Family Caregiver Support:

Policies, Perceptions and Practices in 10 States Since Passage of the National Family Caregiver Support Program

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Overview

Texas, the second-most populous state in the nation, is large and diverse, with nearly one in three persons of Hispanic origin. The southwestern state has the fourth-largest number of older persons in the United States, the second-largest population of older Hispanic persons and the third-largest population of older African Americans.

The state's current long-term care system serving older persons and adults with disabilities is complex and fragmented, with many programs that have differing eligibility requirements. Home and community-based services range widely. Partly because of the state's strong antitax sentiments, these services are funded largely through Medicaid waivers and relatively small state programs. Texas is, however, one of the only states to commit tobacco settlement revenues to caregiver support by appropriating funds for respite care.

Prior to passage of the National Family Caregiver Support Program (NFCSP), no comprehensive statewide caregiver support program existed in Texas. The state's developing caregiver support services are characterized by:

- Flexibility to meet the individual needs of family caregivers at the local level
- Variable program design and services throughout the state
- Decentralized policy development and program administration

Texas respondents noted that the major service needs of family caregivers are (1) caregiver education and training, (2) counseling, (3) help in navigating the system and (4) general support services.

As Texas develops its caregiver support program and seeks to streamline its home and community-based service infrastructure, the development of uniform assessment standards and a consistent statewide approach to accessing and delivering services will be a key consideration.

Introduction

Texas represents a "new" state that is explicitly providing a range of caregiver support services, beyond limited respite care through state funds, as a result of the passage of the NFCSP. The project team conducted a site visit on June 17 and 18, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Texas Department on Aging
- Family Caregiver Support Program (NFCSP funded)

Texas Department of Health
- Texas Council on Alzheimer's Disease and Related Disorders (state funded)

Texas Department of Human Services
- Community Based Alternatives Aged/Disabled Medicaid waiver
- Consolidated Medicaid waiver
- Respite Care program (state funded)
- In-Home and Family Support voucher grant program (state funded)
- Consumer Managed Personal Assistance Services (Social Services Block Grant and state funded)
- Community Alzheimer's Resources and Education (CARE) program (federally and state funded)

Stakeholders interviewed were from:
- Texas Association of Area Agencies on Aging
- Alzheimer's Association, Austin Chapter
- Austin Independent Living

Six programs are featured in this profile:

1. Texas NFCSP
2. Aged/Disabled Medicaid waiver
3. Consolidated waiver
4. In-Home and Family Support program
5. Respite Care program
6. Community Alzheimer's Resources and Education program

Background

Texas is a large, diverse southwestern state with a population of 29.9 million residing in 254 counties.[1] The state has substantial rural, low-income and minority populations. Although two-thirds of the population live in urban areas, 196 of the state's 254 counties are rural.[2] In 2000, personal income per capita was $27,871, below the national average of $29,676.[3] About 16.7% of Texas's population live below the federal poverty level (vs. 13.3% U.S.).[4] Texas ranks 35th nationally in percentage of households with Internet access.[5] The racial makeup of the state's population also differs significantly from that of the United States as a whole. Compared to the national average, Texas has more than twice the proportion of Hispanic persons (32.0% vs. 12.5% U.S.) and a slightly smaller percentage of African Americans (11.5% vs. 12.3% U.S.)[6] (table 1).

An estimated 2.8 million persons in Texas, or 13.3% of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). Texas ranks fourth nationally in the number of older persons (ages 60+) residing in the state.[7] Texas has more than three times the percentage of Hispanics ages 60+ as the nation on average (17.6% vs. 5.4% U.S.).[8] In fact, Texas has the second largest population of Hispanic older persons in the United States.[9] With almost the same proportion of African Americans ages 60+ as in the United States as a whole (8.6% vs. 8.4% U.S.),[10] Texas also has the third highest proportion of African American elderly in the country.[11]

Texas ranks 46th nationally in the proportion of its population ages 85 and older. In 2000, 238,000 persons, or 1.1% of Texas's population, were ages 85+.[12]

An estimated 1,790,931 family caregivers reside in Texas. These family caregivers provide about 1.7 billion hours of caregiving per year at an estimated value in 1997 of $13.6 billion.[13]

Texas is traditionally a conservative, low-service state with a general philosophy that residents "take care of their own." The state legislature takes an active role in enacting long-term care policies and programs. In addition, Texas has a strong network of effective advocates and has some history of offering limited support services for family caregivers through the Department of Human Services, rather than through the Department of Aging. In contrast, the "taking care of their own" philosophy might explain why state policy attention to caregiver issues has emerged only recently.

