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Redirecting Public Long-Term Care Resources

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Redirecting Public Long-Term Care Expenditures

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REDIRECTING PUBLIC LONG-TERM CARE RESOURCES

Home and community-based services, such as personal care, home health, adult day care, respite care, adult foster homes and assisted living facilities, are a growing component of long-term care services. In 2002, Medicaid home and community-based services for persons of all ages constituted 30 percent of total Medicaid long-term care expenditures, up from about 14 percent in 1991 (Burwell, Sredl and Eiken, 2003). Likewise, according to the U.S. Congressional Budget Office, home and community-based services were about 30 percent of total long-term care expenditures (including Medicare, Medicaid, Older Americans Act program, out-of-pocket payments, and private insurance) for the older population in 2000 (U.S. Congressional Budget Office, 1999). With the aging of the population, especially the rapid projected growth in the population aged 85 and older, demand for long-term care services, including home and community-based services, is sure to grow substantially.

From a policy perspective, creating a more balanced delivery system by expanding home and community-based services and reducing reliance on institutional care where possible is a major goal of the U.S. Department of Health and Human Services (including the Administration on Aging and the Centers for Medicare & Medicaid Services), Area Agencies on Aging, State Units on Aging, Medicaid agencies, and many providers and consumers. There are at least four policy rationales for expanding home and community-based services. First, older people strongly prefer home and community-based services to institutional care. In one study, 30 percent of older people indicated that they would rather die than move to an institutional setting, with an additional 26 percent “very unwilling” to move (Mattimore et al, 1997). A 2003 study found that 81 percent of persons over 50 would prefer to avoid nursing home care even if they needed 24-hour care (Gibson, 2003). In a study of Maryland residents, aged 40-70, approximately two-thirds of respondents rated nursing home care as “somewhat” or “very” disagreeable (Eckert, Morgan and Swamy, 2004).

Second, older people living in the community have substantial unmet needs for personal care and other home and community-based services. These unmet needs often lead to higher rates of adverse events, including discomfort, weight loss, dehydration, falls, burns, skin problems, missed meals, inability to follow special diets, missed doctor visits, and having to

wear dirty clothes, factors that affect both quality of life and costs for the long-term care populations (LaPlante et al., 2004).

Third, a key element in the preference of older people for home and community-based services is the assumption that quality of care for these services is superior to that of nursing home care. Numerous studies have found substantial amounts of substandard care in nursing homes (Institute of Medicine, 2001, U.S. GAO, 1998, 1999a, 1999b, 2000). In particular, older people associate the ability to stay in their own homes through home and community-based services with retention of independence and control over care decisions (Gibson, 2003). However, remarkably little data is available about the quality of home and community-based services.

Fourth, and finally, policymakers often assume that home and community-based services are a less costly way of providing long-term care, particularly for those who require custodial care. Thus, the presumption is that home and community-based services can better meet the preferences of people with disabilities while achieving savings for states and the federal government. This is a controversial argument, and more research is still needed (Wiener et al, 2004).

The movement towards more home and community-based programs has been further bolstered by the 1999 ruling of the U.S. Supreme Court in *L.C. & E.W. vs. Olmstead*, in which the court stated that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment” (*Olmstead v. L.C.*, 521 U.S. 581, 119 S.Ct.2176). Interpreting the Americans with Disabilities Act, the court ruled that states must make reasonable modification in their long-term care programs and activities to make home and community-based services available to those with disabilities (Rosenbaum, 2000). Although this right to noninstitutional services is not unlimited and may be bound by state fiscal limits, consumer advocacy groups across the country have used the court’s decision to push for more home and community-based services (Wiener, Stevenson and Kasten, 2000).

States have considerable flexibility and show substantial variation in how they finance and organize publicly-funded home and community-based services. In all states, Medicaid, the federal-state health and long-term care program for low-income families, is the principal source of financing for long-term care, including home and community-based services. Medicaid is

attractive to states because the federal government shares in the costs, but at the price of conformity with federal rules and regulations. Although home health is a mandatory benefit, personal care and home and community-based services waivers are optional for the states. In 2002, 31 states and the District of Columbia offered personal care as a Medicaid optional benefit through the state plan (Burwell, Sredl and Eiken, 2003).

In order to have greater flexibility over services and more fiscal control over utilization and expenditures, many states are increasingly relying on Medicaid home and community-based services waivers to finance their noninstitutional long-term care services. In 2002, a total of 47 states and the District of Columbia had home and community-based services waivers for older people or waivers for older people and younger persons with physical disabilities (Eiken and Burwell, 2003). These initiatives are called “waivers” because certain standard features of the Medicaid program (e.g., all services must be offered statewide) are “waived” or do not apply to this portion of the program. Medicaid waivers are also attractive because states may cover an exceptionally broad array of services, including many nonmedical services not otherwise reimbursable by Medicaid.

Medicaid waivers also provide states with substantially more control over expenditures than is normally the case for home care under Medicaid. For example, eligibility for Medicaid waivers is limited to beneficiaries who need an institutional level care--nursing home care for older people. In addition, states must establish in advance the maximum number of people they will serve during the course of a year. Thus, states may establish waiting lists for waiver services, something not permitted in the regular Medicaid program. Finally, in order to help achieve cost effectiveness, states must limit average Medicaid expenditures for waiver beneficiaries to the same or less than the average Medicaid cost of nursing home care or other institutional care.

In addition to Medicaid, funding from the Older Americans Act, the Social Services Block Grant, and other federal and state programs rounds out the financing system for home and community-based services. The Older Americans Act provides federal assistance for community support services for persons aged 60 and older. These funds are distributed through the Aging Network, which consists of 56 State Units on Aging, 655 Area Agencies on Aging, 244 Tribal and Native organizations, two organizations serving Native Hawaiians, and over 29,000 service providers. Aging Network activities include access services such as information and referral and

transportation services, nutrition programs, home and community-based supportive services, family caregiving support, and social, volunteer, and legal services for older people. At the state and local levels, many State Units on Aging and Area Agencies on Aging also administer and coordinate programs funded by Medicaid, the Community Service and Social Service block grants, and programs supported by state and county general revenue funds (Gage, Wiener, Walsh et al., 2004; Kane, Kane and Ladd, 1998). Indeed, two-thirds of State Units on Aging administer Medicaid home and community-based services waivers for older people and younger persons with disabilities. Aging Network members also advocate on behalf of older people.

Other Older Americans Act initiatives are targeted at caregivers. The Alzheimer's Disease Demonstration Grants to States Program, which was enacted in 1990, and the National Family Caregiver Support Program, which was enacted in 2000, were created to encourage states to support informal caregivers by providing limited funding to the states to develop support systems for family members who care for older people with disabilities (Feinberg et al., 2002). States who received these grants have established support activities such as intensive case management services, voucher support, respite workers, adult day care facilities, with an emphasis on outreach to minority caregivers in rural and urban settings (Schulz, 2000).

The Social Services Block Grant provides states with limited funds for a large range of social services for the low-income population. State-funded programs are designed to fill in gaps by offering services that Medicaid will not cover, extending eligibility to persons who do not meet Medicaid's financial or functional eligibility criteria, or to provide services (such as home modifications) generally not available through other sources.

This report is a study of five states—Wisconsin, Washington, North Carolina, Missouri, and Texas—which have adopted innovative strategies to change the balance between institutional and noninstitutional long-term care services. They vary in terms of which agency (Aging or Medicaid) has taken the lead in creating a more balanced system and whether it has been directed by state, county, or local initiatives. A major focus of this report is on the role of the State Unit on Aging and the Area Agencies on Aging in reforming the long-term care system. With its broad perspective on older people, the Aging Network in each of these states plays a unique role.

For each state, three major questions are addressed:

- What is the policy environment and administrative structures for home and community-based services, and what role does the Aging Network play in the development of community-based service systems?
- To what extent has the state implemented certain innovations to expand home and community-based services and better meet the needs and desires of older people and younger persons with disabilities? These innovations include consumer-directed home care, coverage of various forms of residential care, expansions of the range of services, integration of acute and long-term care services, nursing home transition programs, control of the nursing home supply and consumer involvement in satisfaction surveys and quality assurance.
- How do people needing long-term care access the long-term care financing and delivery system, and what new tools are being used to improve assessment and care planning?

In brief, this review of initiatives in five states highlights ongoing efforts to create a more balanced financing and delivery system for long-term care. *Table 1* summarizes the home and community-based services system in each of the five states. The case studies suggest at least five key issues for other states, Area Agencies on Aging, providers and consumers that are interested in reform.

- First, more than money is at stake in efforts to change the balance between nursing home care and home and community-based services. Expanding home and community-based services is also a matter of values and is a political process involving competing visions of how older people and younger persons with disabilities should have their long-term care needs met.
- Second, although statewide implementation of initiatives sometimes occurs, they are often preceded by important planning and data collection initiatives and smaller scale demonstration projects. A number of federal, state and private foundation initiatives are underway to aid states and local agencies to try new approaches to long-term care.
- Third, there is a cornucopia of different service initiatives with which states are experimenting. Not all states are implementing all of them, but there is a wide range of activity under way.

- Fourth, in order to improve policymaking, increase efficiency and simplify access for beneficiaries, several states are actively addressing the administrative fragmentation of the long-term care system through a variety of mechanisms designed to coordinate decisionmaking and provide single points of entry.
- Finally, all states are under fiscal stress, which has hampered the expansion of home and community-based services and other reforms. Relative to many other state services, long-term care services generally have escaped major cutbacks, but finding funds for expansion is increasingly difficult.

Table 1
Selected Characteristics of Home and Community-Based Services Systems for Older People and Persons with Physical Disabilities in Wisconsin, Washington, Texas, North Carolina and Missouri, 2003

| Characteristic | Wisconsin | Washington | North Carolina | Missouri | Texas |
|---|--|------------|--|--------------------------------------|--|
| Percentage of total long-term care expenditures for home and community-based services | 23 | 43 | 41 | 20 | 43 |
| Home and community-based services expenditures per older person | \$566 | \$765 | \$612 | \$412 | \$577 |
| State funded programs play major role | Yes | No | Yes | No | No |
| Medicaid personal care covered outside of waiver | Yes | Yes | Yes | Yes | Yes |
| Waiting lists for Medicaid home and community-based services waiver | Yes | No | Yes | No | Yes, called "Interest lists" |
| State administration consolidated | Yes | Yes | No, although efforts are underway to achieve this goal | Yes | In process under Health and Human Services Commission |
| Consumer-directed services | Yes, except for state plan Medicaid personal care | Yes | No, although small demonstrations underway | No, although small projects underway | Yes, but little use by elders |
| Assisted living covered under Medicaid home and community-based services waiver | Yes | Yes | No | No | Yes, but low demand |
| Nursing home transition program | Yes | Yes | Yes, but small | Yes | Yes |
| Integration of acute and long-term care | No except for PACE and Wisconsin Partnership Program | No | No | No | Yes, STAR+PLUS in Harris County; plan to expand to most of state |
| Consumer involvement in satisfaction surveys | Yes | Yes | Yes | Yes | Yes |
| Efforts to control nursing home supply | Yes | Yes | Yes | Yes | Yes, Medicaid bed allocation mechanism |
| Single point of entry for public programs | Yes in 5 Family Care Counties. Not elsewhere | Yes | No | No | No |

SOURCE: RTI International case studies.

WISCONSIN

Demographics

In 2000, Wisconsin had a total population of 5,363,675 people, of whom 702,553 persons (13.1 percent) were age 65 or older (Administration on Aging, 2003). This percentage was above the national average of 12.4 percent. Among all the states and the District of Columbia, Wisconsin had the 18th highest percentage of the population that was seniors. While the total population of the state is projected to grow by 4.7 percent by 2020, the population age 65 and older is projected to grow far faster: 73 percent for those age 65-74, 18 percent for those age 75 to 84, and 36 percent for those 85 and older (Gregory and Gibson, 2002).

In 2000 Wisconsin ranked 39th in the nation among states and the District of Columbia in the percentage of its elderly population that was an ethnic or racial minority (Administration on Aging, 2003). Of the population age 65 and older in Wisconsin, 95.9 percent was White; non-Hispanic; 0.8 percent was Hispanic/Latino; 2.3 percent was Black/African American; and 0.5 percent was Asian. American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and those of two or more races were each less than one percent of seniors (Administration on Aging, 2003). Milwaukee has the largest concentration of minority elders.

Most of Wisconsin is rural, but overall the state is more densely populated than the United States overall. Most Wisconsin residents live in urban areas, including 67.7 percent of residents age 65 or older in 2000 (Gregory and Gibson, 2002). In 1999, 9.5 percent of Wisconsin's older people (age 65 and over) had incomes at or below the federal poverty level, below the national average.

Policy Environment

State policy and administrative responsibility for long-term care in Wisconsin is primarily located in the state Department of Health and Family Services (DHFS), with authority distributed among divisions within the agency:

- The Division of Health Care Financing has overall responsibility for the Medicaid program and administers the nursing home, home health, personal care and other Medicaid state plan services (known in Wisconsin as “card” services).
- The Bureau of Aging and Long-Term Care Resources in the Division of Disability and Elder Services is responsible for the Medicaid home and community-based

services waivers for older people and persons with physical disabilities and the state-funded home care programs, including the Community Options Programs. The Bureau is also the State Unit on Aging and is responsible for Older Americans Act programs and the Area Agencies on Aging. The Office for Persons with Physical Disabilities, which manages contracts with Independent Living Centers and the state assistive technology program, is also part of the Bureau.

- The Bureau of Quality Assurance, also in the Division of Disability and Elder Services, is responsible for regulation and monitoring adult day care, adult family homes, community-based residential facilities and nursing homes. The Bureau also has oversight over certain providers, such as home health agencies and hospices.
- The Center for Delivery Systems Development, which is also part of the Division of Disability and Elder Services, oversees the state's Family Care program, an innovative financing and delivery demonstration. Created in 1996 and originally part of the Department's planning and budgeting office, the Center was charged with coordinating the redesign of the state's long-term care system which led to the creation of Family Care (Wiener and Lutzky, 2001; Wisconsin DHFS website, 2004; Wisconsin Biennial Report, 2003; State Information Packet, 2003).

Other public stakeholders have important roles in policy development and in the management of the long-term care system:

- Counties play a major role in administering Medicaid home and community-based services waivers, the state-funded Community Options Program, the Community Aids program and county-funded long-term care services. The county-based system is believed to maximize responsiveness to local conditions and preferences, although at the cost of geographic variation and perhaps inequity in access, expenditures and program design.
- The state's six Area Agencies on Aging are nonprofit organizations consisting of multiple counties, except in Milwaukee County and Dane County (which includes Madison), where the Area Agencies on Aging cover one county and are county government agencies. The other four Area Agencies on Aging include multiple county and tribal aging units. The agencies provide a wide range of services such as information and assistance, nutritional assessments, home delivered and congregate meals, transportation, caregiver support, benefit specialist services, volunteer opportunities, wellness programs, and other programs for persons age 60 and older, their families and caregivers. The Area Agencies on Aging also provide technical assistance and support to the county and tribal aging units. In addition, the Area Agencies on Aging engage in advocacy activities for older persons. They actively supported the enactment and implementation of Family Care, mobilizing the older population in its support, and they continue to be involved in the work of the state Council on Long-Term Care. The Milwaukee Area Agency on Aging runs the largest Family Care demonstration site, serving over 5,000 elderly persons (Wisconsin DHFS website, 2004).

Consumer groups representing older people and younger people with disabilities are also well-represented in the policy process in Wisconsin, both on various advisory boards, including

the Wisconsin Council on Long-Term Care Reform, and through sophisticated, well-organized consumer advocacy organizations. The Coalition of Wisconsin Aging Groups (CWAG), the leading consumer advocacy organization, is a coalition of over 600 aging groups and over 8,000 individual members. Unlike many aging advocacy groups, the Coalition of Wisconsin Aging Groups has consistently made long-term care a major priority and was a major force in the enactment of the Family Care demonstration (CWAG, 2004). Another major advocacy organization for older people is AARP, which has a large membership and significant financial resources, which it mobilized in support of the creation of Family Care.

The disability movement, while less unified, is very active as well, and has often cooperated with the Coalition of Wisconsin Aging Groups in pursuing common goals. The major organizations are the Disability Advocates Wisconsin Network (DAWN), a cross disability network funded by the Wisconsin Council on Developmental Disabilities, and the Wisconsin Coalition for Advocacy, a private nonprofit organization. Other active groups are the Southeastern and South Central Wisconsin Chapters of the Alzheimer's Association, and ARC Wisconsin (Wisconsin DHFS, 2004; DAWN, 2004; and, Wisconsin Bureau of Aging 2001).

