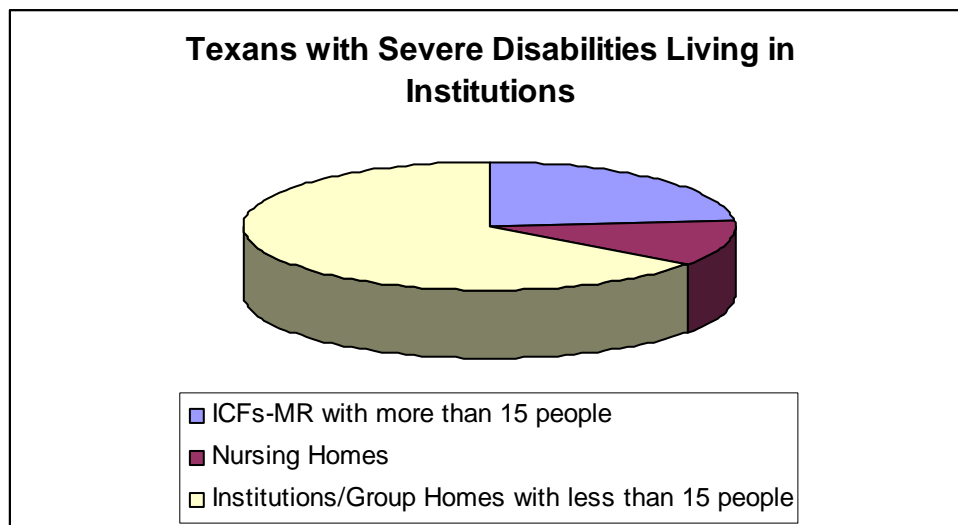
Many individuals with significant disabilities are at risk of institutionalization if they are unable to secure community supports and services. Texas has developed mechanisms, such as Rider 28, 78th Legislative Session (formerly Rider 37, 77th Legislative Session), also known as "Money Follows the Person." Rider 28 allows individuals to move from nursing facilities to community-based services, taking their Medicaid long-term care dollars with them. To take advantage of Rider 28, the individual must reside in a nursing facility until a community care worker completes a written eligibility determination that specifies when that person is eligible to receive services. This option is not yet available for individuals in ICFs/MR.

Institutional Bias

Texas continues to have a strong institutional bias in funding for long term care services. The 2004 Braddock Report on the State of the States in Developmental Disabilities reports that Texas ranks 25th in spending for institutional services, but 44th in spending for community services. While the majority of states decreased the number of people living in institutions and the number of state run institutions, only three other states moved as few people out of institutions (by percentage) as Texas between 1995 and 2002.¹⁵

Currently, anyone who meets income and resource requirements and needs long term care is entitled to receive services as long as they are willing to be admitted to an institutional program, such as an ICF/MR or a nursing home, to receive those services. However, services in one’s home or in other small community settings are not an entitlement. The federal government stipulates that the average per-person cost for a state’s waiver services cannot exceed the average per-person cost for institutional services. In Texas, there is a further limitation – the average cost for some waivers may not exceed 80% of the cost of institutional services. “Cost caps” exist on waiver service that stipulate the highest amount that may be spent for the services for any one individual, unless specifically approved. (See Appendix C: Summary of Texas Medicaid Waiver Program.) In addition, there may be further restrictions on what types of services a person may be able to receive through a waiver, regardless of whether or not the cost of those services would exceed the cost cap.

Individuals may very likely have to wait a number of years to receive services in their homes – even when it would be less expensive and intrusive. Unfortunately, some individuals and their families cannot afford to wait. Families of children with disabilities who have placed their children in nursing homes and/or ICFs/MR frequently report they only did so because they had no other choice – it was the only way they could access the services they need for their child. The Family-Based Alternatives project, funded in part by HHSC and TCDD, has demonstrated that many of these children are able to live in homes, with families, when appropriately supported.



Lack of Sufficient Formal Mechanisms for Consumer Participation

House Bill (HB) 2292 of the 78th Legislature reorganized all health and human services agencies and programs and replaced all agency governing boards with advisory councils. These policy councils are advisory only, with rulemaking and policy authority vested with the HHSC Executive Commissioner and the Governor. These changes raise the concern that key health and human service policy decisions may become less open and accountable to the public and, in particular, to the people who need those services. Many

strong disability advocates who have played key roles in the development of services in Texas are parents of individuals with disabilities who are now becoming older. They are less likely to be as assertive or active in the future as they have in the past. It is important for policymakers to realize that more of an effort must be made to reach out to young people with disabilities, more so their parents, and to examine whether this may require a change of approach.

TCDD Recommendations

- 1. The Health and Human Services Commission (HHSC) should ensure that health and human services agencies invest dollars in the waiver services that represent the preferences and desires of people who need and/or are waiting for services, within the allowable funding guidelines.**
- 2. Amend the home and community-based Medicaid waivers to ensure that every waiver includes the full array of services without altering any waiver's cost cap.**
- 3. Reduce the time and number of people waiting for Medicaid waiver services and other publicly-funded community-based supports.**
- 4. Require HHSC, with consumer, family member, and stakeholder involvement, to conduct ongoing evaluation and reporting of the data regarding the number of children in institutions, the number waiting for community services, and the quality of permanency planning efforts.**
- 5. Reduce the number of children and young adults under age 22 who are living in institutions.**
- 6. Expand Rider 28 of HB 1, which ensures that people moving from nursing homes into the community can take their Medicaid long-term care dollars with them, so that it applies to all types of institutions and so that the money allocated to support a child or adult in any institution can be transferred to purchase community waiver services.**
- 7. Support families with children with disabilities living at home until those children may legally advocate for themselves by expanding family-based alternatives, restoring funding for the In-Home and Family Support (IHFS) Services Programs for children with disabilities and special health care needs, providing for family-based crisis stabilization and respite for families, and providing adoption subsidies for children with disabilities.**
- 8. Support funding for paid care coordinators for existing Community Resource Coordination Groups (CRCGs) to facilitate coordination across agencies in communities.**

- 9. Include *independent* case management/service coordination as a waiver service, and ensure that the case load of case managers is adjusted to reflect the complexity of the needs of the people served.**
- 10. Relevant state agencies, with broad stakeholder input, should expand the availability of wrap-around services and flexible funding for persons with complex needs.**
- 11. Increase funding for Centers for Independent Living to assist people who wish to move out of institutions into their own homes in communities.**
- 12. Restore Medicaid and the Children's Health Insurance Program (CHIP) to their 2003 service levels.**
- 13. Increase funding for the Children with Special Health Care Needs Program to support health care benefits, outreach, case management, and family support.**

Progress Toward Individualized Service Delivery Based on Functional Needs

Texas health and human service agencies, private and public service providers, and people with disabilities and their families have begun to explore multiple ways that service delivery may be more responsive to the functional needs of each individual. Building on the successful passage of the nurse delegation legislation in the 77th Legislative Session and the efforts of the Consumer Directed Services work group established in SB 153(78th Regular Session/2003), progress is being made in allowing individuals to design the service arrangement that best meets their needs. Several approaches have been successful in other states and/or countries and show promise for establishing or expanding in Texas.

Agency of Choice

Consumers often complain that when they need one single service, they have to accept a whole array of services that they do not want or need. Consumers question why the state agency cannot be more economical and flexible in providing for specific needs. The “agency of choice” model allows individuals to select from a wide range of services offered through one service provider and to have as much control as possible over the services they receive without actually becoming an employer. Expanding the agency of choice model would provide a spectrum of service provision that could meet the needs of people with disabilities who have varying desire and ability to direct their own personal assistance services. With agency of choice, Texas is able to offer an array of programs that permit consumers to choose the level of consumer direction that suits their needs.

Self-Determination

Self-Determination can be thought of as a systems change movement, a concept, and a process by which people with disabilities and the people important to them create a “real” life that reflects that individual’s own personal goals and desires. The main components, according to the Center for Self-Determination, are:

- Freedom to live a meaningful life in the community;
- Authority over dollars needed for support;
- Support to organize resources in ways that are life enhancing and meaningful;
- Responsibility for the wise use of public dollars; and
- Confirmation of the important leadership that self-advocates must hold in a newly designed system.

In 2004, the Texas Council for Developmental Disabilities, the Center for Disability Studies, and The Arc of Texas joined together to develop a coalition of state agencies, service providers, advocates, and individuals with disabilities to bring about more opportunities for self-determination in the lives of people with disabilities. The organizations involved with the Texas Self-Determination State Policy Team are receptive to the concept and many are taking key steps toward using elements of this model in how they provide services. For example, Sabine Valley Mental Health and Mental Retardation Center is using existing resources to establish components of Self-Determination in the lives of several people who are receiving services through different waivers – one for each waiver.

TCDD, likewise convinced of the positive changes that could occur, recently allotted more than \$700,000 for a three-year period to create a project that would provide training and technical assistance about self-determination and demonstrate the benefits with a number of individuals in different areas of the state.

Fiscal Intermediaries (Consumer Directed Services)

Fiscal Intermediaries provide people with disabilities with increased flexibility and control over the services they receive. Many states – including Texas – use this model to allow Medicaid program participants and their families to manage how their services are provided. This model allows for the participant or participant’s representative to serve as the employer of his or her individually hired attendant(s). However, an organization that serves as the person’s fiscal intermediary handles the more technical employer-related responsibilities related to payroll activities and filing of employer-related payroll taxes. The fiscal intermediary may also provide the participant with skills training, brokering other benefits such as Workers Compensation or health insurance, or other support functions including assistance with money management. The organization may be reimbursed for financial management services as a waiver service or as an administrative function.¹⁶

The fiscal intermediary model used in Texas is known as “Consumer Directed Services” (CDS) and is currently available in six programs with plans to include it in a seventh – the Texas Home Living (TxHmL) waiver. Consumer Directed Services are expected to be included in the Home and Community-based Services waiver as well. The degree to which waiver service recipients choose to use the CDS option varies from a high of 28 percent to a low of less than one percent.