Table 1. Selected Characteristics of TEXAS and the UNITED STATES, 2000 [a]

	Texas	United States
Total Population Characteristics		
Total Pop.[b]	20,851,820	281,421,906
% African American[c]	11.5%	12.3%
% Hispanic [d]	32.0%	12.5%
Older Population Characteristics		
Pop. 60+[e]	2,774,201	45,797,200
% 60+[f]	13.3%	16.3%
National ranking 60+ [g]	47	NA
Pop. 65+[h]	2,072,532	34,991,753
% 65+[i]	9.9%	12.4%
National ranking 65+ [j]	47	NA
Pop. 85+[k]	237,940	4,239,587
% 85+[l]	1.1%	1.5%
National ranking 85+[m]	46	NA
% increase 1990–2000 60+ pop.[n]	18.3%	9.4%
% White (60+)[o]	71.2%	82.4%
% African American (60+)	8.6%	8.4%
% Hispanic (60+)	17.6%	5.4%
% Asian (60+)	1.5%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.2%	0.4%
Informal Caregiver Characteristics [p]		
# of caregivers (1997)	1,790,931	25,798,370
Caregiving hours (millions) (1997)	1,667.0	24,013.1
Value of caregiving (millions) (1997)	$13,636.0	$196,426.7
Economic Characteristics		
Per capita income [q]	$27,871	$29,676
% of pop. below poverty (1997)[r]	16.7%	13.3%
Internet		
% of households w/Internet access (2001)[s]	38.3%	41.5%
Nat'l ranking of households w/Internet access	35	NA

a Unless otherwise noted, all data are from 2000.
b MapStats-Texas, *www.fedstats.gov* (June 2002).
c Ibid.
d Ibid.

e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.*
f Ibid.
g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.*
h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
i Ibid.
j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States.*
k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
l Ibid.
m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States.*
n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data, www.aoa.gov/Census 2000/stateprofiles/ageprofile-states.html.*
o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000, www.aoa.gov/stats/2000pop/percent60plusxrace-HO.html.*
p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), *www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm* (2001).
r MapStats-Texas.
s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002, www.governing.com/source.htm.* Source for Internet access is the National Telecommunications and Information Administration, 2001.

State Administrative Structure

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies: the Department on Aging and the Department of Human Services. Most of the programs administered by these state agencies rely generally on federal funds with some state match; state-only–funded programs are limited.

The Texas Department on Aging (TDoA), small compared to other Texas state agencies, is a free-standing department that serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP. The governor appoints the executive director, who has cabinet-level status. TDoA consists of approximately 35 full-time staff members, who work with the Department of Health (TDH), and the Department of Human Services on various programs.

The infrastructure of Texas's aging network is a statewide system of 28 Area Agencies on Aging (AAAs), each covering a territory ranging from one to 10 counties. Twenty-five of the 28 AAAs are housed within their local council of government, a regional municipal governing body. Two others, the AAAs serving the Dallas and Houston areas, are located within city government. The local United Way chapter oversees the remaining AAA. The AAAs have also formed the Texas Association of Area Agencies on Aging (T4A), which holds quarterly meetings to report on best practices, among other activities.

The Health and Human Services Commission (HHSC) has oversight responsibility for designated health and human service agencies (including the TDoA, TDH and DHS). HHSC has been the "single state agency" for Medicaid since 1993. Historically, TDH has administered most Medicaid programs, with oversight by HHSC. Recently, however, Texas has reorganized the administration of Medicaid services, and in 2001, most of TDH Medicaid functions were shifted to other agencies under HHSC. Currently, Texas Medicaid programs are administered by various agencies, including

DHS (eligibility and long-term care programs), the Department of Mental Health and Mental Retardation (waiver services for mental retardation) and TDH (family planning and medical transportation).

Texas has nine Medicaid waivers providing home and community-based services.[a] The two that specifically serve the elderly and persons with physical disabilities are the Aged/Disabled Medicaid waiver, known in Texas as the Community-Based Alternatives (CBA) waiver, and the Consolidated waiver, a pilot program providing services to many different populations. The CBA waiver was originally approved in 1994. DHS, under contract with HHSC, administers this waiver. In FY 2001, it delivered services to 26,337 beneficiaries,[b] 70% of whom were older persons. DHS has projected that the Consolidated Medicaid waiver will serve 58 clients in 2002.

In addition to these waivers, the Division of Long-Term Care within DHS administers several other programs that provide services to older persons and their family caregivers. The Respite Care and In-Home and Family Support voucher programs (both state funded) and the Consumer Managed Personal Assistance Services program (CMPAS, funded through both the state and a Social Services Block Grant, Title XX) serve collectively more than 4,600 clients per month. CMPAS does not, however, provide any explicit caregiver support services. DHS also administers the Community Alzheimer's Resources and Education (CARE) program.