The nursing home industry, traditionally a very strong force in shaping long-term care policy, has experienced sharply falling occupancy rates in recent years, with the closure of a significant number of facilities and many in bankruptcy proceedings. In part these developments reflect the high bed supply in the state and somewhat lower Medicaid reimbursement rates than the national average (Bruen & Wiener, 2002).

Long-Term Care Financing

Financing of long-term care is dominated by Medicaid, although the state-funded Community Options Program and Older Americans Act programs play a major role (*Table 2*). Total publicly funded long-term care expenditures for older people and younger persons with physical disabilities were approximately \$1.721 billion in fiscal year 2002. Home and community-based services in Wisconsin were supported through five sources: Medicaid home health (3 percent of total public long-term care expenditures for older people), Medicaid personal care (6 percent), Medicaid home and community-based waivers (9 percent), state funds (4 percent) and Older Americans Act (1 percent). Medicaid nursing facility payments accounted for 77 percent of public long-term care expenditures. In addition to the traditional federal and

state funding, counties are required to contribute a small percentage of Medicaid matching funds for some Medicaid home and community-based services waivers.

Nationally known for its service flexibility and consumer-centered focus, the state-funded and county-administered Community Options Program-Regular (COP-R) provides home and community-based services to Medicaid-eligibles who need an institutional level of care, people who are slightly less disabled but do not meet Medicaid’s functional eligibility requirements, and those persons who need services not covered by Medicaid. The program, which serves persons of all ages and disabilities, began in 1981.

Table 2
Long-Term Care Expenditures for Older People and Younger Persons
with Physical Disabilities in Wisconsin, FY 2002

| | Totals in \$ Millions | Percentage of Total Long Term Care |
|--|--------------------------|--|
| Medicaid Home Health | 57* | 3 |
| Medicaid Personal Care | 108* | 6 |
| Medicaid Home and Community Based Services Waivers | 152** | 9 |
| Older Americans Act | 21* ¹ | 1 |
| State-funded Programs | 65*** | 4 |
| Total Home and Community-Based Services | 403 | 23 |
| Medicaid Nursing Home Care | <u>1,318*</u> | <u>77</u> |
| Total Long-Term Care | 1,721 | 100 |

¹Wisconsin's total OAA allocation, of which 30 to 50 percent is spent directly on long-term care services.

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- * http://www.aoa.gov/about/legbudg/current_budg/docs/FGS_FY_2002_Annual_Allocation.pdf
 - ** Eiken S, Burwell B. Medicaid HCBS Expenditures, FY 1997 through FY 2002. Table 1. May 15, 2003.
 - *** Stoller J. Community-Based Long-Term Care Programs. Informational Paper 48, Wisconsin Legislative Fiscal Bureau, January 2003. Expenditures are for calendar year 2001.
-

In 1987 the state shifted Medicaid eligible Community Options Program beneficiaries into a Medicaid home and community-based services waiver (COP-W), in order to draw down the federal Medicaid match (Wiener & Lutzky, 2001). Like its state-funded counterpart, the Medicaid Community Options Program-Waiver (COP-W) covers a very wide range of services and is consumer-oriented.

Both Community Options Programs have long waiting lists, which have been politically contentious and a focal point for consumer advocacy (Bruen & Wiener, 2002). During calendar year 2002, COP-R and COP-W together served 9,554 people over 65, and 4,224 non-elderly people with physical disabilities. In 2002, 2,752 people with developmental disabilities also received Community Options Program funding. On December 31, 2002, there were 2,384 elders and 2,777 people with physical disabilities waiting for services from the two programs (Wisconsin Department of Health and Family Services, 2003).

The regular Medicaid “card services,” administered at the state level through the Division of Health Care Financing, include the mandatory home health benefit and the optional personal care benefit. Persons on the waiting list for the Community Options Programs may receive Medicaid personal care services, but only if they are eligible for Medicaid through regular financial eligibility standards, which are more stringent than those of the waiver program.

Counties also administer the Community Aids program, a state block grant to the counties which is supplemented by some matching county funding and is used for a variety of social, mental health, alcohol/drug abuse and disability services. While these services are mostly targeted to children and persons with mental illness and developmental disabilities, the program also funds some home and community based services for older people and people with physical disabilities.

Wisconsin’s Alzheimer’s Family and Caregiver Support Program was established in 1985, and provides some funding through the counties to assist low-income caregivers in purchasing services and other aids related to the care of an individual with Alzheimer’s disease. The program has been enhanced since 2000 by a series of Administration on Aging Alzheimer’s Demonstration Grants. A dementia and aggressive/abusive behavior summit of Alzheimer’s experts was held in June, 2002, and informational tools have been developed for Alzheimer’s caregivers (Wisconsin Department of Health and Family Services, 2004; and Administration on Aging, 2004).

Home and community-based services have not been dramatically affected by the state's fiscal crisis, and the state has refrained from cutting these programs as it has other state services. Although funding for the Community Options Program has not been reduced, 2003 was the first time in the history of the program that funding was not increased. Moreover, expansion of the Family Care program to other parts of the state has also been suspended, largely due to budget pressures. At the county level, Community Options Program funding is shifting away from older people with disabilities and younger persons with physical disabilities to serve people with developmental disabilities (Stoller, 2003).

Nursing home payment rates have been tightened in recent years, mostly by reducing payment ceilings for certain categories of cost by limiting inflation adjustments. One nursing home industry analysis claimed that Wisconsin's Medicaid payment ceilings relative to costs were the lowest of any state in 2000 (BDO Seidman, 2003). To aid the nursing home industry, a new Medicaid intergovernmental transfer program was introduced in the state budget for 2001–2003. Most of the additional federal Medical funds generated are used to increase payment rates to nursing homes (Bruen and Wiener, 2002). The General Accounting Office determined that this practice is not legal, and the Centers for Medicare & Medicaid Services has given Wisconsin until 2010 to cease employing it (U.S. GAO, 2004).

Innovations in Home and Community-Based Services

In order to change the balance between institutional and home and community-based services and to make services more consumer-focused, many states are implementing a number of innovations, including: consumer-directed home care, assisted living and other residential care facilities, expansion of the range of services covered, integration of long-term care services and the integration of acute and long-term care services, nursing home transition programs, controls on the nursing home supply, and consumer satisfaction surveys. Wisconsin has incorporated a number of these innovations into the mainstream of its home and community-based services systems. In addition, Wisconsin's Family Care program, which is fully operational in five counties, is one of the most far reaching and comprehensive demonstrations in the country aimed at changing the balance between institutional and noninstitutional services.

Family Care

Established to address the difficulty of seeking care from the large number of programs with varying eligibility standards, Family Care combines a single point of entry with access to a full spectrum of long-term care, both in community and institutional settings. The Family Care program has two components, Aging and Disability Resource Centers (ADRCs) and Care Management Organizations (CMOs). Aging and Disability Resource Centers, which have been established in nine counties, provide a “one stop,” single point of entry for all publicly-funded long-term care services in a county. Older people and persons with disabilities, regardless of eligibility for public services, can receive free long-term care counseling and personalized advice about available long-term care options. For Medicaid eligibles, Aging and Disability Resource Centers provide assessments to determine an appropriate care plan, and assistance in enrolling in a Care Management Organization, if desired. In addition, Aging and Disability Resource Centers provide information and counseling on long-term care to the broader non-Medicaid population, supplying information on services such as transportation, employment, food stamps, home maintenance, and legal assistance, as well as counseling for those having difficulties with Medicare, Social Security, and other public benefits. They are also responsible for providing 24-hour crisis intervention and emergency services. Aging and Disability Resource Centers conduct outreach to older people and younger persons with disabilities. Long-term care facilities are required to inform their residents of the availability of Aging and Disability Resource Centers’ services, and in some cases must refer them for counseling.

Care Management Organizations, which are in place in five counties, are county-government operated, capitated managed long-term care organizations. Of the five counties, four provide services to all types of disabled adults, while one, Milwaukee, serves solely older people (age 60 and older). Importantly, capitation payments to the Care Management Organizations include virtually all Medicaid-, state- and county-funded long-term care services. Counties are at full financial risk for cost overruns, a factor which recently has proved problematic in Milwaukee, which has run a deficit (Umhoeffer, 2004). While enrollment is optional, Medicaid and state funded home and community-based services (including Community Options Program-Waiver and Community Options Program-Regular) in the demonstration counties are only available through the Care Management Organization, which provides a major incentive to enrollment. To ensure that people are not pressured into enrolling, one of the Area

Agencies on Aging acts as an enrollment broker. Another important aspect of the Care Management Organization is that it controls funding for both institutional and noninstitutional care, encouraging a conscious tradeoff between the two types of services and creating a seamless system in which individual needs rather than program demarcations dictate the individual's care (Alecxi et al., 2003; APS Healthcare, 2003; Lewin, 2003; and Wisconsin Council on Long-Term Care, January 2003).

Under the authorizing statute, the goal of Family Care is to serve all persons eligible due to age or disability regardless of financial status. Family Care is an entitlement for Medicaid-eligible persons who need an institutional level of care or who have a lesser level of disability, and for those who were participants in state-funded programs preceding Family Care. For these groups there are no waiting lists for services, a marked difference from the situation for the Community Options Programs in the rest of the state (Justice, 2003). On the other hand, enrollment has been authorized only for a small number of persons not eligible for Medicaid (Wisconsin DHFS website, 2004; Wisconsin Department of Health and Family Services, May 2002). The Family Care program enrollment on December 31, 2002 included 5,283 elders and 696 people with physical disabilities (Wisconsin BALTCR, 2004).

Consumer-Directed Home Care

Consumer direction is an important, well-established component of Wisconsin's home and community-based services programs. Under the Community Options Programs, clients may hire, train, direct and fire their own workers, although the extent to which these options are offered varies by county. Family Care requires that Care Management Organizations offer consumer-directed care. Family members except spouses may be hired to provide paid care in both the Community Options Programs and Family Care, and they constitute a large proportion of consumer-directed providers. The regular Medicaid personal care benefit, however, does not have this consumer-directed option; all services are provided by agencies (Stoller, 2003).

Assisted Living Facilities and Other Congregate Care

Both the state- and Medicaid-funded Community Options Programs cover services for a substantial number of clients in residential care facilities. Residential care services are covered in both residential care apartment complexes (i.e., assisted living facilities) and community-based residential facilities (i.e., board and care homes).

Unlike some states which have embraced non-medical residential settings for persons with disabilities, Wisconsin officials have sought to reduce use of these facilities, believing that they are too institutional and that home-based care is a better, less expensive and feasible alternative. A major issue in Wisconsin is that individuals who exhaust their personal resources paying for residential care may be forced to enter nursing homes because they are too far down the queue on the waiting lists to receive Community Options Program-funded services or do not meet the functional or financial criteria for the programs. To discourage the use of residential care apartment complexes, Medicaid home and community-based services waiver benefits were limited to facilities with no more than eight beds until 2003, when facilities with up to twenty beds became eligible. Larger facilities may participate if they consist completely of independent apartments (Wisconsin DHFS BALTCs, 2003). There have also been efforts to reduce residential care utilization by providing information about home-based alternatives to residents at the point of admission to the facility, but reportedly this initiative has had little effect because it occurs too late in the decisionmaking process.

Expanding the Range of Services

The state- and Medicaid-funded Community Options Programs and the Family Care program offer an exceptionally wide range of services, and the state takes great pride in innovative arrangements which allow individuals to stay at home. In the past, a substantial portion of state-funded Community Options Programs money was used to pay for services not permitted by Medicaid home and community-based services waivers. However, increased flexibility in the interpretation of the federal waiver rules has allowed the Medicaid waiver to fund a broader array of services and for the state-funded program to focus instead on serving persons with more financial resources or persons with dementia who might not qualify for waiver services.

Under the state's Administration on Aging Alzheimer's Demonstration grants, a statewide Wisconsin dementia service network is being developed to focus on improved access to services for minority and underserved families. Among its services, this network will provide funding of up to \$4,000 from the state Alzheimer's Family and Caregiver Support Program for each individual with Alzheimer's. This funding will be available to provide adult day care, respite, and other community-based long-term care services. Crisis response teams are also

under development to address abuse of persons with dementia (Wisconsin Department of Health and Family Services, 2004; Administration on Aging, 2004).

Integration of Acute and Long-Term Care

Wisconsin's efforts to change the long-term care system are firmly rooted in a commitment to a social model of care with a strong nursing component, and influenced by cautiousness toward health maintenance organizations. Family Care was initially proposed as a system that would include both acute and long-term care services, but it was strongly opposed by consumer groups. As a result, Family Care focuses solely on integrating long-term care services, although some informal arrangements are in place to coordinate services between the Care Management Organizations and acute providers (Stoller, 2003).

Integrated acute and long-term care services are, however, available to some populations in Wisconsin. The Program of All-inclusive Care for the Elderly (PACE) site in Milwaukee provides integrated acute and long-term care for frail older people (age 55 and older) on a capitated basis for those persons who need a nursing home level of care. The other integrated care program in the state is the Wisconsin Partnership Program, which operates in four locations. It is similar to PACE but relies much less on adult day care and uses nurse practitioners to coordinate care, allowing participants to retain their own doctors. The PACE and Partnership programs served 1,626 elders and people with physical disabilities in state fiscal year 2002 (Wisconsin BALTCS, 2004).

Nursing Home Transitions

In recent years, Wisconsin has undertaken an active effort to relocate nursing home residents to the community; approximately 500 people have been relocated since 2000. The Wisconsin transition program, Homecoming, began with a federal Health Care Financing Administration nursing home transition grant in 1999 and continued as Homecoming II under a Centers for Medicare & Medicaid Services Real Choice Systems Change Grant in 2001. In order to be eligible, residents must be Medicaid eligible and have lived in a nursing home for at least three months. The program provides community supports and is working to secure an adequate workforce to provide services (Wisconsin Department of Health and Family Services, 2004). A second 2001 Real Choice Systems Change Grant was awarded to an Independent Living Center

to identify additional individuals for transition, train a group of transition specialists, and develop caregiver supports (Centers for Medicare & Medicaid Services, 2003).

At the inception of the nursing home transitions program in Wisconsin, the money associated with those residents was permanently transferred to the Community Options Programs' budgets. Due to budget constraints, however, funding now follows the person, but does not stay permanently in the Community Options Program after the individual leaves the program. Funding for transitioned individuals returns to the Medicaid institutional budget when the individual dies or is readmitted to a nursing home. When nursing beds are closed, however, Wisconsin has a funding mechanism called Community Integration Program II or CIP II, under COP-W, which permanently transfers funding from nursing home services to a separate Medicaid home and community based care allocation (Wisconsin Department of Health and Family Services, 2004). Nursing home residents who are relocated to the community receive preferential access for designated relocation funding through the Community Options Program. Due to flat funding, however, the Department no longer has special funds for relocations and nursing home relocations are currently being funded from existing county allocations of home and community-based services or as a result of bed closures (Wisconsin BALTCs, 2004).

Efforts to Control Nursing Home Supply

There is currently a large excess capacity of nursing facility beds in Wisconsin. The state has 60 nursing home beds per thousand persons age 65 and older compared to a national average of 50 beds per thousand older people (U.S. Census Bureau, 2004; American Health Care Association, 2003). The state has had a moratorium on new nursing facility beds since 1981, but there are not any direct financial incentives for nursing homes to reduce capacity. The industry, however, is growing smaller because of financial pressures. In 2001, about one-seventh of nursing homes were in bankruptcy proceedings, and 5 percent of facilities had closed since 1997. Other facilities have either reduced their number of beds or left them unstaffed. In addition to the impact of excess capacity, nursing home Medicaid per diem payments averaged about 10 percent below costs in 1999 (BDO Seidman, 2001).

As financially distressed nursing facilities close, the state is intervening to facilitate the process and to protect patients. In order to provide resources to maintain quality of care, Medicaid continues payment levels to closing nursing homes at historical levels for three to six

months, even as the home reduces its resident population prior to closure (Bruen & Wiener, 2002).

Consumer Involvement in Satisfaction Surveys and Quality Assurance

Consumers are involved in satisfaction and quality assessment in both the Community Options and Family Care programs. Community Options Programs are assessed by an outside auditor through an annual in-home survey of 400-500 clients and random visits to consumers in their homes. The evaluation measures Community Options Program performance against 22 standards of care developed to assess participant-defined outcomes. Feedback is provided to the counties about system and individual problems. Care managers are also required to contact each client monthly, with in-person meetings at least every three months (Lewin, 2003; Wiener and Lutzky, 2001; Robert, 2001; and, Robert, 2003).