Programs Using Consumer Directed Services, as of September 2003	
<i>HHSC Executive Summary. Effectiveness of Consumer Directed Services. 2/1/2004</i>	
Program or Waiver	Percentage of Clientele Using CDS
Community Based Alternatives (CBA)	.7%
Community Living Assistance and Support Services (CLASS)	28%
Deaf-Blind-Multiple Disability Waiver (DBMD)	2.1%
Primary Home Care (PHC)	.07%
Consumer Managed Personal Assistance Services (CMPAS)	8%
In-Home and Family Support Programs (IHFS) at TDMHMR	.05 to 1%.

Self-Directed Support Corporations (SDSC)/ Microboards

Greater numbers of individuals with disabilities and/or their families are beginning to establish SDSCs, or microboards, to assist in planning and accessing needed supports in their lives. As a legally-recognized entity composed of people who know and care about the person, an SDSC may receive and distribute public funds to support that individual in choosing and obtaining housing, employment, education, and other supports/services that might be needed. In 2001, the Federal Administration on Developmental Disabilities awarded Inclusion Research Institute (IRI) a grant to promote the SDSC model throughout the United States. IRI has been tracking the establishment of the SDSC/microboard approach over the past two years. There are approximately 55 SDSCs/microboards across the United States and the numbers are growing rapidly. Individuals and advocates in Texas have taken steps to develop microboards independently, and TCDD has received requests for assistance to develop a microboard association that might promote further development on a wider scale.¹⁷

Addressing the Shortage of Direct Service Workers

Ensuring that there are enough direct service workers is essential to providing the volume and quality of care needed by Americans in community-based long-term care systems. In 2003, the Centers for Medicare and Medicaid Services (CMS) created a demonstration program to make direct grants to states to address the increasing shortage of direct service workers. In fiscal years 2003 and 2004, 10 CMS grants were awarded to states and other community providers totaling over \$11 million. Six grantees received \$1.4 million each, and five of these grantees will offer health insurance to direct service workers, testing whether that incentive assists in keeping workers in their positions for longer periods. Two other grantees received \$680,000 each to develop educational materials, train service workers, develop mentorship programs and other activities.¹⁸

In 2002, TCDD awarded funds to four Texas organizations to develop and pilot innovative approaches that identify the specific strengths of a community and build on those strengths to increase the number of people who are working as personal assistants in that community. All four grantees were expected to work with the legacy agency Department of Human Services so that agency would have the benefit of seeing the benefits of various approaches.

TCDD Recommendations

- 1. The Health and Human Services Commission (HHSC) and relevant state agencies should expand the use of the Agency of Choice model, with input from the people who are impacted.**
- 2. Encourage, promote, and pilot additional components of Self-Determination in at least one waiver or program (some waivers currently include Consumer Directed Services (CDS) that enable people to have control over personal assistance and respite services).**
- 3. Implement evaluation criteria for publicly funded services and supports to determine the success of achieving outcomes related to self-determination.**
- 4. HHSC and relevant state agencies should expand consumer-directed personal assistance services, with input from people who are impacted.**
- 5. Relevant state agencies should determine eligibility for personal assistance services based on a functional assessment of needs, and pay personal assistants an amount based on the level of support that is provided.**
- 6. Support the development of the direct care industry as a professional industry by encouraging full-time employment, increasing wages, and providing health insurance to all personal assistants/direct care workers.**

Progress in Development of Local Cross-Disability Access Structures

House Bill 2292, passed by the 78th Texas Legislature, required the Health and Human Services Commission (HHSC) to examine ways to streamline the process through which health and human service agencies conduct business in hopes of maximizing efficiency and effectiveness. The bill consolidated the 12 former health and human services (HHS) agencies into one agency and five departments; moved all policy development and rulemaking authority for HHS programs and services to the executive commissioner of HHSC); and directed the commission to determine whether using call centers to conduct eligibility determinations would be more cost effective than the current system. HB 2292 is intended to create cost savings by centralizing administrative functions and to decrease the fragmentation of services across agencies.

Health and Human Services Agency Consolidation

Under the new structure, the Health and Human Services Commission conducts policy development and rulemaking for all health and human services (HHS) programs and functions, manages and directs the general operations of each agency, coordinates administrative functions for all HHS agencies, and determines eligibility for Food Stamps, Medicaid, Children's Health Insurance Program (CHIP), Temporary Assistance for Needy Families (TANF), Supplemental Security Income (SSI) (to the extent permitted by federal law), long-term care services, and community-based support services. Services for people with disabilities are now in the Department of State Health Services (health, mental health, and alcohol and substance abuse programs and services, including state health and mental health facilities and hospitals), the Department of Assistive and Rehabilitative Services (rehabilitation services for persons with disabilities; services for the blind, deaf, and visually impaired; and early childhood intervention services), and the Department of Aging and Disability Services (community-based care and support services to promote independent living; institutional care services through nursing homes, long-term care facilities, assisted living facilities, Intermediate Care Facilities and state schools for people with mental retardation; services for people with disabilities other than psychiatric disabilities; and services for older Texans).

The reorganization most likely will reduce some of the past problems that have been related to fragmentation of services but it also raises new concerns and challenges related to the process through which the new enterprise is responsive to and accessible for people with disabilities. The law replaces agency boards, which had rulemaking authority, with advisory councils that do not. Many disability advocates are concerned that these changes will mean that health and human services policy decisions will become less open to the public.

Call Centers and Integrated Eligibility Determination

HHSC anticipates that additional savings can be achieved by streamlining central office administration, information system support and other eligibility support functions. Using a business case analysis, HHSC concluded that private call centers would be a cost-effective way to determine eligibility for a variety of services – including Medicaid, Food Stamps, Temporary Assistance for Needy Families (TANF) and long-term care. HHSC expects the call centers to save at least \$389 million over the next five years.

HHSC's proposed redesign of the state's eligibility determination systems would establish private call centers to receive and process applications, and consumers would be able to track the progress of their applications through an automated phone system or through a Website. The call centers would encourage clients to apply for state services through the Internet, over the phone and by fax or mail. Although individuals will still be able to request a face-to-face application process, advocates for people with disabilities have noted that the emphasis on application via telephone or Internet might be prohibitive to some individuals, especially if it results in fewer, more distantly located, offices where one may apply in person. HHSC hopes that the entire process will provide, for most people, an easier recertification process and behind-the-scenes coordination to allow clients to access a variety of services – even across agency lines – with one application.

The Texas Real Choice Grant

The Texas Real Choice Grant: Creating a More Accessible System for Real Choice for Long-Term Care Services is a three-year federal project spearheaded by the Centers for Medicaid and Medicare Services (CMS) and stemming from President Bush's 2001 Freedom Initiative. Texas received \$1.4 million for the duration of the grant.

In December, 2002, HHSC announced that the agency would use \$444,000 yearly for three years to test models and practices for long-term care systems change in three counties in and around Sherman/Denison (Texoma area) and 13 counties in and around Belton, Killeen and Waco (Heart of Central Texas).

The Texoma region is receiving \$146,000 per year for three years and is using the funds to test the idea of system navigators placed in a single point of access (location). That single point of access is the Texoma Area Information Center. The project is in a three county rural area where persons of any age with any disability can find needed resources and get the personal assistance of a navigator if they need it. The Heart of Central Texas is receiving \$297,000 per year for three years. The purpose of this grant is to provide guidance to persons with disabilities regardless of age and to persons over age 60, their families and caregivers with the ultimate purpose of instituting systems change in the Long Term Care area. The project will place system navigators in "Aging and Disability Resource Centers" across 11 counties in two of Texas' human services regions as well as in various agencies and organizations. The central Texas project has three desired outcomes 1) people are directed to appropriate services no matter where they enter the system; 2) a single point of access to services; and 3) a technological infrastructure for services agencies to share information.

TCDD Recommendations

- 1. Ensure that people on interest lists receive easily understood information regarding all long-term care services options, including information on other waivers for which they may be eligible.**
- 2. Ensure that pre-admission screening occurs for all children and adults prior to institutional admission and that all options fully explained and understood.**

Projection of Future Long Term Care Service Needs

The level of future need for long term care services is dependent upon more than the numbers of people with disabilities and the extent to which they need supports and services. Investing now in appropriate and sufficient community-based services and supports that enable people to live, learn and work in communities, establish long-term relationships, access appropriate medical care, participate actively in communities of worship and in recreation activities, and have more control of their lives could substantially decrease the extent to which people with severe disabilities require formal services. Supporting families of children with disabilities in ways that keep families intact, ensuring that children with disabilities receive the same quality of education as their peers, and enforcing all aspects of Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA) so those children may grow up to hold jobs of their choosing and for which they are well qualified will no doubt lead to very different outcomes for individuals and society than would occur should the family be forced to place their child in an institution.

Proactive Efforts to Manage Long-Term Care Needs

Access to community-based healthcare and wellness programs likely would decrease the incidence of preventable secondary disabilities or conditions, which sometimes can be more debilitating than the primary disability. The National Center on Birth Defects and Developmental Disabilities (NCBDD) Healthy People 2010 report found that people with disabilities were more likely than the general population to have health related concerns. It also found that 29% of people with disabilities reported no leisure time activity compared with 20% for the general population, and 49% of people with disabilities aged 18 and older reported adverse health effects from stress compared to 34% of the general population.