In 2002, HHSC was awarded a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS). Texas will use the almost $1.4 million to try to make more accessible and better coordinate its system of long-term care services and to assist individuals in making the transition from institutions back into the community.

Overview of State System of Caregiver Support

Texas has some state-funded programs serving the elderly, persons with disabilities and family caregivers, including a stand-alone respite benefit. The philosophy of "taking care of your own," however, seems to account for at least some of the limited growth of those programs. Budget shortfalls and a priority on developing programs for children are also contributing factors.

HHSC has identified caregiver support among the strategic priorities within its coordinated strategic planning effort for 2003–08. These priorities, known as "enterprise strategies," will provide the interagency focus for the HHSC coordinated strategic plan. The priority for caregiver support is to "improve support to families by expanding, developing and coordinating formal, informal and innovative supports for caregivers."[14] The enterprise strategy should effectively raise the profile of caregiver support issues within the Texas long-term care system.

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a Other Medicaid home and community-based waivers are the Medically Dependent Children Program, serving children under age 21 who qualify for nursing facility care; Home and Community-Based Services, providing in-home services to individuals with mental retardation; Community Living Assistance and Support Services, providing home and community-based services to people with severe disabilities, other than mental retardation, that originated before age 22; Home and Community-Based Services OBRA, providing services to persons with mental retardation or related conditions who are determined to be inappropriately residing in a nursing home; Deaf Blind/Multiple Disability waiver, serving people ages 18+ who have been determined legally blind and who have multiple disabilities; Star+Program, a pilot waiver for Community-Based Alternative waiver clients, providing managed care, acute and long-term care services in Harris County; and Mental Retardation-Local Authority, serving people with mental retardation/developmental disabilities in 29 counties.

b In FY 2001, Texas had approval for 26,337 waiver slots, and all slots filled.

Long-term care planning and expansion of home and community-based services has been a recent focus of the Texas legislature, which meets biannually. In the legislature's 2001 session, for example, home and community-based services received a boon from the tobacco settlement. Allocations in the amount of almost $74 million for the state-funded Respite Care program and of another $17.3 million earmarked for home and community-based care indicate recognition of the importance of these services.[15] Despite this, the downturn in the state's economy will likely pose significant fiscal challenges to the legislature when it next meets in 2003.

Before enactment of the NFCSP, caregiver support was not a specifically identified policy issue of state leaders in Texas. Although Texas had some limited state-funded programs that provided ancillary benefits to caregivers, the NFCSP was the first program in Texas "to make it happen" in terms of directly targeting services to family caregivers, according to one respondent.

Housed in DHS, the CARE program, legislatively mandated in 1998, is funded through a mix of Alzheimer's Disease Demonstration Grant funds and state general funds. The program provides some measure of caregiver support through respite services, education, training and support of families. In fact, one state official indicated, although CARE is conceptually geared to serve the person with Alzheimer's, the program and its services "are about the caregivers" in reality.

Respondents gave mixed answers when asked if family and informal caregivers were recognized as a central component of a comprehensive long-term care system. Some state officials responded that family caregivers were essential to the Texas long-term care service delivery system and that Texas relies heavily on family, friends and neighbors to provide care. Another respondent indicated that families are relied on to provide care but are not recognized or supported. A common theme was the philosophy that "families take care of their own."

Program Background/Development

The impetus for the state's family caregiver support program was passage of the Older Americans Act Amendments of 2000, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. Prior to passage of the NFCSP, no comprehensive, statewide caregiver support program had existed in Texas. TDoA allocated funds to the AAAs in the same month that it received them from the U.S. Administration on Aging (AoA), in March 2001. As part of the NFCSP, TDoA also piloted a respite voucher in May 2002. In developing the voucher, and for other program design details, Texas looked to caregiver support programs in both Oklahoma and California.

In the design and start-up phases of the NFCSP in Texas, TDoA involved the AAAs, held public hearings, organized focus groups and partnered with the CARE program to identify providers. Officials from TDoA indicated significant challenges during these early phases, attributing some of the difficulties to a delay in policy development from the federal government. Integrating the new funds into existing services was also a challenge. TDoA has attempted to centralize some of the policymaking and administrative decisions, although the AAAs appear to play a sizable role at the local level. TDoA established an AAA caregiver task force in 2001 to have a forum to identify focus areas, such as policy and program development. TDoA sees the task force as a way to examine what is and is not working under the NFCSP in Texas. The task force, which meets on a quarterly basis, is comprised of AAA directors, caregiver specialists and TDoA staff.