Family Care has 14 standards designed to capture participant-defined outcomes in the areas of self-determination and choice, community integration, and health and safety. A Care Management Organization member outcomes assessment survey is conducted annually with a random sample of program participants and their case managers. Each Care Management Organization receives a report on each of the 14 standards with a quality of life indicator, the percentage of members who reported that their desired outcome is being met, a quality of service indicator, and the percentage of members who received services for a specific outcome. The state also monitors Family Care through 17 clinical, functional, and preventive health measures (Justice, 2003; Lewin, 2003; Wisconsin Department of Health and Family Services, April 2002).

Accessing the Long-Term Care System

Access to the long-term care system in Wisconsin is largely the responsibility of counties. An economic support unit in every county collects financial information that the state uses to determine Medicaid eligibility. Counties are also responsible for intake, functional assessment, and case management for individuals seeking state- or Medicaid-funded Community Options Program services.

In the Family Care demonstration counties, the Aging and Disability Resource Center provides the functional assessment and acts as the single point of entry for a wide range of programs. Financial eligibility, however, is still determined by the county economic support unit. Case management is the responsibility of the Care Management Organizations in the five

counties that have them, and each county has benefit specialists who help older people with obtaining benefits (Justice, 2003, Lewin, 2003).

Data on client functional and health status and service needs in Family Care is collected by social workers or registered nurses using a long-term care functional screening instrument, the automated Wisconsin long-term care functional screen administered by the Aging and Disability Resource Centers. The data entered into the screen goes directly into a state database, the Wisconsin Client Assistance for Re-Employment and Economic Support (CARES) system, which generates a functional eligibility result. The CARES system is used by Medicaid, Family Care, and the Food Stamp and Temporary Assistance for Needy Families programs to determine eligibility, issue benefits and manage the programs. Information from the long-term care functional screen is available to county agencies not currently part of the Family Care demonstration, with about half of the counties currently using the system and the remainder planning to adopt it over the next year. County administrative data, on the other hand, is not maintained in unified or compatible systems (Wisconsin Department of Health and Family Services, 2004; Wisconsin Department of Health and Family Services, March 2002; and, Wisconsin BALTCES, 2004).

Implications for Reform

Wisconsin has a long history of initiatives to create a more balanced long-term care financing and delivery system. Its Community Options Program has a national reputation for flexibility and consumer responsiveness and its Family Care demonstration is one of the most far reaching in developing an integrated financing and delivery system. Wisconsin illustrates five key issues in the reform of the long-term care system.

First, reforming the long-term care system requires the ongoing efforts of both government officials and consumer advocates, including the Aging Network. Legislative passage of the Family Care demonstration and continued increased funding for the Community Options Program has been largely the result of advocacy by older people and state leaders, increasingly working with groups representing younger persons with disabilities. In addition, as frustrating as it often is, change takes time; Wisconsin has been working to create a more balanced system for over 20 years and still is not finished remaking the system.

Second, closely related to the idea that change takes time is that comprehensive reform often cannot be implemented all at once. In these circumstances, demonstration projects can be

important mechanisms to articulate the vision and show the feasibility and desirability of changes in the system. The implementation of the Family Care demonstration in five counties is laying the foundation for potential changes in the system as a whole, although state fiscal pressures currently are preventing taking the program statewide.

Third, there is a very wide range of possible innovations to improve the financing and delivery system for long-term care. Wisconsin has adopted a large number of these initiatives; its long-term care system gives consumers the option of consumer-directed care, offers an extremely broad set of services to meet the needs of individuals, is working to transition people out of nursing homes (although its focus is on preventing initial admission), has a substantial supply of residential care facilities (although they are criticized by many policymakers and advocates as being too institutional), uses its PACE and Wisconsin Partnership Programs to integrate acute and long-term care services, controls its nursing home supply, and surveys consumers about quality of care. Wisconsin's Family Care demonstration combines a single point of entry with a capitated care management organization responsible for both nursing home and home and community-based care; integrating both access to and financing of long-term care services in five counties. Because of Wisconsin's strong reliance on counties to design and administer long-term care, the availability of these initiatives varies substantially across the state.

Fourth, in order to address the fragmentation of the financing and delivery system, Wisconsin has consolidated some administrative functions at the state level and is experimenting with a radical consolidation at the county level through Family Care. At the state level, administration of the long-term care system has been relatively fragmented, but a recent initiative has consolidated many long-term care services, including the Medicaid waiver and Community Options Programs, in the Division of Disability and Elder Services. At the local level, for the counties in which it operates and for the people who enroll, the Family Care demonstration consolidates funding for virtually all long-term care services in the care management organization, with the goal of creating a seamless financing and delivery system.

Fifth, and finally, Wisconsin, like other states, is under substantial financial pressure. Revenues are down due to tax cuts of the 1990s and the sagging economy; at the same time, demand for programs for lower-income people, such as Medicaid, has increased. Home and community-based services in Wisconsin have largely been spared the cuts that other state services have received, but the lack of funds has halted expansion of the Community Options

Program and the Family Care demonstration. The protection of services to older people reflects the effectiveness of the Aging Network and the high regard in which home and community-based services are held.

Wisconsin has a long history of working to expand home and community-based services, and is one of the relatively few states to operate a major home care program outside of Medicaid. It has implemented many service innovations. The state's Family Care program is particularly ambitious and will be watched closely by other states and Area Agencies on Aging.

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WASHINGTON

Demographics

In 2000, 662,148 persons, 11.2 percent of the Washington's population, were age 65 and older. This percentage was below the national average of 12.4 percent. Among all the states and the District of Columbia, Washington had the 6th highest percentage of the population that was seniors. While the total population of the state is projected to grow by 13 percent by 2020, the population age 65 and older is projected to grow far faster: 120 percent for those age 65-74, 46 percent for those aged 75 to 84, and 68 percent for those 85 and older (Gregory and Gibson, 2002).

Washington was ranked 28th in the nation among states and the District of Columbia in the proportion of its elderly population that was an ethnic or racial minority. Of the population age 65 and older in Washington in 2000, 91.2 percent was White, non-Hispanic; 3.8 percent was Asian; 1.6 percent was Hispanic/Latino; and, 1.6 percent was Black/African American. American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and those of two or more races were each 1 percent of elders or less (Administration on Aging, 2003).

Washington's older population is highly urbanized and relatively well off financially. In 2000, 81.1 percent of Washington's older people lived in urban areas, which is higher than the nation as a whole (78.3 of elderly individuals living in urban areas) (Gregory and Gibson 2002). In 1999, about 8 percent of Washington's elderly population had incomes at or below the federal poverty level, well below the national average.

Policy Environment

Washington is characterized by highly consolidated long-term care administration and policy at the state level, with extensive participation by Area Agencies on Aging. Washington's efforts to expand home and community-based services, almost all of which are funded by Medicaid, date to the early 1980s, when it received one of the first Medicaid home and community-based services waivers. Spurred in part by a tightening budget, the state passed major legislation in 1993 and 1995 that began the explicit process of funding the expansion of home and community-based services by reducing nursing home use, a strategy that continues today.

At the state level, virtually all responsibility for long-term care is consolidated in the Aging and Disability Services Administration (ADSA) of the Department of Social and Health Services (DSHS).¹ These responsibilities include all financing, regulation, quality assurance and policy for Medicaid, Older Americans Act, and state-funded programs for nursing homes and home and community-based services. The State Unit on Aging is part of the Home and Community Services division of the Aging and Disability Services Administration. At the local level, the Aging and Disability Services Administration works with the state's 13 Area Agencies on Aging (AAAs). Responsibility for services for persons with developmental disabilities/mental retardation was recently transferred to the Aging and Disability Services Administration. The unification of budgetary responsibilities for both institutional and noninstitutional services encourages policy and budgetary tradeoffs and coordination between the two services.

In 2001 a voter initiative established the Home Care Quality Authority (HCQA), a small independent agency with a majority-consumer board. Modeled after similar public authorities in California and Oregon, its function is to address the needs of older people and persons with disabilities who use consumer-directed home care and the independent providers who supply these services. Its prime goals are to support individuals according to their needs, values, and interests, and to promote a more stable workforce. Its responsibilities are to conduct collective bargaining as the public employer of individual providers, to recruit, establish qualifications for, and maintain a register of individual providers, and to provide training opportunities for consumers and providers (HCQA website, 2004).

Area Agencies on Aging, along with their typical responsibilities for implementing services throughout their planning and service areas, are key components of the Medicaid administrative structure for persons receiving home and community-based services, both for the Medicaid waiver and the personal care benefit. After an initial assessment and authorization by state employees of clients coming into the long-term care system, Area Agencies on Aging assume responsibility for case management of all in-home clients, including the reauthorization of services. Typical functions include negotiating contracts, allocating resources, making operational policy and management decisions within program guidelines, and developing

¹ Prior to 2002, the Aging and Disability Services Administration was the Aging and Adult Services Administration.

budgets for expenditure of Older Americans Act and State Senior Citizen Act funds. In addition, the Area Agencies on Aging are actively involved in the legislative process. One current issue in which they are involved is the question of legal liability when providers honor client choices even when doing so may not be optimal from a safety perspective.

Although the state has a well-organized and politically effective nursing home industry, strong consumer advocates, especially for older people, have provided an effective counterbalance. Consumer advocates have provided much of the political will to redesign the long-term care system and have worked closely with state officials to do so. While there is not a silver-haired legislature, the Senior Citizens Lobby, a coalition of over 20 senior consumer groups, educates consumers and legislators on policy issues affecting older people. The AARP has an active chapter in Washington, which lobbies state legislators to protect funding for important programs for older citizens and supports. AARP Washington supports providing older citizens with home and community-based services. The state nursing home industry is focused on reimbursement and regulatory issues rather than overall system design.

Long-Term Care Financing

Medicaid is the overwhelming source of public funding for long-term care in Washington; the only other meaningful source of funding is the Older Americans Act. This reflects a deliberate state strategy to reduce the role of state-funded programs. In fiscal year 1984, 97 percent of home and community-based services clients had their services financed by state-only funded programs; in fiscal year 2000, only 2 percent of home and community-based consumers had their services financed by state-only funded programs (Wiener & Lutzky, 2001). In 2002, Washington spent \$1.367 billion on long-term care for older people and younger persons with physical disabilities (*Table 3*). Publicly-funded home and community-based services in Washington were supported through five sources: Medicaid home health (1 percent of total public long-term care expenditures for older people and younger persons with physical disabilities), Medicaid personal care (15 percent), Medicaid home and community-based waivers (22 percent), state funds (less than 1 percent) and the Older Americans Act (1 percent). Medicaid nursing facility payments accounted for 61 percent of these public long-term care expenditures.

The state has two major Medicaid mechanisms for providing home and community-based long-term care to older people and younger persons with physical disabilities: the Medicaid

personal care benefit, available to persons who are eligible for Supplemental Security Income, and the Community Options Program Entry System (COPEs), Washington’s Medicaid home and community-based services waiver program. The Community Options Program Entry System, which pays for personal care and housekeeping services for people who need help with certain

Table 3
Long-Term Care Expenditures for Older People and Younger Persons
with Physical Disabilities in Washington, 2002

| | Totals in \$ Millions | Percentage of Total Long Term Care |
|--|--------------------------|--|
| Medicaid Home Health** | 14 | 1 |
| Medicaid Personal Care** | 204 | 15 |
| Medicaid Home and Community-based Services** | 294 | 22 |
| Older Americans Act* | 13 | 1 |
| State-funded Programs*** | 3 | <1 |
| Total Home and Community-based Services | 528 | 39 |
| Medicaid Nursing Home Care** | <u>839</u> | <u>61</u> |
| Total Long-term Care | 1,367 | 100 |

*http://www.aoa.gov/about/legbudg/current_budg/docs/FGS_FY_2002_Annual_Allocation.pdf

**Eiken, S., Burwell, B.; Medicaid HCBS Expenditures, FY 1997 through FY2002, Table 1. May 15, 2003

***Summer, L., and Ihara, E., State-funded Home and Community-based Service Programs for Older Persons. Georgetown University, February 9, 2004

basic activities of daily living, provides services for over 24,000 people and the Medicaid personal care program provides services for over 10,000 persons with disabilities, including older people (Washington Department of Social and Health Services, 2004). Washington also has a Medicaid medically needy residential waiver, which provides coverage in assisted living and similar facilities for older people and persons with disabilities who meet functional requirements similar to those for the Medicaid waiver. Beneficiaries of this waiver have resources or income slightly above Medicaid limits, and receive slightly less medical coverage (Washington DHFS e-mail, 2004; Washington Administrative Code, 2003).

Unlike many other states, the vast majority of people receiving Medicaid home and community-based services in Washington do so under the waiver rather than the personal care program. While the majority of clients are older people, about a third of the clients receiving personal care and waiver services are between the ages of 18 and 64. Again, unlike many states, Washington does not have waiting lists for waiver services, although recently enacted budget constraints may necessitate their establishment.

Washington has a small state-funded program, the Chore program, that provides personal care and volunteer homemaker services to those persons with incomes and assets that exceed Medicaid eligibility levels. The state also funds a respite program, and a Family Caregiver Support program is jointly supported with state funds and Medicaid.

Washington has also received an Administration on Aging Alzheimer's demonstration grant, which funded the Washington State Alzheimer's Project to develop supportive services that are responsive to cultural values. Four main projects focus on different target populations including Chinese, Hispanic, Korean, and Native American elders (Administration on Aging, 2004).

As the result of two ballot initiatives which restricted state expenditures and revenues, Washington has responded to strict budget constraints since the mid-1990s. Initiative 601, passed a decade ago, limits the rate of growth in state expenditures financed from the general fund to the sum of the percentage change in inflation and population growth. Adding to these restrictions, Initiative 695, which passed in 1999, eliminated the state's relatively high motor vehicle excise tax, reducing state revenues by hundreds of millions of dollars. Although the provision was declared unconstitutional by the state Supreme Court on technical grounds, state policymakers have agreed to budget within its constraints. Finally, ballot initiatives approved in 2000 required that the state increase funding for education, limiting the availability of general revenues for other purposes.

In response to these budget restrictions, the state began to promote the expansion of home and community-based services as a cost-cutting measure, financing additional home and community-based services with reduced funding for nursing home clients. The 2001-2003 DSHS budget reduced nursing home payment rates for non-resident care costs while providing some increases for expenses more directly related to client needs, providing a net savings of 1.27 percent on Medicaid nursing home expenditures. In 2003, the state faced a serious fiscal crisis

and cut many social programs in order to balance the budget, although long-term care was not hit as hard as some other services. According to state officials, the legislature directed the Department of Social and Health Services to stay within budget by "any means necessary."

Washington took a number of steps to balance the budget, including:

- The Aging and Disability Services Administration was directed to limit the growth of the number of people in the Community Options Program Entry System waiver to 1.1 percent per year. This will allow an average of about 24,350 people to receive services during the 2003-2005 biennium, which is 1,000 more people than during the preceding year, but approximately 700 fewer than would be served if the program continued to grow without limits.
- The functional eligibility requirements for Medicaid personal care services were tightened; as a result, the state expects about 700 persons will lose eligibility.
- The level of financial resources protected for community-based spouses of Medicaid nursing home residents was reduced from \$90,660 to \$40,000.
- Medicaid reimbursement rates were frozen. The legislature, however, did make an exception for nursing homes to receive a 3 percent rate increase, supported by a \$6.50 per day Nursing Home Quality Maintenance Fee, essentially a provider tax. In addition to paying for itself through the fee, this measure generated increased Medicaid reimbursements which were placed in the state's reserve account (Holahan et al 2004).
- The appropriation for the health care for workers with disabilities program was capped, and the Department of Social and Health Services was given authority to restrict eligibility to meet the cap as necessary.
- Administrative changes, including ending telephone applications and self declaration of incomes for Medicaid coverage and an increase in the frequency of eligibility redeterminations, aim to limit new applicants and more quickly remove individuals who no longer qualify for benefits (Holahan et al 2004).

Innovations in Home and Community-Based Services

In order to change the balance between institutional and home and community-based services and to make services more consumer-focused, many states are implementing a number of innovations including: consumer-directed home care, assisted living facilities and other residential care facilities, expansion of the range of services covered, integration of long-term care services and the integration of acute and long-term care services, nursing home transition programs, efforts to control the nursing home supply, and consumer satisfaction surveys.