Accurate diagnosis, availability of services and supports designed to meet the needs of people with many different types of disability, and eligibility standards that are based on functional needs are necessary to ensure that people with disabilities get the supports most appropriate for them as an individual. Some disabilities in particular appear to be on the increase and some advocates express strong concern that appropriate services are not available and accessible to the extent they should be. For example, the Centers for Disease Control and Prevention reports:

- Autism now affects one in 250 births;
- Rates of Fetal Alcohol Spectrum Disorder are estimated at one per 100 live births in the United States, according to the Substance Abuse Mental Health Services Administration;
- Each year in the United States an estimated 1.4 million people sustain a Traumatic Brain Injury (TBI) and of those 80,000 to 90,000 people experience the onset of long-term or lifelong disability associated with the injury. According to the Centers for Disease Control, 144,000 Texas sustain a traumatic brain injury each year, one every four minutes. The prevalence of disability from TBI is greater than from AIDS, Alzheimer's, stroke, muscular dystrophy, cerebral palsy, or spinal cord injury combined.¹⁹

Even so, advocates for people with autism spectrum disorders, fetal alcohol syndrome, and traumatic brain injury consistently say that the current system of publicly-funded services and supports frequently does not meet their needs. Similarly, many people who have other disabilities report that their needs would be better met – and sometimes met more cheaply – if programs had greater flexibility.

Determining the appropriate amount and level of long-term care services needed in the future becomes difficult at best when the bases of the projection are estimates of changing demographics and a constantly growing understanding of clinical needs. In addition, any means of predicting future need should incorporate current knowledge of those best practices that enable individuals to live more independently and to maximize their strengths and should recognize the expressed preferences of the people using those services.

TCDD Recommendations

- 1. Develop rules that ensure that private health insurance covers personal assistance services.**

Consumer Satisfaction and Consumer Preferences

Across the nation and in Texas, people with disabilities have said overwhelmingly that they have essentially the same needs, preferences, and desires of people who do not have disabilities. They want to live, work, interact, and recreate freely and in communities of their choosing. Services and supports – including those types of public services that are intended to be available to all, such as transportation and education – must be accessible and responsive to the needs of people with disabilities. Even more importantly, there must be a mechanism in place where those services are responsive to *individual* needs and preferences, as people with disabilities are not all the same. This makes it particularly important that policymakers at all levels ensure that people with disabilities are encouraged and supported to participate fully in decisions that affect them. This may require that additional information and training is available to help people understand their rights, and that programs, such as money management programs that may prevent the need for an inappropriate guardianship, are in place to protect those rights. In addition, the service system must continue to develop into one that recognizes the importance of people making the decisions about their own lives and that is flexible enough to be individualized to help people meet their personal life goals.

In their report to the legislature, the Children’s Policy Council explains:

*“Over the past two years, the state has focused on the reorganization and the restructuring of the health and human services system. Now that a new structure is in place, the focus should shift to creating a new health and human services organizational **culture** that focuses on person-centered and family-centered services that lead to opportunities for individuals to lead self-determined lives. The health and human services system should now shift the focus to designing a service delivery system that provides services and supports that meets the individuals needs.”*

United Cerebral Palsy (UCP) of Texas interviewed individuals with disabilities across Texas about their needs and preferences, particularly in relationship to housing. Their stories provide a sample of the needs that exist – needs for increased availability of affordable accessible housing, for enforcement of regulations and compliance issues, for information and technical assistance. More importantly, the stories show the depth of insight that can be gained from asking individuals about their lives and from listening to what they have to say. These interviews give snapshots of one point in time; the challenge is to adapt and humanize systems so that the real stories – the reason the systems exist in the first place – are heard on an ongoing and continuous basis. Eight of these interviews and two personal stories collected by Texas Mental Health Consumers follow the recommendations.

TCDD Recommendations

- 1. Include people with disabilities and family members in the training of professionals, on state level committees that make recommendations regarding policy that affects people with disabilities, and in the development and implementation of services that impact them.**
- 2. Support increased funding for alternatives to guardianship programs, such as money management assisted decision-making programs.**
- 3. Develop alternative(s) for making placement and healthcare decisions for children living in institutions when parents or other legally authorized representatives cannot be located.**

Carmen

Carmen loves water, music, shopping, hamburgers and SpongeBob SquarePants. These tidbits about the 13-year-old come out during a lively discussion with Carmen's family – father, Esteban; mother, Carmen; and sisters, Maria and Yarene. The conversation is punctuated with the patter of busy little feet, courtesy of Yarene's daughter, Luz. The only one missing is Carmen's little brother who is at school.

Carmen's parents and siblings say they love and value her for the unique contribution she makes to the family as a whole. They also believe – strongly – that attending to Carmen's well-being, today and in the future, is a family responsibility they all gladly accept.



Carmen has Rett's Syndrome – a rare neurodevelopmental disability that only girls have. Currently in middle school, Carmen attends special education classes in the Marble Falls school district. She receives assistance through a variety of services from the school, human service agencies, family support groups and others. But none compare with the extraordinary attention and support Carmen gets in her own home, from her own family.

Six years ago, the family moved from Los Angeles. They were alarmed and discouraged because Carmen's school there repeatedly refused to investigate why she came home with so many cuts and bruises. They moved to Marble Falls on the advice of a cousin who described the small Hill Country community as welcoming and supportive.

From the beginning, they found that to be true. Esteban, who came to Texas with years of experience in gardening and landscaping, found work with a local company. With a friendly nature and strong work ethic, he made friends easily. One friend, in charge of the town's housing agency, helped the family purchase a home with a loan designed specifically for low-income families. Life was good.

After three years, Esteban opted to start his own landscaping business. As the only one who drives, he is the family's "go to guy" for transportation – including frequent trips for Carmen's appointments with doctors, specialists, teachers and others. "I didn't feel right about having to leave my job so frequently," Esteban says. "In my own business, I can plan my work around what my family needs." Esteban's wife and oldest daughter work landscaping jobs with him. Maria participates in a home school program that allows her to be on hand when Carmen and her brother come home from school. Everybody pitches in to keep both business and home running smoothly.



While acknowledging a number of friends and acquaintances who are ready and willing to help, the family prefers to take care of their own needs. “We try not to depend on other people,” Esteban says. Still, there was one nagging problem they couldn’t find a way to solve on their own. The two small bathrooms in their home were not accessible for young Carmen. They were cramped and lacked handrails. Getting to the toilet was a challenge, and the shower was inaccessible. Her mom had to lift Carmen in and out – endangering them both, especially as Carmen grew.

Esteban did not have the funds to pay for modifications. He started asking around, and hoped someone in his circle of friends, customers and acquaintances would have an idea. Carmen’s teacher came upon information about United Cerebral Palsy of Texas’ (UCP Texas) home modification efforts through the Texas Home of Your Own (HOYO) program. Fortunately, the program had funds from a home barrier removal allocation from the Texas Department of Housing and Community Affairs (TDHCA). HOYO agreed to provide the maximum funds allowed to modify the home to assure that Carmen could remain with her family. They developed a plan to convert the existing garage into a fully accessible bedroom and bathroom.

When all of the bids submitted by contractors came in well over the program’s limited budget, the small town grapevine kicked into gear. Carmen’s teacher mentioned the problem to a friend at a local mortgage company, who mentioned it to a friend at church, who just happened to be the president of the Marble Falls Habitat for Humanity chapter.

Habitat for Humanity usually does not do home modifications, but Habitat volunteers committed to doing the work if someone else could come up with the funding for the materials. This was a first-of-its-kind arrangement for the organization.

Habitat did quality work at a minimum cost thanks to the construction volunteers who donated their time and expertise to Carmen’s room. A retired builder volunteered to lead the effort. A master electrician donated labor and only charged for materials. A master plumber pulled the necessary permits and inspected the work at no charge. The city waived the usual construction fees. Before all work was completed, not only did Carmen have a new room, her dad had a new storage building for the lawn equipment previously stored in the garage.



Carmen now has plenty of room to maneuver her wheelchair in her room, and the bathroom is spacious and equipped with safety bars, a roll-in shower and a sturdy shower chair – no more lifting for Mom.

Esteban says he and his family are in awe of the organizations for their kindness and assistance. He can't imagine this happening in California. "People in this town have much better hearts," he says. "We work hard to do things for ourselves, but this was something we couldn't do alone. We are so grateful to those that have helped Carmen and us."



Heather

In the fall of 2001, at age 21, Heather’s life changed dramatically in an instant. An accidental shooting resulted in her having quadriplegia. The following months brought a stay at a rehabilitation hospital in San Antonio and, then, a series of moves to different nursing homes as she searched for a place to live that wasn’t “horrible.”

In December 2002, Heather moved into her first apartment in Universal City on the outskirts of San Antonio. The apartment complex, which only housed people with disabilities, offered rental assistance to its residents. That helped with finances, but Heather wasn’t keen on the segregated

setting. The location was problematic, too. “There was nothing even remotely near there,” Heather says. She preferred to be closer to places to eat and shop – especially a store to buy arts and crafts supplies.

With assistance from a community integration specialist from Advocacy, Inc., Heather applied for a Section 8 voucher from the city’s housing authority and located a relatively accessible unit in an older apartment complex. It was just the type of place Heather was looking for, and the landlord promised to make the bathroom accessible. In April 2003, she moved in.