Texas has been innovative in its use of administrative funds received under the NFCSP. TDoA has kept 5% to hire a caregiver coordinator, conduct trainings and increase awareness of caregiver issues through public information campaigns. The rest of the funds have been used in several ways. First, TDoA has contracted with a legal services center to provide a statewide hotline and provide services to grandparents raising grandchildren. At the time of the site visit, TDoA was also in the process of conducting a caregiver survey to obtain data on caregivers residing in the state. Finally, the agency has created a series of "caregiver capacity-building grants." These funds provide seed money in the amount of $15,000 each to build on informal infrastructures in the community. Responding to a request for proposals were AAAs, churches and other community organizations. A faith-based respite program is an example of a project funded through this grant program.

Most rewarding: Key informants noted that the most rewarding aspect of the program's development has been having new funds to support family caregivers. Additionally, the ability for AAAs to bring on designated caregiver staff has been helpful. State officials also indicated that the innovation of AAAs in providing services has been rewarding.

Biggest challenge: Key informants cited some significant challenges in the start-up phase of the NFCSP. First, reporting requirements have posed problems. Although the caregiver is the identified client, eligibility for NFCSP-funded services—namely, respite and supplemental services—is based on activity of daily living (ADL) deficits of the care recipient. This has made it difficult to "get a handle on who is the client." Worker shortages have also been problematic, particularly in vast rural areas of the state of Texas, where trained respite providers are sometimes difficult to find. The 25% match requirement mandated in the federal legislation was another challenging issue identified. Key informants noted that the required match was problematic because it was more than any other required under Title III Services. TDoA and the AAAs have worked to identify other sources of match, including in-kind.

Funding

In FY 2001—the first year of federal funding under the NFCSP—Texas received $6.2 million in federal funds. The majority of the federal funds were carried over to FY 2002. In FY 2002, the federal share of NFCSP funds was increased, with Texas receiving a total of $7 million, or 9.1% of TDoA's total budget.

DHS expenditures under the CBA Aged/Disabled Medicaid waiver were $355.6 million in FY 2001. This waiver for Texas alone is nearly three times the entire federal appropriation for the NFCSP, which received $125 million in FY 2001. The state Respite Care program was funded at $1.13 million; the In-home and Family Support voucher program at $6.5 million; the Consolidated Medicaid waiver at $1.5 million;[c] and the CARE program at $2.5 million. Combined, these programs represent just under 10% of the total DHS budget.

Texas was one of four states to negotiate an independent settlement with the tobacco industry prior to and separate from the multistate agreement.[16] Texas is scheduled to receive approximately $17 billion over a 25-year period from its settlement. The legislature has established several endowments to provide for education and public health, although none of these funds is earmarked for home and

c Figures are for projected expenditures for FY 2002.

community-based care. In addition to these endowments, Texas has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid and to support home and community-based care. Funds appropriated specifically for caregiver support services include $73.9 million allocated in 2001 for respite care.[17] In addition, $17.3 million was provided to expand home and community-based care, and another $61.3 million was for Medicaid simplification.[18]

Key informants described the current budget situation in Texas as "bleak" and expected that situation to continue to weaken. An across-the-board cut in state general revenue would have a broad impact on programs. Officials from the TDoA indicated that they are strategizing on ways to save funds, though with the influx of federal dollars under the NFCSP, the department's funds have actually increased over the past two years. At the time of the site visits, some AAAs thought they might have to have return some of the federal NFCSP funds because they were concerned that they could not come up with the match required under federal rules. State officials indicated this was no longer an issue.

Medicaid officials expect a significant shortfall, with respondents predicting a shortfall of anywhere from $5 billion to $8 billion by the end of this year. Because of the biennial legislative session, key informants have predicted that the impact will be felt even more in the following two years when the legislature prepares its next two-year budget.

Program Administration

TDoA sees its role in developing and implementing the state's first caregiver support program to be in the areas of service design and the development of rules and reporting standards. State officials commented that they have provided a lot of support to the AAAs in the implementation of this program, yet some stakeholders have expressed concern about what they considered to be limited state guidelines in this regard.

Publicizing the new Texas caregiver support program has been primarily the responsibility of the AAAs. TDoA is working with employee assistance personnel in the corporate sector, and is developing interdepartmental partnerships with agencies such as TDH to publicize services through its Council on Alzheimer's Disease.

State Medicaid officials at DHS identified their role as administrators, policy developers and monitors for the state's long-term care programs, including home and community-based Medicaid waivers, nonwaiver Medicaid services and state-funded long-term care programs. DHS is responsible for directly providing case management within the home and community-based waivers but has the flexibility to contract out this service. In addition to administering the CBA Aged/Disabled and Consolidated Medicaid waivers, DHS administers several programs that provide services to assist caregivers. Nonwaiver services include the Consumer Managed Personal Assistant Services (CMPAS), the In-Home and Family Support voucher program, CARE and the state-funded Respite Care program.