Washington has implemented almost all of these new approaches.

Consumer-Directed Home Care

As part of its long-standing commitment to a social model of long-term care, consumer-directed home care is not only a mainstream component of community-based services in Washington, it is the dominant model. Approximately 60 percent of Medicaid home care beneficiaries use consumer-directed home care rather than agencies. In line with programs in other states, a recent Aging and Disability Services Administration survey of all clients assessed during 1998 found that 52 percent of independent providers were family members.

Clients in both the Medicaid personal care program and Community Options Program Entry System have a choice of using licensed home care agencies or independent providers. Under the independent provider option, the worker is a direct employee of the client, with the state assuming responsibility for paying workers and taxes. With assistance from the Area Agencies on Aging's case manager, the client is responsible for hiring, supervising, and finding replacements for the caregiver.

Although recently abandoned, a major factor shaping home care in Washington was a long-standing state policy that required clients who needed more than 112 hours of service per month to use independent providers. Devised principally as a cost containment mechanism, the rule was intended to keep in-home per person expenditures below 90 percent of the average cost of nursing facility care.

During the 1999 legislative session, the legislature authorized in-home nurse delegation in the Medicaid home and community-based services waiver. Previously, this option was only available in community residential settings. Nurse delegation allows nursing assistants to perform certain tasks—such as administration of prescription medications—normally performed only by licensed nurses. A registered nurse must teach and supervise the nursing assistant, as well as provide nursing assessments of the patient's condition.

Assisted Living Facilities and Other Congregate Care

Reflecting the influence of Oregon's long-term care system, assisted living facilities and adult family homes are a major component of Washington's publicly-funded community-based services. The service components of assisted living and adult family homes are covered under the Medicaid home and community-based waiver and personal care services are provided in congregate residential settings. In Washington, adult family homes tend to be small, family run

businesses serving three to five people, and assisted living facilities tend to be larger and possibly more like an institutional setting. About a quarter of persons receiving home and community-based services are in these various congregate residential settings.

Quality of care in these facilities is a significant concern, accentuated by the fact that the state has had to pay millions of dollars in liability damages from negligence lawsuits. To address these problems, new training requirements have been imposed and inspections have been increased. The new requirements stress outcomes over processes. Inspections now average one every 18 months instead of every two years, and the frequency of visits varies with the results of the inspections.

Washington recently added a pilot program that covers dementia care and expanded disabilities care in the assisted living and adult family home setting. Dementia care must be provided and an increase in the reimbursement rates was approved for those facilities that offer services to clients with dementia.

Expanding the Range of Services

The Community Options Program Entry System waiver covers a very broad range of services. As noted above, consumer-directed home care and residential services outside of nursing homes are important components of the long-term care delivery system. These Medicaid services are supplemented by a wide range of support services purchased by the Area Agencies on Aging. [should we list these?]

Integration of Acute and Long-Term Care

Reflecting its commitment to the social model of long-term care, Washington does not have a major initiative to integrate acute and long-term care services. However, it recognizes that many of its clients have substantial medical needs. To address the needs of these clients, the state is integrating more nurses into the assessment and care planning process. In addition, the Medicaid Integration Partnership of the Department of Social and Health Services has been analyzing the potential benefits of providing services in a more integrated fashion to older people and people with disabilities and is planning a demonstration project to test these concepts.

Nursing Home Transitions

Washington has aggressively worked at identifying nursing home residents who could live in the community and arranging their transfer to that noninstitutional setting. Reducing the nursing home census has been a key element in obtaining funding for increased home and community-based services. In 1993 the state planned an expansion of home and community care to be financed largely through relocating 750 nursing home clients over the 1993-1995 biennium. In 1995, the legislature authorized the Aging and Disability Services Administration to further limit nursing home utilization by systematic diversion and voluntary relocation of clients to home and community settings, passing a budget assuming a reduction of Medicaid nursing home residents by 1,600 clients over the 1995-1997 biennium. In 1995, Washington also began an intensive program of case management, again seeking to relocate nursing facility residents back to their homes. By providing expanded eligibility for persons who have incomes above 300 percent of the federal SSI benefit rate, the recently implemented medically needy waiver makes more persons potentially eligible for transfer to the community. Partly in response to these initiatives, Medicaid nursing home utilization dropped from a peak of 17,448 residents in fiscal year 1993 to about 12,500 in fiscal year 2002, despite an increase in the number of older people in the state (Washington DSHS, 2004).

Washington has been awarded three Centers for Medicare & Medicaid Services Real Choice Systems Change Grants since 2001. A Nursing Facilities Transitions grant was awarded to the state to assist with providing planning, services, housing, and assistive technology assistance to facilitate transitions to the community. Another grant focused on case management for transitioning individuals with mental illness and multiple disabilities, and on self-directed care, including training for consumers and the development of consumer-directed service payment options. The state has also received a Money Follows the Person Grant, which will deal with assessment, planning and quality improvement issues in community-based living (Centers for Medicare & Medicaid Services, 2003).

The state also financially supports transitions to the community through a number of mechanisms including:

- The Civil Penalty Fund assists nursing home residents with funds collected from nursing facilities for being in violation of state statutes and regulations, and can be used to support residents' transition into the community, paying for such services as transportation to potential community relocation settings, environmental

- modifications, assistive technology, short-term independent living services in a community setting, or compensation for loss of funds or property due to theft or fraud.
- An Assistive Technology Fund provides financial assistance for durable medical equipment, assistive technology devices or services, minor home modifications and repairs, and evaluations of assistive technology needs. This fund can only be used after other sources of support have been exhausted.
 - The state allows new nursing facility residents to retain more than the standard Medicaid nursing facility personal needs allowance, up to 100 percent of the federal poverty level, during the first six months of a nursing facility stay. Residents can use this income to maintain their community residence, facilitating their return home.
 - The residential care discharge allowance is a one-time payment of up to \$816 to cover items such as rent, security deposits, utilities, telephone, or the purchase of furniture, bedding, household goods and supplies, or minor home modifications, and is available to Medicaid residents who are transitioning to a less restrictive setting.
 - As part of its Centers for Medicare & Medicaid Services nursing facility transition grant, Washington established a fund that state-employed case managers or Area Agency on Aging staff can access to purchase independent living consultation services or assistive technology to support a resident's transition or maintenance in the community. State-employed case managers or staff from the Area Agencies on Aging can access this fund to purchase independent living consultation services or assistive technology to support a resident's transition or maintenance in the community.

Efforts to Control Nursing Home Supply

Washington currently has 34 nursing home beds per 1000 persons age 65 and over, far below the national average of 50 beds per 1000 older persons (U.S. Census Bureau 2004, American Health Care Association, 2003). Washington limits the supply of nursing home beds as part of its cost containment goals. Since 1978, Washington has required a certificate of need for new construction of nursing homes. To limit new construction, Washington includes utilization of home and community-based services in its calculation of whether there is unmet need for nursing home beds, and requires the conversion of hospital beds to nursing home beds if possible prior to allowing new construction.

Washington also has a bed banking policy that encourages withdrawal of unused beds and bed conversion to assisted living facilities. The state allows facilities to bank beds through two mechanisms – one for facilities that are closing and would like to retain or sell the rights to these beds, and one for facilities that would like to bank beds for alternative use (e.g. to convert

nursing home beds into assisted living beds). Beds which are “banked” are counted as available beds in the state’s calculation of unmet need.

Consumer Involvement in Satisfaction Surveys and Quality Assurance

As part of their quality assurance activities, the Aging and Disability Services Administration conducts some direct interviews with clients and surveys of case manager performance. Response rates are fairly high, but a large number of caregivers are family members, so ratings may not fully reflect the quality of care provided. Another concern is that some clients may not openly voice dissatisfaction for fear of losing services. The Area Agencies on Aging require providers to monitor consumer satisfaction, using surveys to assess satisfaction with case managers. Residential interviews are part of the inspection process at adult residences as well. The Home Care Quality Authority also conducts focus groups for consumers to monitor satisfaction.

Accessing the Long-Term Care System

There is a single point-of-entry for all state-supported long-term care services. Applicants apply to the local office of the Aging and Disability Services Administration, which conducts a functional and financial assessment to determine eligibility for Medicaid and other programs. The Aging and Disability Services Administration provides case management for people in nursing facilities and residential care facilities, including adult family homes and assisted living facilities. If clients are eligible for home care, initial care plans are developed by the Aging and Disability Services Administration and then responsibility for clients is transferred to a local Area Agency on Aging, which provides ongoing case management and reauthorization of services. Face-to-face reassessments are done annually. Area Agencies on Aging make payments to agency providers and then are reimbursed by the Department of Social and Health Services; independent providers are paid directly by the state. A major issue for Area Agencies on Aging is funding for case management services. Caseloads are high (85 to 100 persons per case manager) and funding for these services has not kept pace with inflation or with rising caseloads.

In order to be eligible for the Medicaid home and community-based waiver, individuals must have incomes below 300 percent of the federal Supplemental Security Income benefit level. In order to receive services from the Chore program, individuals must be age 18 or older, not

eligible for other programs (including Medicaid) and not have assets exceeding \$10,000 for one person and \$15,000 for two persons. Services are offered on a sliding fee scale. Applicants must need help with personal care and at risk of placement in a long-term care facility.

A major new initiative is the implementation of the Comprehensive Assessment Reporting Evaluation (CARE) system, which is a computerized assessment and care planning tool used by local Aging and Disability Services staff. With this system, staff are able to interview clients in their own homes and input the data electronically using laptops, creating a permanent agency database. The new tool has two goals. First, the new assessment instrument is designed to be more objective and reliable in its measurement of client needs, focusing more on the client's health status. Second, based on the assessment, the instrument will be used to develop more consistent and equitable care plans, since the tool can automatically generate a care plan and recommend referrals. These assessments will ultimately determine payment levels for residential care as well. For home care clients, the assessment information will be used to classify clients into fourteen clinical categories. The client's classification category, the amount of informal support available, and other factors regarding instrumental activities of daily living determine how many hours the client is eligible to receive in-home care. The assessment can also document other needs and make recommendations, even if benefits to address them are not currently available.

New protocols are being developed for determining when nursing care should begin, and for dealing with falls, skin care, and medication management. None of these protocols, however, is currently scheduled for statewide implementation.

Implications for Reform

Washington has a highly developed system of home and community-based services that provides care to a substantial number of older people and younger persons with disabilities. It is among the nation's leaders in use of consumer-directed home care and residential care facilities, such as assisted living facilities and adult foster homes. The case of Washington suggests at least five key issues for reform.

First, changing the balance between institutional and noninstitutional services is not only a financing issue, it is also a philosophical and political issue. Washington has had a strong vision of system reform that it has pursued for over two decades. Notably, despite the long standing efforts, reform is still a work in progress. Consumer advocates and state officials, with

the help of the Aging Network, have consistently pushed for changing the balance of care towards home and community-based services.

Second, while many states have used planning initiatives, data collection and demonstration projects to further their vision of reform, Washington has mostly implemented its reforms statewide, without intermediate steps. State budget pressures, mostly created by voter initiatives to limit state expenditures and revenues, have forced Washington to find fiscal solutions without demonstration projects. On the other hand, the vision of a more balanced delivery system and a belief in home and community-based services provided officials with guideposts for how to change the long-term care system.

Third, states are implementing a wide range of mechanisms designed to improve the financing and delivery system for long-term care. While Washington is involved in a large number of service delivery innovations designed to make services more responsive to older people and younger persons with disabilities and to provide them with more choices, a major focus is on consumer-directed home care and residential care facilities. Both service innovations are not only offered, but they are widely used.

Fourth, in order to address the fragmentation of the financing and delivery system, many states are working to improve coordination at both the policy and administrative levels. Relying heavily on Area Agencies on Aging, Washington has developed one of the most integrated administrative systems in the country. The single point of entry system means that older people and younger persons with disabilities have access to a unified system that can direct them to the services they need.

Fifth and finally, in this time of fiscal crisis, all state budgets are under stress. For most of the 1990s, Washington was able to use the budget constraints as a way to expand home and community-based services, arguing that it was a more cost-effective system of providing care than nursing homes. Thus, unlike many other states, Washington was able to leverage fiscal limitations to further rather than hinder long-term care reform. More recently, however, Washington's fiscal crisis has been of a magnitude that expansion of home and community-based services has slowed significantly.

Washington has worked to change the balance between nursing home and home care for approximately 20 years. The state's long-term care system is notable for its single point of entry system and its heavy use of residential care facilities and consumer-directed services.

Washington's expansion of home and community-based services has largely been funded by a decline in nursing home use.

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NORTH CAROLINA

Demographic Characteristics

In 2000, 969,048 persons, approximately 12 percent of North Carolina's population of 8.3 million people, were age 65 or older, slightly less than the national average of 12.4 percent (Administration on Aging, 2003). Among all the states and the District of Columbia, North Carolina had the 37th highest percentage of the population that was seniors. While the total population of the state is projected to grow by 17 percent by 2020, the population age 65 and older is projected to grow far faster: 62 percent for those age 65-74, 39 percent for those age 75 to 84, and 78 percent for those 85 and older (Gregory and Gibson, 2002).

In 2000 North Carolina ranked 15th in the nation in the percent of its elderly population that was a racial or ethnic minority (Administration on Aging, 2003). Of the population age 65 and older, 82.1 percent was White, non-Hispanic and 15.8 percent was Black/African American. American Indian/Alaska Native, Native Hawaiian/Pacific Islander, Asian, Hispanic/Latino, and those of two or more races each were less than 1 percent of the North Carolina elders (Administration on Aging, 2003).

Many of North Carolina's older residents live outside an urban area (41.1 percent in 2000) and have low incomes. In 1999, 16.9 percent of older people in North Carolina had incomes at or below the federal poverty level, which makes North Carolina the state with the third poorest elderly population in the country (Gregory and Gibson, 2002).

Policy Environment

A large number of agencies within the North Carolina Department of Health and Human Services (DHHS) are involved in the financing, delivery and regulation of long-term care. At the local level, counties play a critical role in managing long-term care services. A North Carolina Institute of Medicine study of long-term care is influential in setting policy directions. The task force found the extensive fragmentation among the Department of Health and Human Services agencies to be the greatest challenge facing the long-term care system. In response to their recommendations, the state created a position of Assistant Secretary for Long-Term Care in the Office of the Secretary of the Department of Health and Human Services. In addition, they established a long-term care "cabinet" to coordinate all of the divisions responsible for long-term

care. At the county level, county commissioners were encouraged by the report to designate a lead agency to organize the local planning process for long-term care. The state is supporting these efforts by providing data and technical assistance.

Of the eight divisions involved with long-term care in the Department of Health and Human Services (DHHS), three are particularly important for home and community-based services for older people:

- The Division of Aging and Adult Services (DAAS) is the State Unit on Aging and has responsibility for Older Americans Act programs, guardianship, adult protective services, and Special Assistance, which finances residential services provided to low-income persons in adult care homes through state and county funds. It assumed oversight of the adult social services programs in September 2003, in a change that the DHHS Secretary said would improve coordination in policy development, program support, communications, and fiscal management. The Division has primary responsibility for the largely state-funded Home and Community Care Block Grant. It provides information and education about long-term care and advocates for the well-being of older people.
- The Division of Medical Assistance (DMA) is responsible for the Medicaid program and administers its benefits, including home health, personal care, home and community-based services waivers, and nursing home care.
- The Division of Social Services (DSS) oversees financial eligibility for Medicaid services through county departments of social services.

Counties in North Carolina play a strong role in the design and financing of home- and community-based services for both state-only and Medicaid-funded programs. The 102 counties allocate and administer the Home and Community Care Block Grant. In addition, North Carolina is one of 10 states that require counties to share in the non-federal portion of Medicaid costs; county funds comprise 5.6 percent of the total cost of Medicaid payments (North Carolina Division of Aging, 2003). While the Division of Medical Assistance oversees Medicaid home and community-based services waivers at the state-level, counties are primarily responsible for the day-to-day administration of the waivers at the local level. County commissioners select a “lead agency” to run the waiver programs in their areas. Although all counties administer Medicaid waiver programs, it is optional for them to do so, which lessens the control of state agencies over the program.

There are 17 Area Agencies on Aging, each located within regional Councils of Government. Area Agencies on Aging responsibilities include: monitoring the Home and Community Care Block Grant; providing advocacy, coordinating program and resource

development; administering funds and conducting quality assurance; and supplying training and capacity building services (North Carolina Division of Aging, 1999). The Area Agencies on Aging have been actively involved in discussions about the future of long-term care and are one of several organizations influencing long-term care reform.