Fifteen months later, Heather packed to move again. The owner who promised the modifications left the week after Heather arrived. The new owner refused to honor the verbal agreement and has not modified the apartment. He also refused to install a ramp that Heather says would make navigating through the complex easier and safer.

Beyond the physical barriers, Heather says the owner’s attitude about her disability makes her feel unwelcome. “He has said that I’m a liability because I’m paralyzed,” she says. “That was after a former attendant came back to my apartment and robbed me. The owner also doesn’t like that I had to call an ambulance a few times when I got sick.

Heather thinks there may be something other than ignorance and insensitivity behind the owner’s lack of accommodation. “I think he’s trying to get rid of all the Section 8 tenants,” she says, noting that she may be one of only two voucher recipients left in the complex.

While she contemplates filing a discrimination complaint, Heather's immediate goal is to get moved, get her things organized again and get back to work on the Website she's creating for people with spinal cord injuries. It took a while to find a suitable apartment, she says, for reasons that a lot of people with disabilities will recognize. "I'd get a list of supposedly accessible apartments that accept Section 8 from the locator service," she says, "and they were in a bad part of town or I couldn't get in the front door – or both."

The apartment Heather has chosen is the second one she located this time around. She had to pass on the first one when the landlords didn't come through with all of the promised modifications. Heather says, even with the hassles, apartment living is much better than the nursing home. "I like the privacy and having more control over my life," she says. "It's almost like normal, like it was before my accident."

Alvin

When Alvin went from the hospital to the nursing home, he expected to stay there about eight weeks for rehabilitation of a back injury. That was almost two years ago. The 55-year-old, Waco-area native says it's hard to believe it's been that long, but until recently he didn't know he had much choice. "Basically, I'm still here," he says, "because I didn't have any other place to go."



Alvin says he was not familiar with services that might be available to him and trying to figure them out from the confines of a nursing home isn't easy. He was trying to get help from the local housing authority when the nursing home social worker connected him with the Heart of Central Texas Independent Living (HOCTIL). With funds from a federal nursing home transition grant, HOCTIL helps people who want to move from nursing homes into the community.

Currently, Alvin's income is a monthly Social Security disability payment just over \$500. With a Section 8 housing voucher, he should have enough funds to rent a one-bedroom apartment. Finding that apartment in Waco, however, remains challenging. One-bedroom units – the only type HUD regulations will allow him to lease – are scarce in complexes that accept Section 8 vouchers. Alvin is still confident he will be moving and, most likely, sooner rather than later.

Before his hospitalization, Alvin worked two jobs – in a school cafeteria during the day and with a janitorial service at night. Home was a local motel room rented by the week. Alvin says once he gets readjusted to community life, he will see about returning to work, if his back condition allows. His plans include getting up to speed on using a computer. More than anything, Alvin looks forward to reclaiming two things that are important to him: independence and privacy. He is anxious to enjoy simple pleasures like sleeping and waking on his own schedule and being in control of when and what he eats.



Dawn

Dawn, a 26-year-old who has Fetal Alcohol Syndrome (FAS), explains that one of the biggest barriers she faces is that she doesn't fit into people's idea of what a person with a disability can and cannot do. "A lot of people seem to think if I just try harder I can do anything I want. They don't understand what's happening in my brain. I may look like somebody who's doing OK," she adds, "but that's not the whole picture of me." Because Dawn has many skills and works hard to be independent, some people have difficulty recognizing she has a disability and understanding the type or level of support she needs.

"I need help solving problems, managing money, defeating my addictions and planning my life," Dawn reveals. FAS is a disability not well understood by schools, social service agencies or the general public. Some people with FAS have more severe cognitive impairments, and as she says, "The system knows more about how to work with them."

Throughout her school years, Dawn attended special education classes. She graduated and went to community college for a while and earned certification as a nursing assistant. She says she hasn't been able to capitalize on these successes, though, because the disability gets in the way. Trying to be more independent, Dawn has lived with boyfriends and in a few halfway houses for people with alcoholism. The halfway houses, particularly, didn't have a clue about how to support someone with FAS, she says.

Dawn currently lives with her parents in Round Rock, north of Austin, Texas. She has two months of sobriety under her belt and two new jobs – as a hostess at a local restaurant and as a photographer's assistant. Dawn feels she is not ready to live by herself, but she is determined to keep things on track this time and is glad for the soft place to land. However, like many others her age, she feels like she is too old to be living at home and longs to live somewhere more appropriate for an independent young woman.

When asked about her ideal living situation, Dawn isn't choosy – she would like to have a roommate or even find a halfway house intended specifically for people with FAS. She is actively looking for people her age with personal experience with FAS. It is hard for her to find folks who relate to her experience and needs; yet, that would mean more to her than anything. "I think it would help so much to be able to talk to people who understand what I'm dealing with. I'd like to share ideas and experiences – and learn how to move on from here."

Robert

Robert lives in his boyhood home in a nice El Paso neighborhood, with his father, Joe. It's a practical arrangement, but Robert, at age 51, yearns to be his "own man" – the head of his own household. "I've always wanted to raise a family on my own," Robert says. "I may be old, but that is still what I want."

Robert's mobility and speech are significantly impaired by cerebral palsy, and he requires a fair amount of support to carry on a daily routine. Personal assistants come by twice a day to help Robert get up, bathe and dress. Joe, who is retired from the military and state government, fills in between their visits, providing transportation, assistance with meals and help with the assistive technology Robert relies on to move around and communicate.



Robert says he feels lucky to have such a loving and devoted father, but he would also like more privacy than he gets under the same roof as his father. He does have his own space in the house where he can watch television, listen to music and work on the computer. However, Robert often feels he needs to meet his friends at the park or mall because "they don't feel comfortable here."

There are several obstacles Robert must overcome to realize his dream of living on his own – beginning with his own "fear of the unknown" and his father's worries "that the attendants won't show up on time and things like that." The two have looked into buying a duplex, but he says there are not many suitable duplexes available in El Paso.

Several years ago, Robert enrolled in the first-time homebuyer education class offered by the Texas Home of Your Own (HOYO) Coalition, but he dropped out when he was laid off from the job he held with Goodwill Industries for 25 years. Unemployed for five years now, Robert continues to look for work. He is currently participating in a program at the local community college that helps people with disabilities find jobs. For Robert, employment is a prerequisite to fulfilling his dream of living on his own – dream he does not intend to let go.



Susie

For the moment, Susie, who has mental retardation, shares her small apartment with her 16-month-old son, Noah, and her sister Dana. Dana is taking steps to be Noah's legal guardian and get a Section 8 housing voucher of her own. At that time, Dana and the toddler will move to another part of town, and Susie will stay put, even though she has some reservations about the apartment and neighborhood. They would rather live together somewhere with room enough for the three of them and Dana's teenage daughter. That way, Susie could have a bigger role in her son's day-to-day life. However, Section 8 regulations don't allow it, so the sisters plan to schedule time together as often as possible.

Susie is 42, and for most of her adult life she has lived in a series of group homes with as many as five other people. She remembers life in a group home as being "pretty strict," with rules about when to get up and go to bed, as well as when and what to eat. She says she didn't feel free to come and go as she pleased and had little privacy. However, the main motivation behind leaving the group home was a physical beating from two of her housemates that sent Susie to the hospital.

Before she moved to this neighborhood on the outskirts of downtown San Antonio, Susie lived by herself in an apartment complex. It was more convenient to her job at Randolph Air Force Base, especially on weekends when the base is closed to public transportation and Susie relies on a ride with her supported employment provider. She also liked the old neighborhood better than her current place because it seemed safer and was closer to the stores and other places she likes to go.

Susie left that apartment because she had grown tired of being teased and taunted by other residents of the apartment complex; their comments made her uncomfortable and unhappy. She decided to move out just a short time before she needed to renew her lease for the apartment, and the quick decision didn't leave her much time to find a new place. With Dana's help, she found this apartment near downtown, and she is focused on moving forward. Her proximity to the San Antonio College sparked a desire to get a General Equivalency Diploma (GED), and on her own, Susie approached the college admissions office about her goal.

Now, on days when she doesn't have to go to work, she attends classes and works to further her education, establish a comfortable home, and care for her family.

Vicky & Fernie

Raising two boys – one with significant disability and health issues – hasn't been easy for Vicky, a single mom with limited income. Once, years ago, her mother volunteered to keep Steve for a while, to lighten the load. Vicky declined the offer, vowing to keep her family under one roof.

Today – 15 year years later – she has made good on that vow. Though Steve is away in the military, he stays in close contact with his mom and brother. Vicky and Fernie live in a small brick home in El Paso. This house – rented with the Section 8 housing funds – is the “fourth or fifth” in which Vicky and Fernie have lived. Prior to renting, Vicky purchased a mobile home, but found it too difficult to keep up with the payments and maintenance while going to school and raising a family.

Vicky is looking for a more permanent housing situation and is working toward owning her own home again. “I would prefer to be in one place and not move so much,” she explains, “because it will be so much better for Fernie. He needs to be involved in his neighborhood and community. It takes a little while for him to get familiar with his surroundings and it's hard when we have to move so often.”



Ideally, Vicky says, her new home will be located within walking distance from Fernie's school, a pharmacy, grocery store and park. Hopefully, she adds, the streets will not be too busy, so Fernie can continue to ride his beloved three-wheeler through the neighborhood. Mobility is also becoming an issue for Vicky, herself. She is losing her vision to a degenerative eye disease. She is taking a correspondence course to learn Braille and works with independent living caseworkers to learn how to support Fernie and manage her household as her sight diminishes.