State officials observed that Texas has a complex and fragmented long-term care system, with many programs and services with different sources of funding for different age groups and disabilities. In recent years, under the leadership of HHSC, the state has attempted to address uniformity across departments and programs to reduce fragmentation. Both state officials and stakeholders commented that this goal is relatively recent and that Texas still has "a long way to go."

Program Eligibility/Assessment Process

Eligibility for the state's family caregiver support program is consistent with federal requirements under the Older Americans Act: the program is open to family or informal caregivers of any age who provide care to persons age 60 or older, as well as caregivers ages 60 or over who care for children ages 18 or younger.[d] For respite and supplemental services, the older person (age 60 or older) must need help with at least two ADLs or two instrumental activities of daily living (IADLs). In Texas, both the family caregiver and the care recipient are considered the client in the program. The new client population of family and informal caregivers has been a source of confusion among both TDoA officials and AAA staff, however.

Client assessment standards are not uniform across the state, although AAAs do use a standard intake form that is completed by phone or in-person. TDoA recently adopted the DHS community care assessment for its home and community-based programs, although questions regarding family caregivers are extremely limited. As part of this assessment process, informal care is taken into account in the authorization of paid services for the care recipient. Officials of TDoA described the goal of the assessment as first identifying any ADL impairment, however, and then determining whether the client has a family caregiver for support. Although the assessment tool focuses on both the care recipient and the caregiver, little information is asked about the family caregiver, and as respondents pointed out, some AAAs focus more on caregivers than others. One respondent characterized the assessment process as "highly variable."

Eligibility for the CBA Aged/Disabled Medicaid waiver is consistent with federal requirements: the waiver is for those who receive Supplemental Security Income (SSI) or meet income and resource limits (up to $1,635 per month in income and less than $2,000 in assets). Waiver recipients must also be 21 years of age or older and must meet the medical criteria for Medicaid nursing home level of care. Respondents noted that the care recipient is the identified client in the program, consistent with Medicaid policy.

Each of Texas's nine waivers has its own eligibility criteria for its specific target population and its own assessment process. HHSC is in the process of developing a uniform functional assessment tool, now being tested, to be used for all ages and types of disabilities across programs and services. Consistent with Medicaid policy generally, respondents noted, extent of informal care (i.e., whether or not the care recipient has a family caregiver) is taken into account in the authorization of paid services for the care recipient. Although the assessment focuses on the care recipient, respondents noted some emphasis on who the caregiver is; whether or not that person is willing, reliable and dependable to provide care; and what impact providing care could have on the caregiver's own work situation. Respondents indicated that services might be reduced for a care recipient with a high level of family support.

Texas also has implemented a program that allows families to self-screen for Medicaid eligibility. Known as the State of Texas Assistance and Referral System (STARS), the on-line tutorial offers care recipients and their families the option to self-screen as the first step in determining eligibility for Medicaid programs administered by DHS and other state agencies.

d This includes caregivers ages 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

Services

All five of the permissible NFCSP service components are being provided in Texas, although not necessarily by each AAA. The AAAs either subcontract for caregiver support services or provide them directly. Services that AAAs provide directly include facilitating support groups, developing resource materials such as fact sheets, and conducting trainings.

Regarding respite care, the AAAs are authorized to provide in-home care, adult day services, overnight care in a facility and respite weekends. Not all types of respite services are always available, however. To help overcome the increasing lack of respite providers throughout the state, especially in rural areas, TDoA, in partnership with the AAAs, has been looking at the concept of mobile respite to bring respite care to underserved communities.

TDoA has also created a respite voucher so that families can contract directly for respite services on their own. The state has recommended a cap of $300 per quarter, so as not to exceed federal tax guidelines, but AAAs have the flexibility to exceed this cap. Caregivers are allowed to bank respite benefits, but state officials indicated this is rarely necessary because of the flexibility in the program. Only a caregiver who does not live with the care recipient may receive a respite voucher. This is because the voucher is intended to serve families who are not eligible for respite through the state-funded In-home and Family Support program.

Respite care is a covered benefit in both the CBA Aged/Disabled and Consolidated Medicaid waivers. Respite care in the CBA waiver is capped at 30 days per year, whereas the Consolidated waiver has a 45-day cap. Although these caps exist, Medicaid officials emphasized the flexibility to authorize higher caps, citing a rider that DHS cannot deny services if the denial would be detrimental. Of 30,000 Aged/Disabled waiver clients, only 1,290 use respite care. Beneficiaries are more likely to utilize the most attractive feature of the Aged/Disabled waiver, the provision of access to unlimited prescription drugs with no co-payment. This benefit alone may motivate some to participate in the waiver, according to Medicaid officials.