Consumer involvement in policymaking occurs at both the state and local level. The North Carolina Senior Tar Heel Legislature has been active in long-term care issues, providing information to older adults on the legislative process and matters under legislative consideration and promoting citizen involvement and advocacy on aging issues. They have been active in obtaining funding for the Home and Community Care Block Grant. The Governor's Advisory Council on Aging provides recommendations to the governor and the secretary of the Department of Health and Human Services on long-term care issues. Recommendations included expanding human services for older people, improving coordination among state agencies, developing a statewide information and assistance system, and promoting understanding of problems affecting older adults.

In 1999, the North Carolina General Assembly acknowledged the problems facing the state's long-term care infrastructure in maintaining a proper balance between institutional and non-institutional services and ensuring adequate funding levels and a supply of services. These concerns were based on the substantial number of state agencies involved in long-term care, the limited scope of services offered and the large projected increase in the number of older persons.

To help facilitate changes, the North Carolina Department of Health and Human Services and the legislature asked the North Carolina Institute of Medicine (IOM) to develop a comprehensive plan for long-term care that could be used as a road map for creating a more balanced long-term care system. To meet this directive, the Institute of Medicine established a taskforce with 49 members, including state legislators, county commissioners, local governments, long-term care providers, industry associations, consumer advocacy groups and businesses. The taskforce held 11 daylong meetings between November 1999 and December 2000. Their report, *A Long-Term Care Plan for North Carolina: Final Report*, was released in January 2001 (North Carolina Institute of Medicine, 2001).

Long-Term Care Financing

Medicaid is the overwhelming source of funding for long-term care for older people in North Carolina, although Older Americans Act and state-funded programs play an important

gap-filling role (*Table 4*). In 2002, North Carolina spent \$1.512 billion on long-term care for older people and younger persons with physical disabilities. Publicly-funded home and community-based services in North Carolina were supported through five sources: Medicaid home health (6 percent of total public long-term care expenditures for older people and younger persons with physical disabilities), Medicaid personal care (18 percent), Medicaid home and community-based waivers (14 percent), state funds (2 percent) and Older Americans Act (2 percent). Medicaid nursing facility payments account for 59 percent of these public long-term care expenditures.

Table 4
Long-Term Care Expenditures for Older People and Younger Persons
with Physical Disabilities in North Carolina, FY 2002

| | Totals in \$ Millions | Percentage of Total Long Term Care |
|--|--------------------------|--|
| Medicaid Home Health** | 97 | 6 |
| Medicaid Personal Care** | 269 | 18 |
| Medicaid Home and Community Based Services Waivers** | 205 | 14 |
| Older Americans Act*** | 28 | 2 |
| Home and Community Care Block Grant* | 23 | 2 |
| Total Home and Community-Based Services | 622 | 41 |
| Nursing Facilities* | <u>890</u> | <u>59</u> |
| Total Long-Term Care | 1,512 | 100 |

*LL Summer and ES Ihara, “State-Funded Home and Community-Based Service Programs for Older Persons,” (Washington, DC: AARP Public Policy Institute, forthcoming 2004).

**S. Eiken and B. Burwell, “Medicaid HCBS Expenditures, FY 1997 through FY 2002,” unpublished memo, (Cambridge, MA: The MEDSTAT Group, May 15, 2003); and, B. Burwell, K. Sredl, and S. Eiken, “Medicaid Long-Term Care Expenditures in FY 2002,” unpublished memo, (Cambridge, MA: The MEDSTAT Group, Inc., May 15, 2003).

***Administration on Aging web site, “AoA Title III/VII Older Americans Act State Allocations Table 1, http://www.aoa.gov/about/legbudg/current_budg/docs/FY01_04%20Amounts.pdf.”

Starting in 1992, state and federal categorical funding for home and community-based services was consolidated into a Home and Community Care Block Grant to the counties. The two principal purposes of the creation of the Home and Community Care Block Grants were to

give counties greater discretion, flexibility and authority in determining services, funding levels, and service providers, and to streamline and simplify the administration of services. The grant incorporates Older Americans Act and Social Services Block Grant funds (for respite care), portions of the state in-home and adult day care appropriations, other state funds, and participant co-payments. The block grant funds are distributed to the counties based on a funding formula that takes into account the number of persons who are elderly, poor, non-white and living in rural areas.

Within a broad “menu” of 18 services, counties have great flexibility in how they spend the funds. With direct input in the planning and decisionmaking process from older people who serve on an advisory committee appointed by the county commissioners, the county commissioners approve a funding plan for the Home and Community Care Block Grant that defines the services to be provided, the funding levels for services, and the community service providers to be involved. During the state fiscal year 2002, expenditures for the Home and Community Care Block Grant were approximately \$52 million, of which almost half was state funded.

The Medicaid program covers personal care as a state plan benefit and operates four Medicaid home and community-based service waivers, of which the most important for older people is the Community Alternatives Program for Disabled Adults (CAP/DA). This program provides a package of services to allow adults (age 18 and older) who qualify for nursing facility care to remain in their homes. The allocation of Community Alternatives Program for Disabled Adults “slots” across counties is based on historical usage and not on the need in a geographic area. As a result, the number of individuals served by county varies considerably. Administered by the Division of Medical Assistance, Community Alternatives for Disabled Adults has long waiting lists for services. The program paid for services for 12,779 people in state fiscal year 2001.

Like other states, North Carolina is facing serious fiscal problems. Medicaid has contributed to these budget stresses. For example, expenditures for the Medicaid personal care benefit increased from \$154 million in fiscal year 1999 to \$263 million in fiscal year 2002, approximately a 72 percent increase (Burwell, Sredl and Eiken, 2003).

Overall, long-term care services have been insulated from major funding cuts, but have sustained some significant reductions over the last few years and some initiatives are stalled for

lack of funds. Some observers attribute the advocacy efforts of the Senior Tar Heel Legislature and other consumer advocates from preventing even greater cuts in spending. The following initiatives have been implemented to reduce or control spending:

- As of December 2002, the maximum Medicaid personal care benefit decreased from 80 hours per month to 60 hours per month. However, on November 1, 2003, Medicaid implemented the new Personal Care Services-Plus (PCS-Plus) program to provide 20 additional hours of PCS each month to eligible recipients. All requests for PCS-Plus must undergo prior approval by the Division of Medical Assistance.
- From October 2001 to July 2002, the state froze admissions to the Community Alternatives Program for Disabled Adults waiver so that no new people could be served. During that period, the number of persons receiving waiver services declined by about 20 percent. In 2002, the legislature appropriated additional funds that allowed for new admissions to the program, but not enough to continue the previous growth in the number of beneficiaries.
- The maximum allowable monthly level of per person expenditures under the home and community-based waiver has not increased since 2000, effectively lowering the permissible level of expenditures as a percentage of the average cost of nursing home care.
- Funding for the Home and Community Care Block Grant was cut by \$1 million for fiscal year 2003, about a 4 percent cut in absolute terms, not adjusting for inflation.

Innovations in Home and Community-Based Services

In order to change the balance between institutional and home and community-based services and to make services more consumer-focused, many states are implementing a number of innovations including: consumer-directed home care, assisted living facilities and other residential care facilities, expansion of the range of services covered, integration of long-term care services and the integration of acute and long-term care services, nursing home transition programs, control of the nursing home supply, and consumer satisfaction surveys. North Carolina has experimented with a number of these new approaches.

Consumer-Directed Care

Consumer-directed home care currently is available to a very limited extent. Under current Community Alternatives Program for Disabled Adults rules, for example, clients cannot directly hire and fire their in-home aide providers. In extremely limited circumstances, agencies may hire family members that clients want as caregivers. In addition, in some areas, the Administration on Aging-funded caregiver support programs are using vouchers to pay family members.

North Carolina has several initiatives designed to expand the availability of consumer-directed services. Part of North Carolina's Real Choice Systems Change Grant from the Centers for Medicare & Medicaid Services includes provisions to develop models of consumer-directed care for older people and younger persons with disabilities. This effort is being combined with the Department of Health and Human Services' Community-integrated Personal Assistance Services and Supports (CPASS) grant from the Centers for Medicare & Medicaid Services, which will assess relevant fiscal and regulatory policies in terms of their support of consumer-directed care and will help prepare providers to offer such care. In March 2002, the Division of Aging and Adult Services was one of five state agencies nationwide to secure a small grant from the National Association of State Units on Aging to begin a process of determining how consumers might have increased opportunities to make choices and direct their own care. The Department of Health and Human Services has developed a broad-based work group including consumers and providers to explore this issue (North Carolina Division of Aging, 2003). Most recently, the Centers for Medicare & Medicaid Services approved North Carolina to pilot consumer-directed care as an Independence Plus waiver for its Community Alternatives Medicaid Program for Disabled Adults. Similar to the Cash and Counseling Program, the Independence Plus waivers provide beneficiaries with an individual budget to purchase services.

Assisted Living Facilities and Other Congregate Care

North Carolina has a large supply of non-medical residential care facilities. These facilities vary greatly in the level of care provided, but all are licensed as assisted living facilities. In 1995, after a long legislative debate, the General Assembly recognized three types of assisted living residences; adult care homes, group homes for persons with developmental disabilities, and multi-unit assisted living with services. The General Assembly defines assisted living facilities as "any group housing and services program for two or more unrelated adults, by whatever name it is called, that makes available, at a minimum, one meal a day and housekeeping services, and provides personal care services directly or through a formal written agreement with one or more licensed home care or hospice agencies. Settings may include self-contained apartment units or single or shared room units with private or common baths." Because the definition is so broad, many board and care homes qualify as assisted living facilities in North Carolina.

While the Medicaid home and community-based services waiver does not cover care in these residential settings, Medicaid personal care services are provided. Some observers believe that many of the facilities serving low-income persons tend to be institutional in character. North Carolina has a state Supplemental Security Income payment called Special Assistance, which is only available to low-income persons who reside in residential care facilities. North Carolina now also supports a Special Assistance (SA) In-Home program to provide an option for in-home care for older people and persons with disabilities who are at risk of placement in an adult care home but who desire to live in a private residential setting. Currently, this option is available in 61 counties. To qualify, the individual must meet the eligibility criteria for Medicaid and meet all other Special Assistance eligibility requirements. For fiscal year 2002, 262 clients age 60 and older were assisted through the Special Assistance In-Home program.

Expanding the Range of Services

The Medicaid home and community-based services waiver covers a fairly standard set of services, including case management, adult day health, in-home aide services, supplies (including reusable incontinence undergarments, disposable liners for undergarments, incontinence pads for undergarments, oral nutritional supplements, and medication dispensing boxes), home mobility aids (including wheelchair ramps, widening of doorways for wheelchair access, safety rails, non-skid surfaces, handheld showers and grab bars), preparation and delivery of meals, respite care, and personal emergency response systems (North Carolina Institute of Medicine, 2003).

To expand the range of services available to meet the highly individual needs of people with disabilities, the North Carolina Institute of Medicine Task Force on Long-Term Care developed a list of “core” long-term care services and recommended a planning process to make sure that all communities have a broad continuum of care.² The Division of Aging and Adult Services is leading a departmental initiative to support counties in their evaluation and planning of “core services.” The North Carolina IOM report emphasized the importance of local planning for services in order to ensure a match with local resources and preferences.

² The goal is for each county to offer core services which include; nursing home, adult care home, home healthcare, in-home aide services, care management for high-risk clients, nursing services, transportation, durable medical equipment and supplies, adult day/day healthcare or attendant care, home delivered meals, housing and home repair and modification, long-term care information and referral services, and medical alert or related services.

Integration of Acute and Long-Term Care

North Carolina is just beginning to examine the integration of acute and long-term care. They are in the design phase of a chronic care coordination project focused on high cost/high risk cases that will begin to address this issue.

Nursing Home Transitions

North Carolina has received a Centers for Medicare & Medicaid Services Nursing Home Transitions Grant to develop mechanisms to help people relocate from nursing homes to the community. As of 2003, the grant had transitioned 13 people out of nursing homes into community settings. Over the three years of the grant, the goal is to transition 80-100 nursing home residents into community settings. According to state officials, the low number of people transitioned is attributable to the high level of disability among nursing home residents in North Carolina, making it difficult to identify people who can be moved to the community. Medicaid eligibles relocated from nursing homes to the community are able to jump the queue to obtain home and community-based waiver services, but counties do not receive additional funding for these clients. Funding for these clients must come out of the existing allocation of waiver 'slots' provided to the counties.

Efforts to Control Nursing Home Supply

Compared to national averages, North Carolina has a relatively low supply of nursing home beds with slightly higher occupancy rates. As of December 2003, North Carolina had 42 beds per 1000 older people compared to 50 beds per 1000 older people nationally; the average occupancy rate was 89 percent in North Carolina compared to 85.6 percent nationally (authors' calculations based on data from the American Health Care Association, 2004; and the US Census Bureau, 2003). As part of the effort to control the supply of institutional services, North Carolina has a certificate of need program for nursing homes and assisted living facilities. Responding to the large increase in the number of facilities, the state imposed a moratorium on new construction of assisted living facilities for three years starting in 1997.

Consumer Involvement in Satisfaction Surveys and Quality Assurance

The Division of Aging and Adult Services mandates annual satisfaction surveys for congregate and home-delivered meals programs. Some providers opt to conduct client

satisfaction surveys in other program areas as well. In addition, the Division has undertaken statewide surveys of nutrition programs, in-home services, and Ombudsman services, and the Division has participated in the Administration on Aging's Performance Outcomes Measures Project for the past four years. No satisfaction surveys are conducted for Medicaid services.

Accessing the Long-Term Care System

Access to long-term care is relatively fragmented in North Carolina, with efforts to coordinate intake and case management across long-term care financing systems slowed due to budget constraints. The North Carolina Institute of Medicine report recommended that the state adopt a "no wrong door" approach to long-term care access. By implementing this approach, a client or caregiver can contact any of the state or county agencies involved in home and community-based care and receive accurate and relevant information. As part of this strategy, the state conducted a study in spring of 2003 to determine the feasibility of developing a consolidated statewide database of service providers that can be used for information and referral. This database will be web-based and accessible to citizens as well as human service providers. The Department of Health and Human Services is moving forward with project implementation.

Financial eligibility for Medicaid and other programs is determined by the county department of social services. Applicants for home and community-based services must have their physician complete a one-page FL-2 form, which is submitted to the state's Medicaid fiscal agent for level of care determination. Applicants for the Medicaid home and community-based services waiver must need a nursing home level of care in order to qualify for services. A revised, more comprehensive form has been developed but not implemented because of budget constraints.

Counties contract with "lead agencies" to administer the Medicaid home and community-based waiver at the local level. Lead agencies for the waiver program are responsible for conducting a 12-page standardized assessment, developing a care plan, and providing ongoing case management for consumers. The assessment is usually administered by a nurse and social worker. A lead agency can be a department of social services, health department, hospital, or aging agency. In some cases, the lead agency also directly provides services. While this arrangement raises questions of conflict of interest, a recent study by the North Carolina Institute of Medicine did not find any systematic evidence of problems (North Carolina Institute of

Medicine, 2003). People receiving only Medicaid personal care receive some case management, but the amount is less than received by waiver beneficiaries.

The Community Alternatives Program for Disabled Adults program is monitored in two ways. First, consultants conduct annual on-site reviews of each program. Second, the state contracts with Medical Review of North Carolina (MRNC) for a monthly, paperwork-oriented review of a random sample of cases. In October 2003, the Division of Medical Assistance announced changes in its quality assurance program for Community Alternatives Program for Disabled Adults. Working with the Medical Review of North Carolina, the changes involve moving away from the current manual audit-based system to an automated system designed to provide better information to the State and the local lead agencies. In addition, to help evaluate the extent to which waiver services are targeting people who would otherwise be admitted to a nursing home, the acuity levels of Community Alternatives Program for Disabled Adults beneficiaries will be assessed using a revised FL-2 form that incorporates elements of the Minimum Data Set used for nursing home residents. The goal of the revised form is to better compare community alternatives program for disabled adult beneficiaries to nursing home residents. The Department is also conducting a study that will compare clients of adult day services and adult care homes with nursing facility clients. In 2004, North Carolina received a joint Administration on Aging and Centers for Medicare & Medicaid Services grant to develop an Aging and Disability Resource Center, which will provide a single entry point and comprehensive information.