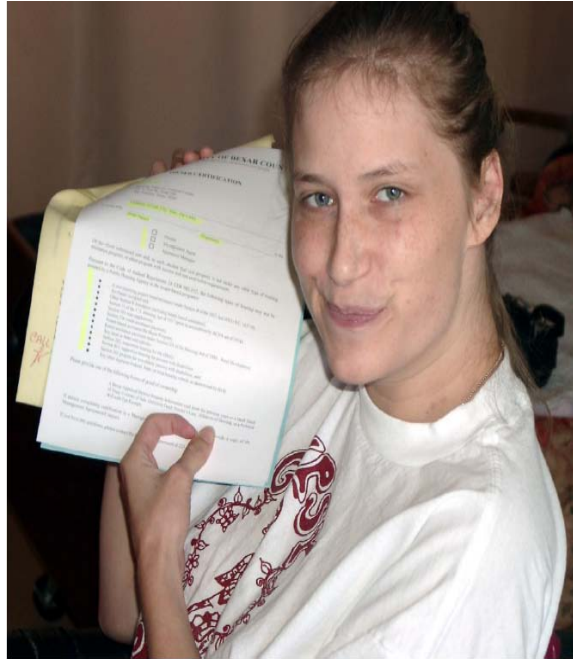
Adversity only seems to fuel Vicky's optimism and determination to provide the best possible future for Fernie. She is participating in United Cerebral Palsy of Texas' Home of Your Own (HOYO) program, which assists people with disabilities who want to be homeowners. Currently, she's working to clean up her credit report to be a better candidate for financing.

Grateful for any roof over her head, Vicky does not complain about renting for now. “But, I think it will better when I know Fernie's future is more secure in our own home,” she says.

Brook

After months of waiting, the Section 8 housing voucher finally arrived for Brook, age 27 and the youngest resident in one nursing home in San Antonio. The voucher is Brook's ticket to life as she knew it before January 2004, when she was hospitalized for a urinary tract infection.

Brook has Frederick's Ataxia, a hereditary neuromuscular disease that causes muscle deterioration and loss of coordination. Her first symptoms appeared at age 14. By 17, she started using a wheelchair full-time. Now she needs assistance to transfer in and out of the wheelchair.



When she checked into the hospital, Brook had every intention of returning to the small apartment she shared with her boyfriend. It wasn't especially accessible, but it was what she could afford. "Apartments that were accessible were usually more expensive," Brook explains. She made do, and was looking forward to returning when she left the hospital. But a conversation with her doctor resulted in an unexpected and significant change in plans.

"I was talking to him about the number of infections I was getting," Brook recalls, "and he said, 'I have a place you can go. It was this nursing home. I thought I'd stay here a few weeks until the infection was under control, then I'd go home. Only later did I realize I was stuck here.'" Brook says she was not familiar with her rights or options. She didn't know how to begin to get out. Fortunately, the nursing home's social worker was familiar with the Center on Independent Living (COIL) and its program, funded by a federal grant, to help people return to community living.

With COIL's assistance, Brook applied for a Section 8 housing voucher which, combined with her income from disability benefits, would allow her to move out of the nursing home and into an accessible apartment. Somehow, the application got lost at the state agency in Austin responsible for processing it. Two months passed before Brook knew she would have to repeat the cumbersome process of making an appointment with the San Antonio Housing Authority to pick up the application, making another appointment to turn it in and so on. Brook persevered. Finally, on a happy day in late August, her efforts were rewarded when the voucher arrived.

The COIL specialist who worked with her all those months helped to check out various Section 8 apartments. They found one in a safe part of town with the accessibility features important to Brook – not the least of which is a roll-in shower.



Brook can barely wait to regain her independence and spend more time with her boyfriend and friends. They’ve stuck with her through this time, but haven’t been keen on spending time with her in the nursing home. She’s also looking forward to being in control of her schedule, menu and activities.

Brook’s biggest frustration is the Section 8 rule that prevents her from living with her boyfriend. Her mom lives several hundred miles away, and Brook considers her boyfriend to be the only family she has in San Antonio. The adjustment to living apart is a big one. Still, she is moving forward and happy to be shedding the confines of the nursing home. “I’m hoping it’s going to be great,” she says.



Michael

Adapted from “The Stories Behind the Faces”
by the Texas Mental Health Consumers

My name is Michael, and I am an individual with Schizophrenia. I have been dealing with Schizophrenia since 1994. I have been in treatment since then, and I have benefited from various groups, counseling, supported housing and employment services, in addition to the clinical services I received. I think that staying on the right medicine, talking to the doctor, and taking medication as prescribed, in addition to the services I received, has made a difference in my recovery.

Currently, I receive medical services from the nurse and doctor. I also meet with my service coordinator, rehabilitative specialist, and the housing staff on a monthly basis to maintain my independence. At one time, I received supported employment services, and I had a sheltered job doing janitorial work. The supported housing service helped me to transition into the community and to secure Section 8 housing and my own apartment. I have been in my own apartment for over eight years. Living independently has made me feel successful.

When services were cut in the past, I had difficulty adjusting. It made me feel sad, and caused problems in getting my needs met. I had difficulty in getting transportation to and from the nurse and doctor appointments. I was also not able to participate in classes that empowered me to deal with my illness. I had learned how to talk about my problems with the doctor and caseworker through these classes and groups. I also participated in activities like picnics and other recreational activities that helped me feel better and practice how to talk to others. Before the cuts, I was participating four times a week and now I only have individual sessions one time a week. This slows me down, because now, I must wait until staff are available and see them only if it meets the reduced schedule. Before the cuts, I was able to make appointments more easily. This lack of opportunity has increased my sadness and creates more problems for me to deal with. I’m worried.

If funding for services in the mental health budget are cut or reduced, many of the services I currently rely on would be limited or discontinued. This would increase my symptoms, since I tend to isolate myself when I do not have supports and quality of services. I feel comfortable with the staff and am able to communicate and cope better as a result of medication and services. I am also able to live independent of my family. I can also communicate and relate to them better because of the skills I have learned. I am proud of having received training as a Peer Facilitator, which helps me to deal with my illness, and also to help others.



Angela

Adapted from “The Stories Behind the Faces”
by the Texas Mental Health Consumers

My name is Angela. I am a 22-year-old single mother, with a 2-year-old little boy named Ian. For the longest time after I had given birth to my son, I suffered from post-partum depression. I thought I could handle it and that it would eventually blow over, but I was wrong. A year later, I was hurting myself through self-mutilation and popping painkillers. My family told me to get help, but I refused. I didn't feel like I had a problem, until one day I cut my arm so badly I almost hit a vein. That's when I went to get help.

I go to Bluebonnet Trails MHMR two times a week for counseling check-ups, and I take Zoloft and Buspar. I have been extremely happy, enjoying life to the fullest. I wake up every morning to a beautiful son, thanking the people at Bluebonnet Trails and myself, for getting the help I so desperately needed. The mental health system has helped me in so many ways, such as helping me get involved in Mental Illness Awareness (MIA) meetings and events. I attend MIA every Thursday, for every meeting. I also attended a Capitol Day “No Budget Cuts” rally in Austin (sponsored by the Disability Policy Consortium and the Community First Coalition). I got to meet a lot of folks just like me, and I know now that I am not alone in this battle with manic depression.

I also have a wonderful job in a nursing home taking care of the elderly and loving them. It allows me to get to know myself better by letting the elderly watch me learn and grow. It would be a disaster for the legislature not to fund the services that I need to stay in a positive state of mind. It takes a lot of bravery and courage for a person to express, “I need professional help,” and “I want to become free of all the negative feelings I have inside.” It's all about being honest with yourself and taking care of what needs to be taken care of. We have enough problems in this world; we don't need any more. We all want to find serenity in ourselves in some way or another. Don't we?

Section III: Community Based Services and Supports for People with Developmental Disabilities

“Disability Issues” have been viewed historically as issues related to medical needs, rehabilitation services and other long-term care services and supports. Biennial Report legislation, directs TCDD and TOPDD to provide information on “consumer” needs as they relate to service delivery. The vast majority of people with disabilities do not want to live in institutions; they want to live in their own homes, with their families and friends. Many (if not most) of the day-to-day barriers faced by people with disabilities living in communities are related to having the same needs all citizens have, such as housing, transportation, employment, and education.

A disproportionate percentage of people with disabilities are living in poverty and depend solely upon those public services that are intended to be available to everyone. However, people with disabilities and their families are under-represented in the planning processes around these. Consequently, these services – to which they are as entitled as any other citizen – frequently are not responsive to their needs. This section describes some of the most pressing barriers and needs around housing, transportation, employment, and education issues and offers recommendations for barrier removal. The most lasting solution, however, to making these services more accessible and responsive is to ensure that people with disabilities and their families are involved in all phases of planning and implementation.

Housing

The Texas Department of Housing and Community Affairs (TDHCA), serves as the state’s lead agency for affordable housing, related community services, energy assistance programs, and colonias activities. The agency has a mission to help Texans achieve an improved quality of life through the development of better communities. TDHCA administers programs that encourage the production of affordable and quality multifamily housing; assists individuals and families to purchase homes, repair homes, and secure affordable rental housing; and improve the living conditions of people who are homeless or low income.

In May 2003, TDHCA and the Texas Council for Developmental Disabilities entered into a Memorandum of Understanding to study the housing needs of low income Texans with disabilities. TDHCA’s study addresses demographics and housing need, policy and research, and current housing programs. To assist TDHCA in analyzing the need for and availability of housing stock for people with disabilities, TCDD contracted with United Cerebral Palsy of Texas to conduct 27 focus groups around the state and to interview people with disabilities individually. All focus groups discussed housing needs, experiences, and preferences. Two groups were conducted in each of the 13 TDHCA regions; one consisted of people with disabilities and/or family members of people with disabilities, and the other was made up of service providers (including developers, lenders, public housing authorities, and other service providers). A final focus group was made up of members of the Disability Policy Consortium.