DHS has also capped reimbursement based on provider type. Hospital-based respite has a $67 per day maximum, for example, whereas in-home respite limits vary from $35 to nearly $50 per day. Adult day service provider reimbursements are capped at $13 per half day.

Significant waiting lists also exist for Medicaid waiver services. One state official estimated that 60,000 to 70,000 people are on waiting lists (known as "interest lists") to be assessed for waiver eligibility and indicated that some 10,000 people are added to these lists per year, with an average wait time of 11 months. Another respondent noted that those on the interest list for the state-funded In-Home and Family Support program could wait up to five years for services. Further, a respondent observed that "people that access waiver programs in Texas get a good package of services; those that don't, don't get much." One qualifying factor for DHS non–Medicaid waiver services is the establishment of "unmet need," for example. A care recipient who already has a caregiver may not qualify for state-funded programs that would provide services (i.e., respite care) that would assist that caregiver in remaining in the caregiving role.

Other DHS-administered programs also provide some services that support family caregivers. Additionally, the In-Home and Family Support program provides direct grants to individuals and/or their families for goods and services. These grants have a $3,600 annual maximum. Consumers and/or their families can use the money to purchase a variety of goods and services, including respite, attendant care and chore services. The state-funded Respite Care program also serves family and informal caregivers. This program has a respite cap of 14 days (336 hours) per year. The CARE program provides respite services and home modifications to assist dementia caregivers.

Major services needed by caregivers: At TDoA, caregiver education, training, counseling and general support services were identified as the major services needed by caregivers. Respondents indicated that these services allow caregivers to make the decision to use respite care and to access services earlier. As other key informants indicated, "Everything we do in Texas is related to the care recipient, which indirectly benefits the family caregiver." Stakeholders cited information, case management, in-home assessment and help in navigating the system as essential in supporting family and informal caregivers. Expanding on this, one respondent indicated that families do not know what services are available and how to access them.

Table 2. Family Caregiver Support Services in Texas

Program	Texas NFCSP	Aged/Disabled Medicaid Waiver [a]	Consolidated Waiver	In-Home and Family Support Voucher Program	Respite Care Program	Community Alzheimer's Resources and Eduction (CARE)
State Administrative Responsibility	Texas Department on Aging	Texas Department of Human Services	Texas Department of Human Services	Texas Department of Human Services	Texas Department of Human Services	Texas Department of Human Services
Local Service Delivery	AAAs [b]	DHS: care management Local service provider agencies: other services	DHS: care management Local service provider agencies: other services	No contract providers; written bids submitted by vendors to clients	Local service provider agencies	CARE sites throughout the state
Funding Source	Older Americans Act, Title III-E	Federal and state funds	Federal and state funds	State funds	State funds	State general funds, federal Alzheimer's Disease Demonstration Project
Expenditures FY 2001–02	$7.0 [c] million	$355.7 million	$1.5 million [d]	$6.5 million	$1.1 million	$2.5 million [e]
Client Population	Family & informal caregiver	Care recipient	Care recipient	Care recipient	Care recipient	Family caregiver & care recipient

a In Texas, this waiver is known as the Community-Based Alternatives (CBA) waiver.
b AAAs = Area Agencies on Aging.
c Funding is for FY 2002.
d Projected expenditures are for FY 2002.
e This funding level is for FY 2002 and is the source of the required matching funds under the federal Alzheimer's pilot program.

Table 2. Family Caregiver Support Services in Texas (continued)

Program	Texas NFCSP	Aged/Disabled Medicaid Waiver	Consolidated Waiver	In-Home and Family Support Voucher Program	Respite Care Program	Community Alzheimer's Resources and Eduction (CARE)
Eligibility Criteria:						
Age	60+ care recipient Family caregivers of persons age 60+	21+ care recipient	Any age care recipient	4+ care recipient	18+ care recipient	Any age family caregivers & care recipients
Income	None	$1,635/month $2,000 resource limit	$1635/month $2,000 resource limit	Co-payment beginning at 105% of state median income	$1,635/month $2,000 resource limit	400% of poverty level $10,000 resource limit
Functional Ability	For respite & supplemental services, care recipient must have at least 2 ADLs or IADL needs	Nursing home eligible	Nursing home eligible	Physical disability that substantially limits ability to function independently	Care or supervision needed; unpaid caregiver needs relief from caregiver responsibilities	Diagnosis of Alzheimer's or dementia
Uniform, Statewide Caregiver Assessment	No	No	No	No	No	Yes
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite, home modifications	Respite	$3,600 annual stipend for respite care and supplemental services; $3,600 lifetime maximum for home modifications or assistive technology	Respite	Respite, home modifications
Respite Cap	$300 per quarter (recommended)	30 days	45 days	$3,600 annual	14 days (336 hours)	Cap varies by site
Consumer Direction	Yes	No	No	Yes	No	No
Family Caregivers Paid as Respite Providers	Yes	No	No	Yes	No	No

Consumer Direction

Although Texas has a long history of consumer-directed care programs, services options for older persons and their caregivers are currently limited. Within the NFCSP, consumer-directed options are limited to the respite voucher previously described. Family members, except for spouses, can be paid respite providers.