Implications for Reform

North Carolina has been working since the early 1990s to create a more balanced long-term care system. Several factors have shaped the North Carolina system of home and community-based services, including the North Carolina Institute of Medicine's report on long-term care, various service delivery initiatives, especially recent demonstrations involving the development of consumer-directed services; the efforts by the Department of Health and Human Services to coordinate policy and services, the use of the Home and Community Care Block Grant as a mechanism to coordinate services, and the state's fiscal situation. North Carolina presents a number of examples of five key issues in the reform of the long-term care system.

First, involving a broad range of stakeholders in the decision-making process is important to obtain buy-in for the choices that are ultimately made. The North Carolina's Institute of

Medicine's long-term care project included a very large number of participants in the long-term care system and the eleven days of meetings allowed for the expression of a very wide range of views, helping to provide legitimacy for the final report.

Second, planning initiatives, data collection, and demonstration or pilot projects can be important mechanisms to lay out the vision, build justification, and test methods for expanding home and community-based services. North Carolina policymakers view the Institute of Medicine Report as a catalyst for change and a comprehensive roadmap to guide them towards a balanced system of long-term care in North Carolina. The report outlined a step-by-step guide for the relevant agencies to follow to create a greater balance between home and community-based services and nursing home care. The release of the report and the high profile status of the task force members generated considerable media attention and consequently greater public awareness and support for long-term care issues.

Third, states are implementing a wide range of mechanisms designed to improve the financing and delivery system for long-term care. North Carolina has experimented with a number of these innovations, especially consumer-directed home care and nursing home transitions. In both cases, the initiatives were financed by Centers for Medicare & Medicaid Services Real Choice Systems Change grants; these initiatives are currently demonstration projects at the local level and have not been implemented statewide.

Fourth, in order to address the fragmentation of the financing and delivery system, states are working to improve coordination at both the policy and administrative levels. The North Carolina Home and Community Care Block Grant consolidated several funding sources in order to coordinate the service delivery system and offer seniors more options. More recently, in response to the North Carolina Institute of Medicine's critique of fragmented decisionmaking in long-term care, the Office of Long-Term Care and Olmstead was formed within the Department of Health and Human Services, the position of Assistant Secretary for Long-Term Care and Family Services was created and a long-term care cabinet, which includes division directors responsible for long-term care, was established.

Fifth, and finally, in this time of fiscal crisis, all state budgets are under pressure. The current fiscal situation in North Carolina has prevented policymakers from implementing many of the recommendations contained in the Institute of Medicine report. In spite of the difficult

budgetary situation, the state continues to attend to the pressing issues of long-term care and to establish guidelines to address them (North Carolina Division on Aging, 2003).

North Carolina has been working to reform the long-term care system for over a decade. Especially important in shaping the expansion of home and community-based services has been the Home and Community Care Block Grant, the report of the North Carolina Institute of Medicine, and the efforts at policy coordination within the state Department of Health and Human Services.

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MISSOURI

Demographics

In 2000, 755,379 individuals, 13.5 percent of Missouri's 5.6 million citizens, were age 65 and older, more than the national average of 12.4 percent (Administration on Aging, 2003). Among all the states and the District of Columbia, Missouri had the 11th highest percentage of the population that was seniors. While the total population of the state is projected to grow by 4.5 percent by 2020, the population age 65 and older is projected to grow far faster: 51 percent for those age 65-74, 14 percent for those age 75 to 84, and 29 percent for those 85 and older (Gregory and Gibson, 2002).

In 2000 Missouri ranked 30th in the nation among states and the District of Columbia in the percentage of its elderly population that was an ethnic or racial minority (Administration on Aging, 2003). Of the population age 65 and older in Missouri, 91 percent was White, non-Hispanic and 7.1 percent was Black/African American. Hispanic/Latino, Asian, American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and those of two or more races were each 1 percent of elders or less (Administration on Aging, 2003).

In 2000, 31.7 percent of older people were living in non-urban areas (Gregory and Gibson, 2002). In 1999, 10.6 percent of older people had incomes at or below the federal poverty level, about the same as the nation as a whole.

Policy Environment

Responsibility for home and community-based services in Missouri is shared among several state agencies, and is allocated among agencies according to the target population. For older people, responsibility is consolidated in the Department of Health and Senior Services. Within this Department, the Division of Senior Services and Regulation (DSSR) is responsible for administering the Medicaid personal care benefit and the Medicaid aging and disabled home and community-based services waiver. The Division of Senior Services and Regulation also acts as the State Unit on Aging and is responsible for Older American Act and state-funded aging services programs. In this role, the Department of Health and Senior Services works with the ten Area Agencies on Aging across the state to provide services and information to seniors. While

the Division of Senior Services and Regulation has no responsibility for paying nursing homes, it licenses facilities and regulates quality of care in these institutions.

The Division of Medical Services in the Department of Social Services and the Family Support Division (formerly the Division of Family Services) act as payors for the Medicaid program. The Family Support Division is also responsible for the administration of child support enforcement, income maintenance and self-sufficiency programs and rehabilitation services for the blind. The Division of Medical Services is the single state agency responsible for the administration of the Missouri Medicaid program. While the Family Support Division determines general Medicaid eligibility, financial eligibility for Medicaid home and community-based services waivers is determined in conjunction with the Division of Medical Services.

The current administrative structure is the result of a reorganization that occurred in 2001, which moved the Division of Senior Services and Regulation from the Department of Social Services to the new Department of Health and Senior Services. Prior to the move, advocates for older people unsuccessfully argued for a separate department of aging as a way of raising the policy profile of issues affecting older people. As a compromise, the Division of Senior Services and Regulation moved from the Department of Social Services, where it was one of fourteen divisions, to an agency where it is one of just three divisions. This helped to give aging issues greater visibility. Despite gaining greater prominence, the Division did not receive significant additional funding. The reorganization also was designed to improve coordination between the Senior Services and Health Divisions.

The state's ten Area Agencies on Aging are mainly responsible for managing Older Americans Act and state-funded programs; they also provide information and referral. Only recently have they begun to be involved with Medicaid, primarily through the provision of home-delivered meals. A small amount of Social Service Block Grant funds are utilized by the Area Agencies on Aging.

Other stakeholders include a number of provider and consumer groups. Mandated by the Older Americans Act, the Governor's Advisory Council acts in conjunction with the Department of Health and Senior Services to advise the governor on issues relating to older Missourians. The state also has a Silver-Haired Legislature which maintains an active advocacy role in senior issues and has had a significant impact on legislation and policy. As in most states, the nursing

home industry also plays an influential role in long-term care policy. In Missouri, the nursing home industry is more highly organized and more politically active than home care agencies.

In addition to the three departments that address long-term care issues and the network of Area Agencies on Aging across the state, there are several commissions and councils which advocate for consumer-focused home care. The Home and Community-Based Services and Consumer Directed Care Commission was created by the governor to address the U.S. Supreme Court's *Olmstead* decision and to expand community options. This Commission made 76 recommendations that became the center of the state's long-term care planning and legislative activities. These recommendations focus on caregiver compensation, housing, informed choice, flexible funding, employment, waiting lists, and monitoring and reporting.

Additionally, the Personal Independence Commission, consisting of state officials, consumers, family members, and legislators, was created to advise the governor on the implementation of the recommendations of the Home and Community-Based Services and Consumer Directed Care Commission. The Personal Independence Commission also examines existing programs and services, monitors the transition of institutionalized individuals into home and community-based settings, and is charged with identifying a lead agency and structure for implementing the Centers for Medicare & Medicaid Services Real Choice Systems Change Grant (Missouri Department of Labor and Industrial Relations, 2004). Although persons with developmental disabilities and older people have traditionally had separate service and financing systems, the *Olmstead* decision has prompted discussions about collaboration between the two groups.

Long-Term Care Financing

In Missouri, financing of home and community-based services is dominated by Medicaid, although Older Americans Act, Social Services Block Grant and state-funded programs play a role (*Table 5*). Publicly-funded long-term care expenditures for older people and younger persons with physical disabilities totaled approximately \$1.523 billion in fiscal year 2002. Of these expenditures, publicly-funded home and community-based services in Missouri were supported through five sources: Medicaid home health (<1 percent of total public long-term care expenditures for older people and younger persons with physical disabilities), Medicaid personal care (12 percent), home and community-based waivers (6 percent), state funds (1 percent) and

Older Americans Act (2 percent). Medicaid nursing facility spending accounted for 80 percent of these public long-term care expenditures.

Missouri’s heavy relative use of the Medicaid personal care option compared to home and community-based services waivers is unique among the states studied for this project. The personal care option allows the states to target a less disabled population than is required for the waivers.

As a result of an extensive public planning process funded by the Administration on Aging, the Missouri Care Options program was established in 1993, partly as a Medicaid home and community-based services waiver. Establishment of this program marked the beginning of the state’s systematic efforts to create a more balanced delivery system. Administered by the Division of Senior Services and Regulation within the Department of Health and Senior Services, Missouri Care Options was created with the goal of postponing or preventing nursing home placement.

Table 5
Long-Term Care Expenditures for Older People and Younger Persons
with Physical Disabilities in Missouri, FY 2002

| | Totals in \$ Millions | Percentage of Total Long Term Care |
|--|--------------------------|--|
| Medicaid Home Health** | 5 | <1 |
| Medicaid Personal Care** | 185 | 12 |
| Medicaid Home & Community Based Services Waivers** | 84 | 6 |
| Older Americans Act*** | 23 | 2 |
| State-funded Programs* | 15 | 1 |
| Total Home and Community-Based Services | 312 | 20 |
| Nursing Facilities** | <u>1,211</u> | <u>80</u> |
| Total Long-Term Care | 1,523 | 100.0 |

*Interview, Missouri Division of Senior Services.

**S. Eiken and B. Burwell, “Medicaid HCBS Expenditures, FY 1997 through FY 2002,” unpublished memo, (Cambridge, MA: The MEDSTAT Group, May 15, 2003); and, B. Burwell, K. Sredl, and S. Eiken, “Medicaid Long-Term Care Expenditures in FY 2002,” unpublished memo, (Cambridge, MA: The MEDSTAT Group, Inc., May 15, 2003).

***Administration on Aging web site, “AoA Title III/VII Older Americans Act State Allocations Table.” Available at: http://www.aoa.gov/about/legbudg/current_budg/docs/FGS_FY_2002_Annual_Allocation.pdf.

Missouri Care Options offers information to clients about long-term care options, especially home and community-based services. All persons applying for Medicaid nursing home care are screened so that each individual has the opportunity of using home and community-based services instead. In addition, Missouri Care Options provides home and community-based services which includes services to persons in residential care facilities. The services available through Missouri Care Options include help with activities of daily living, help with complex physical needs, companion services to relieve family caregivers, help with housekeeping, laundry, meal preparation, shopping and other services, in-home nursing care, supervised adult day care programs and home delivered meals. The program also works with eligible nursing home residents to discuss transitioning to the community. As part of these efforts, Missouri Care Options created community counselor positions in hospitals to assist in transitioning residents to the community, but these staff were eliminated in the recent budget cuts. To be eligible for Missouri Care Options services, applicants must be 18 or over, eligible for Medicaid, and have functional limitations that are deemed medically severe enough to qualify for nursing home care, but able to be served in the community. In state fiscal year 2002, Missouri spent \$15 million for Division of Senior Services and Regulation in-home care.

During the late 1990s, home and community-based services grew at a rapid rate. From 1996-2001 Missouri increased spending on Medicaid home and community-based services waiver programs for older people and younger persons with physical disabilities from \$173.6 million to \$296.6 million and more than doubled its spending on the Medicaid personal care program from \$63.7 million to \$150.4 million (Burwell, Sredl and Eiken, 2003).

In this time of state fiscal crises, Missouri is struggling to balance its budget, but has largely exempted home and community-based services from major budget cuts. Indeed, Medicaid home care reimbursement rates increased slightly in fiscal year 2003, but no payment increase is planned for fiscal year 2004. Because of budget pressures, certain reform initiatives have been eliminated and state officials are seeking ways to improve efficiency. Recent changes include:

- Elimination of telephone reassurance, outreach workers in hospitals and clinics, and a seniors' volunteer program.
- Closer monitoring of the nursing home pre-admission screening process.
- Review of the levels of service authorized by case managers to make sure that they are not excessive.

- Freezes on the state-funded (non-Medicaid) component of the Missouri Care Options program (although there is no waiting list for the Medicaid home and community-based services waiver).
- Cuts in case management staff within the Department of Health and Senior Services so that caseloads per staff member are now between 150 and 200 clients, which some observers consider to be high and may adversely affect the quality of services.

Innovations in Home and Community-Based Services

In order to change the balance between institutional and home and community-based services and to make services more consumer-focused, many states are implementing a number of innovations including: consumer-directed home care, assisted living facilities and other residential care facilities, expansion of the range of services covered, integration of long-term care services, integration of acute and long-term care services, nursing home transition programs, consumer satisfaction surveys, and nursing home supply controls. Missouri has experimented with a number of these new approaches.

Consumer-Directed Home Care

Consumer-directed services are just beginning in Missouri. Although supported by state officials and especially younger people with disabilities, home care agencies remain skeptical of this approach, arguing that there is an increased risk for fraud and abuse with such a system. Consumer-directed home care is available under the Medicaid home and community-based services waiver administered by the Division of Vocational Rehabilitation in the Department of Elementary and Secondary Education, but only about one percent of all persons receiving personal care choose this option. Missouri Care Options does not offer this option. In an effort to reach rural populations, the Central Missouri Area Agency on Aging has experimented with consumer-directed respite care as part of its caregiver support program, allowing for the payment of family members. They have also recently begun offering consumer-directed options for transportation.

Assisted Living Facility and Other Residential Care

Facility licensure in Missouri does not distinguish between assisted living and other levels of care. Although the service component of residential care facilities is not covered through the Medicaid home and community-based services waiver, Medicaid personal care services can be provided in congregate care facilities. In 2000, the legislature authorized five

“aging in place” demonstrations to divert older people living in residential care facilities from moving into nursing homes. These demonstrations provide a full range of physical and mental health services even as health care needs change. Another recent initiative established specialized facilities for persons with dementia; these facilities must meet specific criteria for staffing, training and fire safety.

Expanding the Range of Services

The emphasis in Missouri has been on increasing the number of people receiving home and community-based services rather than on expanding the range of services covered. For example, in 2000 the state lowered the minimum age for the Medicaid aging and disabled home and community-based services waiver from 65 to 63. During that same year, the range of covered services was expanded by adding home-delivered meals to the Medicaid home and community-based services waiver. Other recent innovations in services, such as telephone reassurance and adult day care without a health component, have not been widely used.

The Administration on Aging’s National Family Caregiver Support Program, which was implemented by the Area Agencies on Aging, was important in expanding the range of community-based services for caregivers of older people and elderly individuals who are caring for children under the age of 18. The Administration on Aging’s Alzheimer’s Demonstration Grants have allowed for a statewide expansion of respite initiatives. With current budget pressures, the focus is on maintaining existing services.

Integration of Acute and Long-Term Care Services

Although not a major focus of state policy, Missouri recognizes that many persons with disabilities also have complicated medical needs. In response, the Division of Senior Services and Regulation hired thirteen registered nurses to provide consultant services to social workers developing care plans for in-home services. Through the Medicaid program, Missouri also provides funding for the Program of All-inclusive Care for the Elderly (PACE) in two locations. The state has also approved five aging-in-place and twenty Alzheimer pilot projects with the goal of providing “wrap around” services to elders to allow them to stay in their own homes.

Nursing Home Transitions

The major goal of the Missouri Care Options program is to postpone or prevent nursing home placement. As noted previously, all persons applying for Medicaid nursing home care are screened so that the individual has the opportunity to be redirected to home and community-based services. In 2000 and 2001, Missouri enacted *Olmstead*-related provisions which allow individuals eligible for Medicaid-funded nursing home care to have Medicaid funds follow the person to the community. To date, these provisions have not been widely used. During the 2001 legislative session, the Missouri's Medicaid Buy-In Program was established, which created a grant fund to help pay the costs associated with the transition from a nursing home to the community. It also mandates training for representatives of the disability community to provide information on community-based options for individuals in institutions. Using a Centers for Medicare & Medicaid Services Real Choice Systems Change grant, the state funds a pilot program in which volunteer advocates talk with nursing home residents about home and community-based options and make referrals to the Division of Senior Services and Regulation.