The TDHCA Study

TDHCA encountered several difficulties in the data gathering process, including:

- Definitions of “disability” that are not consistent across all programs;
- A lack of awareness by property owners regarding whether or not a tenant has a disability;
- Differences in accessibility requirements that make it difficult to assess the amount of publicly-funded housing units accessible to persons with disabilities;
- Difficulty in determining the types of modifications that might be needed by people with various disabilities; and
- Inconsistencies in terms used to describe units available to persons with disabilities which would lead to inconsistency in data concerning “accessible” units available to people with disabilities.

Despite these limitations, TDHCA was able to provide a substantial amount of information to illuminate housing issues as they relate to people with disabilities. The study also provides a breakdown by TDHCA regions with statistics and information relative to each region. This information can be used to implement the recommendations presented here and in their study.

TCDD Housing Study Focus Groups

The purpose of the focus groups and interviews conducted by UCP of Texas was two fold: gather information on a wide range of housing-related issues from a wide range of people; and allow people with disabilities and people who provide housing for people with disabilities a chance to speak directly about their experiences. While the groups were asked the same questions, the difference in group composition (for example, one group included people who were homeless, some groups drew from rural areas, some drew from urban areas) was designed to ensure that a variety of viewpoints were represented. Because of the variations in group composition, no valid comparison of one region to another can be made.

Individuals with disabilities who participated had a variety of disabilities and situations: cerebral palsy, cognitive disabilities, hearing impairments, mental illness, substance abuse disorder, HIV/AIDS, etc. They included single mothers, married individuals with and without children, and older Americans. Some of them lived alone; some lived with family or with roommates. Others lived in halfway houses, nursing homes, regular apartments, and single family homes. Some owned and some rented. Although the groups represented a wide variation in disability, family status, and living situation, several themes reoccurred across the spectrum:

People with disabilities consistently said:

- The community of people with disabilities is varied, and so are their needs. There are different levels of accessibility needs, so some housing designs will not work for different people. The preferred housing situation is having individualized modifications.

- Most of the participants were not content with their living situation and had difficulties due to needs for physical modifications, but also experienced issues related to safety, inadequate transportation, long waits for accessible housing, and discrimination. Individuals stated that rental property with low rent prices – that which they could afford without subsidies – is usually substandard.
- When asked if they thought people with disabilities “liked” to live together, the overwhelming majority of participants scoffed at the idea and stated that they preferred to live as independently as possible.

Developers, Public Housing personnel, Lenders, and Service Providers consistently said:

- They had little to no experience working with people who have disabilities.
- The laws and regulations are confusing and difficult to understand, and people were unaware of formal training about Fair Housing.
- Building contractors are not educated about the laws and regulations surrounding projects.
- They had insufficient information about housing needs of people with disabilities.
- “Without vouchers, you are destined for substandard housing.” Concerns exist related to a lack of services and amenities (such as air conditioning and heat) in older houses, safety issues, poor quality, and a lack of monitoring or any quality assurance process.
- Attitudes of landlords and neighbors are barriers to community integration. Participants stated they had encountered views ranging from “Not In My Back Yard” to a lack of understanding that there is a need for housing for people with disabilities – particularly in areas where a state school is one of the predominant employers – because “they” “have a place to go.”
- It appears that consumers frequently won’t follow through on housing discrimination complaints because they are afraid of retaliation.

People in all groups confirmed that people with disabilities have a very difficult time finding housing that is affordable, accessible, and integrated.

Affordability

People with disabilities continue to be the poorest people in the nation. As a national average, Supplemental Security Income (SSI) benefits in 2002 were equal to only 18.8 percent of the one-person median household income. According to the Consortium for Citizens with Disabilities Housing Task Force Report, *Priced Out in 2002*, for the first time ever, the average national rent was greater than the amount of income received by the 3.7 million non-elderly adults with disabilities living on SSI income. In 2002, the average rent for a modest one bedroom rental unit in the United States was equal to 105 percent of the SSI benefit, up from 98 percent in 2000. In 2002, people with disabilities were priced out of every housing market in the nation. Of the 2,702 market areas there was not a single area where modestly priced rents for efficiency or one bedroom units were affordable. Based on a comparison of SSI benefit levels, in Texas, it would require 98.3 percent of a person’s SSI income to rent a one-bedroom apartment. If you live in Dallas (121%), Houston (106%), or Austin (125%), the percent of income needed exceeds 100 percent of SSI benefits.

Although Medicaid generally cannot be used for room and board, a letter was issued on May 9, 2002 to all State Medicaid Directors announcing the coverage of community transition services under Medicaid Home and Community-Based Services (HSBS) waivers. States may bill Medicaid for "security deposits" that are made up of the security deposit and the first month's rent (up to a total of two months rent).

Accessibility

The Texas Department of Housing and Community Affairs (TDHCA) 2003 Community Needs Survey found that for people with disabilities the need for accessible structural housing modifications was ranked as the most important activity ahead of the need for supportive services, rental assistance, and down payment assistance.

Modifying an existing home can sometimes become cost prohibitive but adding accessible features to new home construction can be done for minimal cost. The average cost of adding visitable features to a new home is around \$500. Visitable or first level accessible features include: a step-free entrance into the main floor; a bedroom, kitchen, wheelchair-friendly bathroom, and entertaining area all on the main floor; and every interior door on the main floor has a minimum of 32 inches of clear passage.²⁰

TCDD Recommendations

- 1. Strengthen compliance procedures and improve the current mechanism through which housing complaints and issues are monitored and resolved and require the Texas Department of Housing and Community Affairs (TDHCA) to provide technical assistance related to discrimination and accessibility issues.**
- 2. Require TDHCA to ensure that developers, housing providers and consumers receive and understand training provided regarding the Fair Housing Act.**
- 3. Require TDHCA to actively promote efficient and effective architectural barrier removal and home modification services that address the needs of people with disabilities through the provision of technical assistance and training related to architectural barrier removal.**
- 4. Require TDHCA to include strategies in its strategic plan that result in an increase in the number of regular, integrated, affordable housing units for people with disabilities and other necessary initiatives to adequately address the Health and Human Services Commission's Promoting Independence Plan (implementation of the U.S. Supreme Court ruling in *Olmstead v. L.C.*).**
- 5. Develop mechanisms to promote increased collaboration between agencies that provide housing and provide technical assistance to agencies/organizations to ensure accessibility and compliance with regulations.**
- 6. Direct the Office of Rural and Community Affairs to join in the implementation of Senate Bill 367 of the 77th Legislature to address housing and support needs of the population effected by the Supreme Court *Olmstead v. L.C.* Decision.**
- 7. Develop and promote programs to provide education and technical assistance to encourage more Texas cities to adopt local visitibility ordinances.**
- 8. Require that TDHCA establish a set aside within the Section 8 voucher program for people with disabilities who are effected by the *Olmstead* Supreme Court Decision.**
- 9. Increase appropriations for the Housing Trust Fund.**

Transportation

Transportation allows all Texans, including those with disabilities, to access their communities for employment, education, medical care, civic involvement, religious fellowship, shopping, entertainment, and visiting friends and family. While transportation may be available for strictly medical needs, Texans with disabilities frequently must rely on public transportation for other needs. Many people with disabilities are unable to obtain employment with wages that allow them the luxury of their own vehicle. However, even if one can afford a car, vehicle modifications which would make driving possible are often unaffordable, and some disabilities do not allow a person to drive.

Both the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 as amended ensure that public transportation is an open option to people with disabilities. Through these laws, public transportation is required to be accessible to people with mobility impairments. With the curb cuts, accessible bus stops, kneeling buses and restraints to safely secure wheelchairs, people can and do rely on public transit services.

Unfortunately, Texans with disabilities living in all areas of the state report that public transportation can be unreliable, difficult to use, only available at certain times and in limited areas, and inaccessible. Paratransit services can be difficult to use, and little assistance is available to individuals with disabilities regarding either the use of these services or the complaint and/or appeal process related to these services. A high level of dependence on public transportation is not exclusive to people with disabilities nor are barriers to transportation exclusive to Texas.

The National View

- The 2000 Census indicates that over 10 percent of U.S. households do not have any vehicle for transportation. Sixty-six million people are elderly and/or have a disability.
- 27 million people with disabilities rely on public transit for their independence.²¹
- Over the past six years, transit ridership has steadily increased by more than 22 percent as governments continued to improve and invest in public transit systems.

The Texas View

- The need for transportation services is the top priority issue of those attending community forums across Texas. This requirement for transportation is also a priority for people with disabilities.
- Surveys of Texans show that less than 50 percent of urban households are located within a half mile from a bus stop. In rural areas, less than 13 percent of household are within a half mile walk to a bus stop.

Funding Concerns

Public transportation is a factor in economic development, and it can free low income workers to access the job market as well as shopping. In addition, studies have shown that every dollar invested in transit returns three dollars in local business income. A large percentage of transit funding is derived from federal formula allocations, but as local and state economies continue to falter, budget concerns place significant pressures on public transportation systems.²²

The Texas Department of Transportation (TxDOT) receives federal funds from the Federal Transit Administration and then distributes these funds to local transportation providers. These funds can be used for capital expenses, preventive maintenance and contracted transportation services. Texas is required to contribute 20 percent of transportation costs.