Within DHS, a legislative mandate has required that all Medicaid waivers eventually have consumer direction as an option. Currently, the only two waivers that allow consumer direction are the Deaf/Blind and Community Living Assistance and Support Services (CLASS) waivers. DHS respondents indicated, however, that there is in Texas, "a consumer choice kind of philosophy." The DHS-administered Consumer Managed Personal Assistance Service (CMPAS) program does allow family members to be paid to provide personal care but does not provide caregiver support services.

Texas was one of the first states to include consumer direction under its Medicaid waivers, although the CBA Aged/Disabled Medicaid waiver does not currently permit consumer direction. According to key informants, Texas has one of the largest consumer-directed waiver programs in the country.

With regard to other DHS-administered programs, the In-Home and Family Support program provides a cash grant to families to help pay for respite care, consumable supplies, home modifications and assistive technology. Family members can be paid respite providers, with no restrictions. The state-funded Respite Care program and the CARE program do not have consumer-directed options.

Quality Assurance and Evaluation

TDoA has developed a uniform client enrollment (intake) form for all AAAs. The AAAs now utilize a standard assessment, the DHS community care assessment with limited data collected on family caregivers. TDoA requires that AAAs collect basic information about caregivers, such as expenditures and number of caregivers served, using the AoA's minimal data collection requirements. The system is currently a mix of manual and automation systems.

Texas is not formally collecting data on caregiver outcomes, although officials indicated that they do receive feedback from the caregivers and care recipients that they serve. Although TDoA is required to do annual client satisfaction surveys, they have not so far included family caregivers in this process.

The only program in DHS that appears to be collecting data on caregiver outcomes is the CARE program, which includes caregiver information—such as measures of caregiver health—in its assessment. The department uses a new, web-based system and has not had time to evaluate the strengths and weaknesses of its data collection practices. In its state-funded programs, DHS is not collecting substantive data on the caregivers served through its various respite components. In the CMPAS care program, it does collect information on what the family caregiver is doing to help the care recipient—but not on what help the family caregiver may need. Medicaid officials indicated that their current system, the Texas Integrated Eligibility and Redesign System (TIERS), lags behind in automation. They do plan to implement a new system, called Service Authorization System (SAS) Wizards, which would be a more user friendly and technologically advanced system.

Systems Development

Texas has a complex and fragmented system of support for the elderly, for persons with disabilities and for their family caregivers, administered largely by two state agencies. HHSC, however, is trying to streamline, integrate and coordinate the service system. HHSC, through its "enterprise strategy," has come to recognize family caregivers as an independent constituency within long-term care.

TDoA and AAA respondents noted that their experience in implementing the NFCSP in Texas had been positive overall. They saw the program as an expansion of an existing goal, rather than as implementation of a completely new program. Although TDoA officials identified their role as one of statewide coordination and development of state standards, some stakeholders raised concerns that TDoA has not set standards. Key informants noted that the small size of TDoA staff, at 35 people, has left the department "stretched." In turn, state officials have been concerned about the level of guidance coming from the federal government, indicating that they would like additional guidelines and feedback on policy issues.

Medicaid officials were largely unaware of the NFCSP and of implementation by TDoA and the AAAs. They did indicate, however, that the HHSC umbrella to both DHS and TDoA has identified caregiver support as one of its enterprise strategies, as previously noted. As part of its coordination effort, HHSC will provide a liaison to support the interagency development of consistent policies for caregiver support, and other state agencies will provide related activities. Noted one key informant, "Whether this strategy develops into something concrete will depend on funding."

In the evolving NFCSP, caregiver services are coordinated at the local level by the 28 AAAs. Most of the AAAs have hired dedicated staff, known as "caregiver specialists" to implement the program. They meet informally to share experiences and information.

Although Texas does not have a body whose mission is coordination of family caregiver support services across state departments, many key informants cited the HHSC enterprise strategy as taking on that role. Texas appears to be in the beginning stages of systems development in both DHS and TDoA, which have identified this as a goal, but have not achieved this in the current program structure. One key informant indicated that there are "too many departments in Texas….Texas has a maze" of a long-term care system, and that informant would like to see movement toward a single state long-term care agency.