Efforts to Control the Nursing Home Supply

In 2003, Missouri had 63 beds per 1000 elderly persons age 65 and older, which is higher than the national average, but the occupancy rate for Medicare or Medicaid certified beds was only 76 percent, well below the national average (American Health Care Association, 2003). In order to control the supply of nursing homes, Missouri requires certificate-of-need approval before a home is opened. A general moratorium on certificates-of-need for nursing home beds was imposed in 1983 and not lifted until 2002. While not-for-profit nursing homes tend to support the elimination of certificate-of-need requirements, for-profit homes do not. Many advocates for older people believe that certificate-of-need requirements provide protection for poor quality nursing homes and hinder competition.

Consumer Involvement in Satisfaction Surveys and Quality Assurance

Consumer involvement in quality assurance is part of ongoing contract monitoring and case management. Senior Services staff handle local care issues for individuals with problems. Additionally, clients and staff are interviewed as part of the reviews of in-home providers. Area Agencies on Aging conduct consumer satisfaction surveys for many services, but response rates are often low.

Accessing the Long-Term Care System

Access to long-term care services is accomplished through a number of mechanisms, including Area Agencies on Aging, hospitals, home care agencies and telephone hotlines. Financial eligibility for Medicaid and other state programs is determined by local offices of the Family Support Division in the Department of Social Services, while the functional assessment and care planning is done by the Division of Senior Services and other agencies responsible for Medicaid waivers. Thus, the social workers who are responsible for waiver assessment and case management are state employees. The Division of Social Services has staff covering each county throughout the state. Where appropriate, the Division of Senior Services will refer clients to the Area Agencies on Aging for services. Area Agencies on Aging serve as an access point for the Medicaid aged and disabled home and community-based services waiver and the Division of Senior Services and Regulation screens referrals from the Area Agencies on Aging for eligibility. The Divisions of Senior Services and Regulation and Vocational Rehabilitation currently share assessment tools, level of care determinations, and unmet need criteria in determining care plans. Care management is provided by the lead agency that is best suited to meet the primary need of the individual.

Due to budget limitations, integrated data systems for home and community-based services are limited. Some elements of the assessments do go into a central Social Services database, including identification information, level of care, and care plan. Social Services workers enter data at a local level, but assessments are not computerized. Missouri runs a statewide web-based searchable directory of community resources--Community Connection--providing state residents with information on available programs.

Implications for Reform

In its effort to reform the long-term care system for older people, Missouri is an example of a state with leadership by the State Unit on Aging, which has policy and administrative responsibility for Medicaid personal care and home and community-based services waivers as well as Older Americans Act and state-funded programs. In examining the experience of Missouri in creating a more balanced long-term care system, five themes emerge:

First, changing the balance between institutional and non-institutional services is not only a financing issue; it is also a philosophical and political process. Through the Aging Network

and the Home and Community-Based Services and Consumer Directed Care Commission and the Personal Independence Commission, the buy-in of various stakeholders is being obtained for a new direction for long-term care.

Second, commissions and other planning initiatives can be important mechanisms to establish a vision and lay out specific recommendations for implementing change. For example, in Missouri, the Missouri Care Options program was the result of an Administration on Aging planning grant over a decade ago. The more recent Consumer Directed Care Commission and the Personal Independence Commission are laying the groundwork for expansions of consumer-directed services in Missouri.

Third, there are a wide range of innovations in home and community-based services, most of which are designed to expand options for consumers and to give them more control over the services provided to them. Missouri, like other states, is pursuing some of these innovations, but not others. For example, although still in the early stages, the state is experimenting with consumer-directed services and has committed substantial resources to planning for them (i.e., two commissions). Missouri established a “money follows the person” authority, but it is not widely used. This is a problem that the state has had introducing other services as well, underlining the need for educating consumers. Integration of acute and long-term care services has not been a major focus for the state.

Fourth, there are many ways to overcome the fragmentation of the financing and delivery system in long-term care, including administrative coordination at the state level. In Missouri, the creation of the Department of Health and Senior Services elevated the policy salience of the Division of Senior Services and helped to improve coordination across the various home and community-based programs for older people.

Fifth, and finally, most states, including Missouri, face substantial fiscal pressures which makes expansion of programs difficult. In order to balance its budget, Missouri has been forced to cut many programs, but has generally protected home and community-based services for older people. This reflects the work of advocacy organizations and the Aging Network and is also a sign of the value that government officials place on services to older people.

Missouri has worked to reform the long-term care system for over a decade. The various commissions on consumer-directed care, the Missouri Care Options program, the use of the

Medicaid personal care option and the state employment of case managers are critical to these efforts.

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TEXAS

Demographics

In 2000, 2,072,532 individuals, 9.9 percent of Texas' 20,852,820 citizens, were age 65 and older, significantly less than the national average of 12.4 percent (Administration on Aging, 2003). Among all the states and the District of Columbia, Texas had the 47th highest percentage of the population that was seniors. While the total population of the state is projected to grow by 18 percent by 2020, the population age 65 and older is projected to grow far faster: 89 percent for those age 65-74, 48 percent for those age 75 to 84, and 72 percent for those 85 and older (Gregory and Gibson, 2002).

In 2000 Texas ranked 5th in the nation among states and the District of Columbia in the percentage of its elderly population that was an ethnic or racial minority (Administration on Aging, 2003). Of the population age 65 and older in Texas, 72.6 percent was White, non-Hispanic; 16.7 percent was Hispanic/Latino; 8.4 percent were Black/African American, and 1.3 percent was Asian. American Indian/Alaska Native, Native Hawaiian/Pacific Islander, Asian, and those of two or more races were each less than 1 percent of the state's elders (Administration on Aging, 2003).

Despite its huge geographic area, in 2000, 77.4 percent of Texas' elderly population was living in urban areas, which is slightly above the national average (Gregory and Gibson, 2002). Texas has a large proportion of impoverished elders. In 1999, 13.1 percent of the older population had incomes at or below the federal poverty level, well above the national average of 10.9 percent.

Policy Environment

Texas is a state where long-term care services are provided by numerous state agencies, and policy is determined by the appointed public boards of these state agencies. Texas governors and agency commissioners historically have had much less control of the executive agencies than in other states. At the local level, private sector and other initiatives have been important in redesigning the delivery system.

Texas began efforts to alter the balance between institutional and home and community-based services in the early 1980s, but these efforts reached a critical juncture in the mid-1990s

with the expansion of the Medicaid home and community-based services waivers. Adding to those efforts were Robert Wood Johnson Foundation and Centers for Medicare & Medicaid Services Real Choice Systems Change grants to develop local initiatives to increase collaboration across the Aging Network. In addition, an Alzheimer's Demonstration grant from the Administration on Aging was combined with state and Medicaid funds to establish the Community Alzheimer's Resources and Education (CARE) program. Texas' efforts to change the balance between institutional and non-institutional services are also notable for its initiatives to integrate acute and long-term care services (STAR+PLUS) and its nursing home transition program.

The Texas Health and Human Services Commission oversees and coordinates all acute and long-term care budgeting and policy, but operational responsibility and legal authority for policy resides in eleven individual departments, each with their own policy boards. Following the U.S. Supreme Court's 1999 *Olmstead* decision, the Health and Human Services Commission took the lead in developing the Texas Promoting Independence Plan to expand community-based services. A major strength of the Promoting Independence Advisory Board was that it included a wide range of stakeholders: consumers, consumer advocates, providers, and agency representatives. They reviewed the long-term care system and made recommendations to address issues of access, system capacity and funding, coordination of care, and Medicaid benefits. The Plan also helped build public awareness of community-based care options.

Under the Health and Human Services Commission, the Department of Human Services oversees most Medicaid long-term care services, including home and community-based services, and is responsible for Medicaid eligibility determination. The Texas Department on Aging is the State Unit on Aging. While involved in long-term care issues, its major focus is on other issues affecting older people. The agency funnels Older Americans Act funding to the 28 state Area Agencies on Aging and provides oversight of these agencies.

With the passage of House Bill 2292 in 2003, the state is consolidating the various health and human service units to establish a single vision for long-term care, improve accountability, reduce fragmentation and decrease costs. The legislation collapses the Health and Human Services Commission's eleven agencies into four departments and dissolves the agency policy boards. This reorganization represents a major shift in power, as all legal authority will be in the hands of the governor and his appointed head of the Health and Human Services Commission. In

the new structure, all long-term care operating functions of the Department of Human Services except Medicaid eligibility policy and determination, the entire Department on Aging, and the mental retardation components of the Department of Mental Health and Mental Retardation will be consolidated into a new Department of Aging and Disability Services. This new administrative structure will be implemented effective September 1, 2004. The Health and Human Services Commission will have increased policy authority and responsibility for overall long-term care policy direction. Elderly advocacy organizations generally opposed the reorganization, fearing the loss of independence of the Department on Aging; consumer groups representing younger people with disabilities supported the reorganization as a way of improving coordination across services and populations.

As in other states, the major role of the Area Agencies on Aging is facilitating access and referral, and providing care coordination. They refer people to all available services, not only publicly funded ones. In addition, they oversee gap-filling services for older people on “interest” or waiting lists for Medicaid home and community-based waiver services and people who do not meet the Medicaid functional or financial eligibility standards.

Throughout Texas’s system, consumer groups and providers serve on state agency boards and various advisory committees within the Health and Human Services Commission agencies. However, all of these policy boards and many advisory committees will be abolished in the reorganization, raising concerns about how consumer groups and providers will have their views represented in the decision-making process. Each of the operating agencies as well as the Health and Human Services Commission will have a policy council which will serve as an advisory body.

Consumer organizations representing younger persons with disabilities, especially ADAPT, have been influential in the shift toward community-based services. The Silver-Haired Legislature represents the views of older people on a wide variety of issues. While supportive of home and community-based services, the state chapter of AARP has largely focused on issues of nursing home quality.

Texas has a large supply of nursing home beds, but its occupancy rates are among the country’s lowest. The industry is widely viewed as highly influential on long-term care policy and is very politically active. The home care industry is generally focused on Medicare issues and is viewed as less influential than the nursing home industry.

Long-Term Care Financing

Medicaid is the overwhelming source of funding for long-term care for older people in Texas, although Older Americans Act and state-funded programs play an important gap-filling role (*Table 6*). In 2002, publicly-funded home and community-based services in Texas were supported through five sources: Medicaid personal care (21 percent of total publicly-supported long-term care for older people and younger persons with physical disabilities), Medicaid Day Activity and Health Services (3 percent), Medicaid home and community-based services waivers (16 percent), Older Americans Act programs (2 percent), and state funds (less than 1 percent). Texas limits Medicaid home health to post-acute care and does not consider it a long-term care benefit. Medicaid nursing facility payments account for 57 percent of these public long-term care expenditures.

Texas covers personal care as an optional Medicaid benefit in their Primary Home Care service, which is the largest home and community-based program in the state (Tilly, O’Shaughnessy and Weissert, 2003). Personal care encompasses preparing meals, basic assistance with activities of daily living, and assistance with self-administered medications.

In addition, Texas has Medicaid funding for personal care through the “Frail Elders” option.” Texas is the only state to provide coverage under this option, which provides limited home care services, but not full Medicaid benefits, to certain functionally-impaired individuals with incomes below 300 percent of the Supplemental Security Income payment level (Tilly, O’Shaughnessy, and Weissert, 2003). This federal option was later rescinded, although Medicaid coverage continued in Texas and was recently renamed the Community Attendant Services program.

The Day Activity and Health Services program provides services during weekdays for older functionally-disabled clients residing in the community. The program is supported by Medicaid and state funds, and covers nursing and personal care, physical rehabilitation, nutrition, transportation, and social and educational activities.

Texas operates seven Medicaid home and community-based services waivers, of which the largest is the Community Based Alternatives program (Texas Department of Human Services, 2003). With case management provided by the Department of Human Services, Community Based Alternatives waiver services include adult foster care, assisted living and

residential care services, home delivered meals, nursing services, personal assistance and respite, and physical and occupational therapy. Demand for these waiver services far exceeds the number of funded ‘slots’, resulting in large “interest” lists, requiring waits of up to a year or more. Litigation has been filed contending that the long waiting time is illegal.

Seeking to alleviate the administrative complexities caused by the large number of waivers, Texas has a small experiment in Bexar County (San Antonio) to see if a single waiver can serve a broad range of people with disabilities. Beginning in November 2001, four Medicaid

Table 6
Long-Term Care Expenditures for Older People and Younger Persons
with Physical Disabilities in Texas, FY 2002

| | Totals in \$ Millions | Percentage of Total Long Term Care |
|---|--------------------------|--|
| Medicaid Home Health* | NA | NA |
| Medicaid Personal Care** | 622 | 21 |
| Day Activity and Health Services** | 88 | 3 |
| Medicaid Home and Community- Based Services Waivers** | 480 | 16 |
| Older Americans Act* | 61 | 2 |
| State-funded Programs*** | 5 | <1 |
| Total Home and Community-Based Services | 1,256 | 43 |
| Nursing Facilities* | <u>1,658</u> | <u>57</u> |
| Total Long-Term Care | 2,914 | 100 |

NA=Not available.

*[Http://www.aoa.gov/about/legbudg/current_budg/docs/FGS_FY_2002_Annual_Allocation.pdf](http://www.aoa.gov/about/legbudg/current_budg/docs/FGS_FY_2002_Annual_Allocation.pdf)

**Personal communication from the Health and Human Services Commission, April 2004.

Medicaid Personal Care refers to both Primary Home Care and Community Attendant Services. Medicaid waivers include the Community Based Alternatives waiver, the Consolidated Waiver Program and the Medically Dependent Children Program.

***LL Summer and ES Ihara, “State-Funded Home and Community-Based Service Programs for Older Persons,” (Washington, DC: AARP Public Policy Institute, forthcoming 2004).

home and community-based waivers were consolidated; one administrative agency manages a single set of providers, payment rates, and services for 100 nursing facility-eligible individuals

and 100 intermediate care facility for the mentally retarded eligible individuals regardless of age or disability (50 children and 50 adults for each type) (Texas Department of Human Services, 2003). To streamline administrative requirements, a single functional assessment is used for this consolidated waiver.

Community supports for elders with Alzheimer's disease and their caregivers are provided through the state's Community Alzheimer's Resources and Education (CARE) program. The program is supported by Administration on Aging and state funds, and is administered by the Department of Human Services in conjunction with private partners in the community, usually the Alzheimer's Association or the Area Agency on Aging. Case management and community resource coordination are supplemented by adult day respite, home health services, companion and homemaker services, prescription drug services, transportation, and registration with a national Alzheimer's Association registry, Safe Return (Texas Department of Human Services, 2001)

Like most other states, Texas is under great fiscal pressure and resistance to increased taxes is especially strong. The governor and legislature cut a large number of social programs in 2003, including those financing long-term care services, in order to balance the budget. As a result of these cutbacks, some Area Agencies on Aging are expecting a large increase in demand for their services, which could force a reprioritizing of their services. Cutbacks included:

- The number of "slots" for the Community-Based Alternatives waiver is to be reduced by 15 percent through attrition and a freeze on new admissions.
- Personal care hours were cut by 15 percent for 2004, but then restored when additional federal revenues were obtained.
- State grants for home modifications and other services to help disabled people at home were reduced by two-thirds. Small general revenue-funded programs for Alzheimer's Disease services, respite care, and assisted living facility residents were completely eliminated.
- After resisting for a decade, the legislature enacted enabling legislation directing the Health and Human Services Commission to implement federally-mandated rules requiring estate recovery for Medicaid nursing home residents and beneficiaries of home and community-based services.
- Reimbursement rates to nursing facilities were reduced by 1.75 percent and for community care providers by 1.1 percent.
- The monthly personal needs allowance for Medicaid nursing home residents was reduced from \$60 to \$45.

- Medicaid coverage for glasses, hearing aids, psychological services, and podiatry were eliminated.

Innovations in Home and Community-Based Services

In order to change the balance between institutional and home and community-based services and to make services more consumer-focused, many states are implementing a number of innovations including: consumer-directed home care, assisted living facilities and other residential care facilities, expansion of the range of services covered, integration of long-term care services and the integration of acute and long-term care services, nursing home transition programs, control of the nursing home supply and consumer satisfaction surveys. Texas has experimented with a number of these new approaches.

Consumer-Directed Home Care

The Texas Medicaid program currently allows consumer-directed home care in its personal care program and most of its waivers, including the Community-Based Alternative and the Community Living and Assistance and Support Services programs. While used extensively by younger people with disabilities, not many older people take advantage of this option. Older consumers are reportedly reluctant to take on the required administrative responsibilities. The legislature recently expanded the number of Medicaid waivers for which consumer-directed home care could be an option.