In fiscal year 2004, the Medicaid Non-Emergency program, Medical Transportation Program (MTP) moved from Texas Health and Human Services enterprise to TxDOT to fulfill requirements of HB 3588 and HB 2292 (78th Regular Legislative Session).

TCDD Recommendations

- 1. Investigate and implement options to maximize funding of non-medical transportation.**
- 2. Include the Texas Department of Transportation (TxDOT) in the statewide Promoting Independence Plan and develop a mechanism to promote an agency-wide understanding of the transportation needs of people with disabilities. TxDOT should compel the participation of local transit providers in community efforts.**
- 3. Develop and implement travel training programs for paratransit and a systematic way of gathering and resolving complaints related to paratransit.**

Employment

People with disabilities consistently experience high levels of unemployment. The National Organization of Disabilities (NOD) Harris 2000 Survey of Americans with Disabilities states that those between the ages of 18-64, are less likely to be employed, either full-time or part-time, than people without disabilities. The survey concludes that the unemployment gap correlates with low income levels and inadequate health care for people with disabilities.

Knowing exactly how many people with disabilities would work if they were given the opportunity is problematic. The Department of Labor estimates that 14 percent of the active labor force have some type of disability and 3.35 percent of the active labor force have a severe disability.²³ Some critics claim that current definitions available from existing surveys are too limited to accurately measure disability employment data. The National Council on Disability (NCD) states:

“The Federal Government should not encourage or support the dissemination of employment data until a methodology for assessing employment rates among people with disabilities that is acceptable to leading researchers and demographers in the field and credible to persons with disabilities can be developed.”²⁴

Employment Services for Texans with Disabilities

People with disabilities often need access to a wide range of employment services and supports so they can obtain and keep employment that pays a living wage and can be fully integrated into the workforce.

In Texas, the Vocational Rehabilitation system is designed to provide access to services that will enable people with disabilities to successfully enter (or re-enter) the workforce.

The Department of Assistive and Rehabilitative Services (DARS) has two divisions that provide Vocational Rehabilitation (VR) services: the Division for Rehabilitation Services (DRS) and the Division for Blind Services (DBS). Both DRS and DBS have services which help people who have disabilities prepare for, keep, or get a job. The array of services includes: evaluations and testing; medical services; counseling and guidance; work training (including college, technical schools, on-the-job training, etc.); assistive technology services and devices (including certain types of software, augmentative communication devices, etc.); interpreter services for the deaf/hard of hearing; orientation and mobility training for people with visual impairments; supported employment (job coaches and other supports on a job); transportation (to get to services); personal assistance services (on- or off-the-job); occupational licenses, tools and equipment; and other services to reach a work goal.

The Texas Workforce Commission (TWC) oversees a network of 28 local Workforce Development Boards. These boards oversee varying numbers of One-Stop Career Centers (also referred to as WorkSource Career Centers and Workforce Centers) and 12 satellite centers. One-Stop Centers offer career development information, job search resources and training programs, and they administer the unemployment benefit system.

The centers serve people with disabilities. In accordance with the Workforce Investment Act (WIA), people with disabilities, including Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries, are eligible for core and intensive employment services. While some One-Stop Centers provide services to people with disabilities, others commonly refer all people with disabilities to the state vocational rehabilitation programs for job readiness.

Ticket to Work

The purpose of the federal Ticket to Work Program, as instituted by the Ticket to Work and Work Incentives Act of 1999 (TWWIA), is to encourage beneficiaries of SSDI and SSI to work toward and secure employment. The Ticket program addresses what people with disabilities say is the main barrier to seeking employment: the fear of losing medical benefits through Medicare or Medicaid and long-term care services (such as attendant care) through Medicaid.

The Ticket to Work rolled out in Texas in November 2003. 550,156 Tickets have been issued in Texas (as of November 24, 2004) with 447 individuals enrolled in a Ticket to Work employment program. In Texas, there are 43 private employment networks recognized by the Social Security Administration (SSA) along with the state sponsored vocational rehabilitation services through DARS.²⁵

For both SSDI and SSI recipients, the primary benefit of the Ticket to Work relates to the continuing disability review (CDR) that is done by SSA to determine whether an individual remains “disabled” and thus eligible for continued benefits. Under the Ticket to Work program, SSA suspends any CDR for as long as five years while an individual is in the process of using Ticket related vocational rehabilitation services toward employment.

Both SSDI and SSI recipients under Ticket to Work program are promised an expedited reinstatement of benefits should their disability cause them to lose their employment. In addition, SSDI recipients have an additional benefit under the Ticket program. They are guaranteed Medicare coverage for up to eight and a half years after they are no longer income eligible for SSDI due to employment income.

Medicaid Buy-In

A major disincentive for Texans with disabilities who are willing and able to work is the potential loss of health care coverage (Medicaid) if they earn too much income. Consequently, many individuals either do not seek employment or limit their hours or actual wage level. A Medicaid Buy-In program allows working people with disabilities to pay a premium to participate in their State’s Medicaid program, as though they were purchasing private health care coverage. It can permit higher income and resource levels while ensuring continuation of needed health care coverage, thus providing an opportunity and incentive to seek gainful employment. The development of Medicaid Buy-In programs by individual states was authorized under the Balanced Budget Act (BBA) of 1997 and the Ticket to Work and Work Incentives Improvement Act (TWWIA) of 1999.

Self-Employment and Micro-Enterprises

People with disabilities have turned to self-employment as one solution to the problem of high unemployment. It appears that people with disabilities who work are almost twice as likely to start a business as people without disabilities. Of people with disabilities who are employed, 14% are self-employed. Only 8% of people without disabilities who are employed are self-employed.²⁶

A micro-enterprise is a business that is owned by one person, a partnership, or by a family, has fewer than five employees, does not generally have access to commercial loans, and has a start-up cost under \$25,000. Most micro-enterprises are much smaller, operate with fewer than three employees, and frequently are operated by the owner alone. Because of their low start-up costs, micro-enterprises present one solution for people with disabilities who want to start their own business.

TCDD Recommendations

- 1. Increase appropriations for employment services for people with disabilities.**
- 2. Support the implementation of a Medicaid Buy-In Program that allows people with disabilities to purchase Medicaid health care and services when returning to work, with premiums based on a sliding fee scale.**

Education

The Texas Education Agency reported that in the 2001-02 school year there were 493,771 students, or 11.9 percent of the total student population, enrolled in Special Education Programs in grades 1-12. The percentage of students served in special education programs has remained relatively constant over the past 10 years, with a low of 10.4 percent served in 1992-93 and a high of 12.2 percent served in the 1998-99 and 1999-00 school years. Data shows that African American students, economically disadvantaged students and males tend to be overrepresented in the Special Education population.

The success of Special Education Programs depends upon the quality of the collaboration between school faculty, staff, parents, and students. All are expected to be involved in the development and implementation of Individual Education Plans (IEP) and in planning for the student's transition from public schools to adulthood. However, not all parties receive enough information, training, and/or support to participate fully. Training related to data-based practices that support inclusion, that promote a smooth transition process, and that enable students and families to understand and use principles of self-determination to achieve goals would be beneficial to all. Equally important, the state must recognize that some students require additional supports to help them learn the skills that will enable them to be more independent in the long run.

Training to Support Successful Inclusion

According to the Texas Education Agency, 80% of students receiving special education services are included with their peers who do not receive services in regular classrooms for 50 percent of each school day. Yet very few teachers have received the training they need to support them. Teachers must receive training in inclusion to ensure that special education students receive the accommodations they need to be successful, to ensure that everyone in the class receives effective instruction, and to ensure the teacher's competence and confidence in including special education students in the regular classroom. Some disabilities cause a person to be more inclined to exhibit unusual and/or inappropriate behavior. School personnel need access to training, expertise, and occasionally, additional resources to understand the nature of the disability and effective techniques to prevent or intervene appropriately in these instances. Due to a lack of this expertise in Texas schools, law enforcement has been called in many instances in which the student's acting out behavior likely could have been prevented had the school developed and implemented an appropriate behavior intervention plan for the student.

In addition, parents and students themselves have many questions relating to special education, ranging from eligibility to the definition of appropriate services. The Educational Service Centers (ESCs) are mandated to provide written information and training to both teachers and parents, yet parents rarely know about the existence of ESCs much less about the resources available through these centers.

TCDD Recommendations

- 1. Schools should include joint education and training in self-determination for district staff and faculty, parents, and students receiving transition planning through special education services.**
- 2. Include families and coordinate with state level committees to make recommendations for the development formal and informal services that provide support to families of individuals with disabilities.**
- 3. Monitor and hold schools and relevant agencies accountable with sanctions for not successfully supporting the transition of children to adult services.**
- 4. Establish a permanent high cost reimbursement grant program to authorize additional funding for schools to enable schools to serve successfully students who have unusually high support needs more.**

Section IV: Prevention of Fetal Alcohol Spectrum Disorders and Spinal Cord Injuries

The Texas Office for Prevention of Developmental Disabilities (TOPDD) mission is to help minimize the human and economic losses caused by preventable disabilities. The agency is the state coordinator to address prevention of developmental disabilities in two areas, Fetal Alcohol Spectrum Disorders (FASD) and head and spinal cord injury.