State Involvement of Family Caregivers in *Olmstead* Decision Planning

In response to the recent Supreme Court *Olmstead* decision, the governor of Texas issued an executive order requiring the HHSC to review all services and supports for people with disabilities.[19] HHSC, in turn, established the Promoting Independence Advisory Board, which evolved into the Interagency Task Force on Care Settings for Persons with Disabilities and serves as the state's *Olmstead* task force.[20] Officials of DHS noted that two family caregivers serve on the panel; one provides care for an elderly parent and the other for a teenage son with cognitive disabilities.

Other Policy Issues

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, the key informants interviewed varied in their estimation of the priority placed on caregiver support. Two stakeholders and one state official indicated the priority was "low." One state official and two stakeholders agreed that there was a "medium" priority, and one state official cited a "high" priority on caregiver support.

Number of Key Informants	**Priority on Caregiver Support**
3	→ Low
3	→→→ Medium
1	→→→→→ High

Benefits and challenges: Texas case study respondents identified three aspects of their program that are most beneficial to family caregivers:

- ✧ Respite care
- ✧ Education and training
- ✧ Personal assistance services, which also provide some measure of caregiver relief

When asked to identify the challenges for implementing family caregiver support programs in Texas, respondents noted the following:

- ✧ Limited implementation guidelines from the federal government
- ✧ Challenges with reporting requirements; structuring the program around these requirements
- ✧ High caseloads; more staff needed in Medicaid waiver programs
- ✧ Too many "silos" in the state

Major lessons learned:

- ✧ Because the needs of families vary, families need options and flexibility
- ✧ Regarding caregiver support, "We don't really provide caregiver support—we provide client services," according to one Medicaid official
- ✧ "Families don't feel the responsibility to care the way they used to," another indicated
- ✧ In contrast, another DHS official expressed surprise at how much family caregivers are willing to take on, even when they are experiencing strain themselves, and also at how vital the family caregiver is to the overall health of the client's situation and how fragile the caregiver's own physical and mental health can be

Opportunity for expanding caregiver support: All Texas respondents were pessimistic about new initiatives or the expansion of state-funded programs to support and strengthen family caregivers over the next three to five years. One state official said that caregiver support would not be expanded; another pointed out that efforts to strengthen family supports in Texas are focused on children. Despite this, the HHSC's upcoming focus on supporting family caregivers is promising.

Recommendations for other states: State officials in Texas had several recommendations for other states:

- Share best practices.
- Develop the trust of the community and agencies so they can work together to identify service needs.
- Ensure an adequate funding base.
- Offer more educational programs to help families navigate health and human services programs.
- Start with consolidated programs if you are starting from scratch. Don't create multiple programs and "silos."

Notes

1 MapStats-Texas, *www.fedstats.gov* (June 2002).
2 N. Pindus, R. Capps, J. Gallagher, L. Giannarelli, M. Saunders and R. Smith, *Income Support and Social Services for Low-Income People in Texas* (Washington, D.C.: Urban Institute, 1998).
3 U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), *www.bea.doc.gov/bea/newsrel/spi0401.htm* (2001).
4 MapStats-Texas.
5 Congressional Quarterly, *Governing's State and Local Sourcebook: 2002, www.governing.com/source.htm.* Source for Internet access is the National Telecommunications and Information Administration, 2001.
6 Ibid.
7 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group, www.aoa.gov/aoa/stats/2000pop/percentxstate.html* (April 1, 2000).
8 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Percent of Persons 60+ by Race and Hispanic Origin—by State—2000, www.aoa.gov/aoa/stats/2000pop/percent60plusxrace-ho.html..*
9 Texas Department on Aging, *Demographic Profile of the Elderly in Texas* (March 2000).
10 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Percent of Persons 60+.*
11 Texas Department on Aging.
12 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Profile of General Demographic Characteristics for the United States, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html* (2000).
13 P. Arno and M. Memmott, *Estimated Value of Informal Caregiving: Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
14 Texas Health and Human Services Commission, Coordinated Strategic Planning, *www.hhsc.state.tx.us/StrategicPlans/CSP/Planning/csp_default.html* (updated July 2002).
15 National Conference of State Legislatures, *Major Health Care Policies: 50 State Profiles* (Washington, D.C.: Health Policy Tracking Service/National Conference of State Legislatures, January 2002).
16 J.M. Weiner and N. Brennan, *Recent Changes in Health Policy for Low-Income People in Texas, State Update #23* (Washington, D.C.: Urban Institute, March 2002).
17 National Conference of State Legislatures, *Major Health Care Policies.*
18 Ibid.
19 National Conference of State Legislatures, Home and Community-Based Services Network, "State Findings," Appendix B of *The States' Response to the Olmstead Decision: A Work in Progress* (Washington, D.C.: National Conference of State Legislatures, 2002).
20 Ibid.