TOPDD was created in 1989 when the Texas Conference on Prevention of Mental Retardation and Related Developmental Disabilities recommended to the Governor and Speaker of the House that an Office for Prevention be developed. The Texas Legislature's bill stipulates that the agency address preventable disabilities related to pregnancy (especially teen pregnancy), substance abuse among young people, and accidental head and spinal cord injuries among youth. The governing committee originally appointed three task forces to look at each of these areas. An early recommendation was that the TOPDD concern itself with the prevention of Fetal Alcohol Syndrome and Head and Spinal Cord Injury among youth. At that time there was little attention paid to these preventable disabilities. Shortly after accepting this recommendation, the governing board appointed the Fetal Alcohol Syndrome Consortium and the Child Safety and Injury Prevention Task Force. Their charge was to raise awareness in the state about preventable disability in these areas.

Recently TOPDD collaborated with local and regional entities to expand capacity to identify, diagnose, and intervene with persons at risk for FASD, especially children. At the same time, the Office convened a data task group to establish procedures and policy for the diagnostic teams as they begin to collect and report information about new cases of FASD to the state's Birth Defects Monitoring Division. Soon Texas will be one of only a few states that have a registry of FASD cases.

Why Prevention of FASD Is Necessary

Texas has recognized that Fetal Alcohol Spectrum Disorders (FASD) pose a serious threat to the health and wellbeing of women, children and families in the state. Reports indicate that in the past three years trends for binge and chronic drinking among women are up.²⁷ In 2003 more than 14% of Texas women of childbearing age reported binge or chronic drinking of alcohol. These reports have helped pinpoint geographic areas with a high risk for alcohol-exposed pregnancies. Texas has more than 372,000 live births per year. The Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that one of every 100 live births are affected by a FASD. Based on this, Texas may have some 3,720 affected infants born annually.

The Texas Department of State Health Services (DSHS) also has data about the number of pregnant women who seek either outpatient or inpatient treatment for substance abuse. This data indicates a problem as well. Between September 2002 and December 2003, the agency reported that 1,073 pregnant women were admitted for treatment, and of that, 116 of them were seeking specific treatment for alcohol abuse. In the same period almost 11,500 women with children were admitted for treatment of substance abuse.²⁸ In 1996, an Institute of Medicine report found that alcohol causes more damage to the developing fetus than any other substance, including marijuana, heroin, and cocaine.

FASD Prevention Activity for 2004

TOPDD received \$100,000 from the Texas Department of Mental Health and Mental Retardation (Community Mental Health Block Grant) to address prevention of FASD. The Office subcontracted with five lead agencies in local communities to identify diagnostic teams and intervention specialists' networks. The strategy is to build capacity in the existing system to diagnose, assess, and intervene with individuals at risk for secondary conditions associated with FASD. Additionally, with the diagnosis of their children, some birth mothers at risk for subsequent alcohol-exposed pregnancy may be helped. The capacity to diagnose and provide competent intervention has been strengthened in local mental health and mental retardation service centers, children's hospitals, public health districts, university health science center clinics, and an impressive array of other health and human service organizations in Texas. This budding FASD State System is positioned to serve some 13 million individuals or 60% of the state population. Centers are located in Austin, Fort Worth, Houston, Lubbock and San Antonio.

TOPDD received an award from SAMHSA's FASD Center for Excellence to coordinate a needs assessment and planning process leading to the development of a state plan to address prevention and intervention related to FASD. The \$145,000 contract began in November 2004 and has four additional optional years of funding of some \$276,000 to implement the state plan, if approved. The planning will focus on the following areas:

- Surveillance: Strengthen data collection on women at risk for an alcohol exposed pregnancy (AEP) and/or children at risk for FASD.
- Identification, Screening, Assessment and Diagnosis: Mentor and train professionals in order to expand the capacity to provide uniform and competent services to women and children at risk.
- Integrate Promising Practices into the Existing System for Women and/or Children: Educate leaders who serve these populations and identify strategic places within the system to introduce promising practices.
- Evaluation: Collect baseline data in systems where promising practices are introduced and plan for ongoing evaluation of the impact of these on the problem.
- Funding and Sustainability: Identify ways that the objectives will be supported and permanently integrated into the existing system.

Prevention Activity for Head and Spinal Cord Injury (HSCI) in 2004

The Child Safety and Injury Prevention Task Force has created a replicable education model that has been demonstrated in Dallas, Texas, for three years. The agency and its partners, Scottish Rite Children's Hospital and the Dallas Rotary Club, have a Children's Safety Day event and handbook to guide others in planning and executing a similar event. The Dallas event draws some 250 second-grade children and their parents participate in education and practice about safety and injury prevention. The Task Force provides technical assistance to other communities that wish to replicate the event.

TOPDD Recommendations for Head and Spinal Cord Injury Prevention:

- 1. Improve data collection from emergency room and hospital admissions pertaining to head and spinal cord injury among youth.**
- 2. Identify and champion best practices for prevention of accidental injury and/or birth defects and assess the potential use in the state.**
- 3. Support the existing data collection resources located at the Department of State Health Services that can be used to gauge the risk that women of childbearing age have for an alcohol-exposed pregnancy.**
- 4. Identify efficient methods to raise awareness among high-risk populations about the danger of alcohol consumption during pregnancy.**
- 5. Conduct a need assessment to determine the extent of unreported head injuries in the state.**
- 6. Evaluate costs and benefits of doing prevention versus curative and direct services.**

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Appendix B: Summary of Texas Medicaid Waiver Programs

Waiver	Eligibility Requirements	Average Wait Time	Services	Cost Cap
<p>Home and Community-Based Services (HCS) 1915 (c)</p> <p>and</p> <p>Home and Community-Based Services – OBRA (HCS-O) 1915 (C)</p>	<p><u>People of any age who:</u></p> <p>Have mental retardation and are eligible for ICF/MR at level of care I, V or VI.</p> <p>or</p> <p>Are diagnosed with a related condition, are identified through an annual resident review as inappropriately placed in a nursing facility and in need of specialized services, and Are eligible for ICF/MR level of care I, V, VI, VIII.</p>	<p>6 years</p>	<p>Adaptive Aids Audiology Case Management, Day Habilitation Dental Treatment Dietitian services Language Pathology Services Foster / Companion care Home Modifications Nursing Services Psychological Services Residential Assistance Respite Care Social Work Speech Pathology Services Supported Employment</p>	<p>Not to exceed 125% of the annual rate paid to a small ICF-MR, based on the person’s level of need or 125% of the estimated annualized per capita cost for ICF/ MR services, whichever is greater.</p>
<p>Texas Home Living (TxHmL) 1915(c)</p>	<p><u>People of any age who:</u></p> <p>have mental retardation</p> <p>live in their own or family homes</p> <p>are eligible for ICF/MR level of care I, and</p> <p>are Medicaid recipients prior to enrollment in TXHmL.</p>	<p>No wait list maintained</p> <p><i>Individuals remain on HCS waiting list while receiving some services</i></p>	<p>Adaptive Aids Audiology Behavioral Support Community Support Day Habilitation Dental Treatment Dietitian services Employment Assistance Home Modifications Occupational Therapy Physical Therapy Respite Supported Employment</p>	<p>\$10,000 per year:</p> <p>\$8,000 for Community Living Supports</p> <p>\$2,000 for Professional & Technical Supports.</p>
<p>Medically Dependent Children Program (MDCP)</p>	<p><u>People under age 21 who:</u></p> <p>meet medical necessity criteria for nursing facility because of complex medical needs.</p>	<p>2.5 years</p> <p><i>No wait for Medicaid Nursing Facility Residents transitioning to MDCP</i></p>	<p>Adaptive Aids Childcare-related Supports Home Modifications Respite</p>	<p>Not to exceed 50% nursing facility cost for a comparable level of care.</p>

Waiver	Eligibility Requirements	Average Wait Time	Services	Cost Cap
Community Living Assistance and Support Services (CLASS) 1915 (C)	<p>People of any age who:</p> <ul style="list-style-type: none"> have a developmental disability other than mental retardation, originating before age 22 and affecting function in their daily life; have a demonstrated need for habilitation services and case management; meet ICF-MR/RC level of care VIII; and reside in specific geographic catchment area. 	<p>Almost 4 years</p>	<ul style="list-style-type: none"> Adaptive Aids/Supplies Behavioral Services Case Management Habilitation Services Home Modifications Nursing Services Occupational Therapy Physical Therapy Prevocational Services Psychological Services, Respite Care Speech Therapy Supported Employment Transportation Services Vehicle Modifications 	<p>Not to exceed 125% of average cost of ICFMR/RC cost for Level of Need VIII.</p> <p>Individual exceptions to Cost cap must be approved.</p>
Deaf-Blind Multiple Disabilities (DBMD)	<p>Adults over 18 who:</p> <ul style="list-style-type: none"> are deaf-blind and have multiple disabilities which occurred before age 22; meet ICF-MR/RC level of care VIII; and have a demonstrated need for habilitation services. 	<p>2 years</p> <p><i>No waiting for Medicaid Nursing Facility Residents transitioning to DBMD</i></p>	<ul style="list-style-type: none"> Adaptive Aids/Supplies Assisted Living Behavioral Services Case Management Communication Services Habilitation Services Home Modification Nursing Chore Provider Occupational Therapy Orientation and Mobility Physical Therapy Respite Care Speech Therapy 	<p>Not to exceed 115% of the cost of ICF/MR VIII institutional cost.</p>
Community Based Alternatives (CBA)	<p>Adults aged 21 or over who qualify for nursing home care.</p>	<p>10 months</p>	<ul style="list-style-type: none"> Adaptive Aids Adult Foster Care Assisted Living Emergency Response Services Home Delivered Meals Home Modifications Medical Supplies Nursing Services Occupational Therapy Personal Assistance Services Physical Therapy Respite Care Speech Therapy 	<p>Not to exceed 100% nursing facility cost for a comparable level of care.</p>

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