The Department of Aging now offers a respite voucher under the Older Americans Act which is consumer-directed and allows consumers a wide choice of potential caregivers (the hired caregiver, however, may not routinely live in the home). Administered by local Area Agencies on Aging, the voucher has been especially helpful in rural areas where there are few providers.

Assisted Living Facilities and Other Congregate Care

Residential care facilities have not been a major focus of state policy initiatives, partly reflecting a disagreement among consumer advocates as to whether these settings are part of the institutional or community-based service systems. Assisted living is an option in the Community-Based Alternative waiver, but demand is low. A small, state-funded program supporting this type of care was scheduled for elimination to help close the budget shortfall but was redesigned using other funds.

Expanding the Range of Services

Long-term care is a highly individual service and a broad range of services are needed to meet the needs of people with disabilities. The Aging Network is a key participant in discussions of expanding the range of services for older Americans. Much of the focus of the discussions is on small, state-funded programs, Area Agencies on Aging-funded services, and initiatives in the private sector. The Department on Aging envisions the coverage of a wide range of services as a major function for Area Agencies on Aging. The Harris County (Houston) Area Agency on Aging, for example, funds 20 different services including nutrition, information and referral, personal care, and legal services.

Interfaith CarePartners of Houston is an often-cited example of the provision of long-term care by faith-based volunteers. Starting almost twenty years ago with seed money from the local Area Agency on Aging, the program uses faith-based congregations to offer free companionship, limited personal care services, transportation and other supports to clients with disabilities, including Alzheimer's Disease and AIDS.

Integration of Acute and Long-Term Care

Beginning in 1998 in Harris County (Houston), STAR+PLUS became the nation's first mandatory Medicaid managed care program for both acute and long-term care services for older people and persons with disabilities. As of March 2004, 62,830 beneficiaries were enrolled in STAR+PLUS. Approximately half of the STAR+PLUS members are eligible for both Medicare & Medicaid, including almost all older people. The project requires freedom of choice and home and community-based services waivers in order to mandate participation and provide home and community-based services. According to a recent study by Texas A&M University, member satisfaction is generally high and access to care and quality of care is generally good, although less so for people who use a lot of services (Borders et al, 2002.) Plans are underway to expand STAR+PLUS to all urban areas in Texas, with the exception of the valley region, by September 2005.

As an incentive for beneficiaries to enroll in organizations that were both Medicare & Medicaid managed care organizations, the state lifted its three prescriptions per month limit for beneficiaries in a combination of Medicare+Choice and STAR+PLUS. However, initially no organizations participated in both plans. Thus, for older people and younger persons with

disabilities who are Medicare & Medicaid-eligible, the managed care organizations originally were limited to long-term care services: home and community-based services and 120 days of nursing home care (Tilly, O'Shaughnessy and Weissert, 2003). Medicare-covered acute care was provided separately. In 2002, EverCare, which operated as a Medicaid HMO, received Centers for Medicare & Medicaid Services approval to operate as a Medicare+Choice managed care plan, allowing integrated coverage for dual eligibles in at least one plan.

In addition, there is currently one Program of All-inclusive Care for the Elderly (PACE) site in El Paso, with 628 enrollees in 2003. A second PACE site recently opened in Amarillo.

Nursing Home Transitions

Partly as a result of the state's response to the 1999 U.S. Supreme Court's *Olmstead* decision (the Promoting Independence Plan) and partly as a result of vigorous advocacy by younger people with disabilities, the Texas legislature passed one of the first "money follows the person" initiatives in 2001, Rider 37. State funds to provide housing supplements and support transition costs were essential to implement Rider 37. From September 2001 through August 2003, a total of 2,022 nursing facility residents have been relocated to the community, almost two-thirds of whom were older people (Klein et al., 2004).

Rider 37 established that Medicaid nursing home residents who wished to return to the community and still needed nursing home level care were entitled to Medicaid home and community-based services, allowing them to bypass the queue for Medicaid waiver services. In the original legislation, funds expended for home and community-based services for these beneficiaries were permanently transferred from the Medicaid nursing facility budget to the Medicaid home and community-based services budget.

In 2003, legislative efforts by opponents of the nursing home transition program almost succeeded in repealing the provisions entirely, but were defeated, largely on the strength of the state's argument that the program achieved cost savings. However, Rider 28, which replaced Rider 37 in 2003, makes the budgetary transfers temporary and linked to the individual. Thus, when individuals die or return to the nursing home, the community care funds now revert to the nursing home budget. In addition, a second rider, Rider 7(b)(2) limits the time period a person can exceed the maximum waiver expenditures to no more than 133 percent of the ceiling for six months within a twelve month service period.

Efforts to Control the Nursing Home Supply

Texas has a substantial number of nursing home beds, but occupancy rates are among the lowest in the country. In December 2003, Texas had 56 beds per 1000 older people compared to 50 beds per 1000 older people nationally; the average occupancy rate was 77.5 percent in Texas compared to 85.6 percent nationally (authors' calculations based on data from the American Health Care Association, 2004, and US Census Bureau, 2003).

Texas has long sought to control its nursing facility Medicaid-certified bed supply. However, in 1985, the state repealed its certificate-of-need requirements. For a long period of time afterward, there was a moratorium on additional beds participating in the Medicaid program, which precluded very many new facilities from being built. More recently, a formal "bed allocation" process managed by the Department of Human Services controls the number of Medicaid nursing home beds. In general, the number of Medicaid nursing home beds is frozen, but there are a number of waivers and exemptions to this rule. Additional Medicaid nursing home beds may be granted to facilities with high occupancy rates, small nursing facilities seeking a more efficient size, nursing homes in communities without reasonable access to care, facilities targeting minority populations, nursing facilities with specialized programming for Alzheimer's Disease residents, teaching nursing homes, and facilities located in rural areas. Facilities requesting additional beds must have a record of high quality care. Low occupancy facilities may have their number of Medicaid beds reduced.

Consumer Involvement in Satisfaction Surveys and Quality Assurance

The Area Agencies on Aging conduct consumer satisfaction surveys for their services. In addition, a consumer satisfaction survey of STAR+PLUS was conducted as part of its required external evaluation (Borders, 2002). Consumer satisfaction surveys are conducted for Medicaid home and community-based services waivers.

Accessing the Long-Term Care System

Texas' large size and diversity has contributed to the fragmentation of its long-term care system. This in turn has compounded problems of access. To help alleviate this fragmentation, Texas has instituted a "211" call system, which is a statewide telephone line that connects consumers to information about services provided by their local Area Agency on Aging, the Department of Human Services, and other agencies. The underlying databases for this

information vary depending on whether the 211 answering service in a given area is run by an Area Agency on Aging or a United Way organization. Under the new reorganization, the state plans to contract with a private firm to serve as a “single point of entry” call and application center for all health and human service programs (Holahan et. al, 2004).

Functional and financial eligibility determinations for Medicaid and other Department of Human Services long-term care programs are handled by local offices of the Department of Human Services. These offices also provide case management for persons receiving Medicaid personal care or home and community-based waiver services, although much less case management is provided to personal care beneficiaries. Financial eligibility functions are being transferred to the Health and Human Services Commission.

For several years the state has been working on an integrated, computer-based system called the Texas Integrated Eligibility Redesign System (TIERS), which will determine financial eligibility for a large number of programs. TIERS also provides potential applicants with a web-based financial self-screening tool, called STARS (State of Texas Assistance and Referral System), with links to information about public and private services. STARS was added to the Department of Human Services website (<http://www.txstars.net>) in 2001, and is available in English and Spanish; it is also available for the visually-impaired. The state is also planning a demonstration of telephone call centers, which would determine financial eligibility for a number of programs, including Medicaid. A challenge for the upcoming reorganization is that state agency regions and the Area Agencies on Aging do not have identical boundaries.

Functional eligibility for Medicaid waiver services is assessed on a standard form, DHS Form 2060, which is also used by all Area Agencies on Aging. Rider 31, passed in the 2003 legislative session, requires the state to redesign the assessment tool.

Although they have no formal role in the Medicaid program, Area Agencies on Aging provide information and referral, conduct financial and functional eligibility assessments and provide case management for their own programs.

There are several local initiatives to improve access to long-term care services, which have been aided by the state-funded Texas Long-Term Care Access program, the Centers for Medicare & Medicaid Services Real Choice Systems Change grants, and the Robert Wood Johnson’s Community Partnerships for Older Adults program. In 1999, the Texas legislature enacted Senate Bill 374, which requires the Health and Human Services Commission, the

Department of Human Services and the Texas Department on Aging to assist communities in developing comprehensive, community-based support and service delivery systems for long-term care services. Consistent with that goal, the state has received Real Choice Systems Change grants, which are being implemented by the Texoma and Heart of Central Texas Area Agencies on Aging. These grants will test the concept of “system navigators,” who will act as outreach workers and advocates for individual clients, helping them obtain the supports they need.

Similar in goal to the Real Choice Systems Change grants, Texas has also received two Robert Wood Johnson Foundation grants to improve access to long-term care services in the Houston and El Paso areas by building community partnerships for older adults. The Houston project, Care for Elders, is a 78-agency collaborative effort involving the Harris County Area Agency on Aging, public and private sector funders, long-term care service providers, consumer advocacy groups, health care systems, academics, businesses and the media. In addition to improving access, Care for Elders strives to improve service quality, availability and supply, to raise awareness of the implications of an aging society, and to ensure an understanding of the needs of the elderly and their caregivers in Harris County. The project is based in Sheltering Arms, a well-established 100-year-old United Way senior center, and has just completed its first year of the development grant.

Implications for Reform

Texas has been working to expand home and community-based services since the early 1980s, almost entirely through the use of Medicaid funding. In addition, it has used small demonstration grants from a number of sources to better coordinate home and community-based services. The experience of Texas illustrates five major issues:

First, the movement towards more home and community-based services in Texas is the result of the work of state officials and consumer advocates, especially younger people with disabilities. Advocacy for changing the balance of the long-term care system in Texas often means directly challenging the nursing home industry, which is well-organized and influential. The state planning efforts following the U.S. Supreme Court’s *Olmstead* decision were notable for the broad input that was obtained from a wide range of stakeholders. With the elimination of the policy boards that have run the Health and Human Services Commission operating agencies,

an issue for the future will be how easily consumers and other advocates will be able to present their points of view to the new agencies.

Second, planning initiatives and demonstration projects in Texas have played a major role in establishing a new vision for the long-term care system. The *Olmstead*-inspired Promoting Independence Plan laid out a blueprint for reforming the long-term care system, which emphasizes a greatly increased role for home and community-based services. Through demonstrations grants from the Centers for Medicare & Medicaid Services, the Administration on Aging and the Robert Wood Johnson Foundation, Texas is exploring various ways of increasing coordination and integration of services to improve access for older people with disabilities.

Third, Texas is implementing a number of innovations designed to improve the financing and delivery system for long-term care. In a state as large and diverse as Texas, use of these different options by consumers varies greatly. The two most notable innovations in Texas are its nursing home transition program and the STAR+PLUS program, which integrates some acute and long-term care services in a capitated setting. Texas is also using demonstration grants from the Centers for Medicare and Medicaid Services, the Administration on Aging and the Robert Wood Johnson Foundation to find ways to better coordinate services.

Fourth, fairly radical changes in the state administration of long-term care in Texas have recently been adopted to improve policy coordination and implementation. Administration of long-term care in Texas, as well as most other human services, is highly fragmented. A new reorganization of state government, to be phased in over several years, will consolidate responsibilities for long-term care in a new department.

Fifth, and finally, Texas, like other states, is under substantial fiscal pressure combined with a strong resistance to new taxes. The state is facing the largest revenue drop in its history. The Center for Public Policy Priorities in Austin estimates the shortfall at \$15.6 billion, or 22.4 percent of a projected \$69.7 billion in General Revenue spending (Holahan, et al., 2004). In order to balance the budget, the state cut a number of long-term care services in 2003. While the cuts in long-term care perhaps were not as severe as they were for some other state services, they represented a substantial slowing and, in some cases, reversal of the movement towards home and community-based services. Long-term care services were not cut more substantially largely

because of the advocacy of consumer groups and the importance that the legislature placed on these services and the people they serve.

Texas is a large state with a significant number of people participating in its Medicaid waiver programs; its nursing home transition initiative was one of the country's first. Foundation and federally-funded initiatives at the local level have played a major role. A major reorganization of state agencies is likely to have a major impact on long-term care.

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CONCLUSIONS

This review of initiatives by five states highlights the National Aging Services Network's leadership role in creating a more balanced financing and delivery system for long-term care. The case studies suggest at least five key issues for other states, Area Agencies on Aging, providers and consumers that are interested in reform.

First, changing the balance between institutional and noninstitutional care is not only a financing issue, it is also a philosophical and political process. All of the states highlighted in this project emphasized the importance of involving stakeholders in all aspects of the process to ensure buy-in and acceptance of proposed changes. In addition, advocacy by Area Agencies on Aging, consumer groups for older people and younger persons with disabilities, and community providers is crucial in creating the necessary support for additional funding for home and community-based services and in making other structural changes in the system. Further, states noted that change occurs in increments and takes time – it does not occur overnight. Even the states that have done the most are still changing their system and believe that they have not yet achieved a truly balanced service delivery and financing structure.

Second, planning initiatives, data collection, and demonstration or pilot projects can be important mechanisms to lay out the vision, build justification, and test methods for expanding home and community-based services. For example, planning and policy reports from respected organizations in North Carolina and Missouri were instrumental in laying out a detailed blueprint for reform. It is also important, especially in this period of fiscal austerity, for the Aging Network and other advocates of change to be able to produce data to support their claims of the benefits of moving the system in the direction of more home and community-based services. Demonstration and pilot projects, such as those sponsored by the Administration on Aging (for example, Aging and Disability Resource Centers) and the Centers for Medicare & Medicaid Services (e.g., Real Choice System Change grants), can give a state experience with a proposed innovation and can allow stakeholders to become comfortable with new ways of financing or providing services. The Family Care demonstration in Wisconsin is testing a far-reaching model of integrating long-term care services. In general, a key issue in demonstration projects is sustaining success after the grants have ended and, more fundamentally, finding ways to replicate and implement successful projects and outcomes on a statewide basis.

Third, states are implementing a wide range of mechanisms designed to improve the financing and delivery system for long-term care. These innovations include mechanisms that make home and community-based services more responsive to the needs of individual consumers, such as consumer-directed home care, coverage of congregate residential settings, expanding the range of services, and consumer satisfaction surveys. They also include strategies, such as nursing home transition programs, consolidated funding streams, and the integration of acute and long-term care services, that make the trade off between institutional and noninstitutional services and between acute and long-term care services more explicit. Even among states that have made major commitments to reforming their long-term care systems, there is a great deal of variation in how many and to what extent these strategies have been implemented. Each state must weigh the local values, culture, preferences, social and political concerns in order to determine an appropriate approach for changing their long-term care system. It is unlikely that any single model presented here will be an exact fit for another state; rather, a variety of approaches and models are presented to provide the Aging Network and states with a range of ideas and concepts they can adapt or use as a starting point for their own long-term care systems change efforts.

Fourth, in order to address the fragmentation of the financing and delivery systems, the states in our study are working to improve coordination at both the policy and administrative levels. While some advocates for older people believe that any merging of administrative responsibilities for older people with other populations is detrimental to the Aging Network, this study suggests that consolidation may result in opportunities. All of the study states have had reorganizations to merge, at least to some extent, administrative and policy responsibility for long-term care under a single administrative authority. Washington has probably gone the furthest in this organizational structure, placing almost all responsibility for Medicaid, Older Americans Act, and state programs for nursing homes, residential care facilities, and home and community-based services under a single administrative structure, the Aging and Disability Services Administration, which also serves as the State Unit on Aging. In another example, North Carolina has created an Assistant Secretary for Long-Term Care position and a Long-Term Care Cabinet, including representatives of all of the affected agencies, to coordinate policy development.

And at the local level, access to care is being consolidated into single entry points in several states. Broadly, these single entry points are systems that enable consumers to access long term and supportive services through one agency or organization. In Washington, for example, applicants for public programs are assessed and initial care plans developed by local Aging and Disability Services Administration staff; ongoing case management and reassessments are the responsibility of the Area Agencies on Aging. This consolidation is also the keystone of Wisconsin's Family Care program.

Fifth, and finally, in this time of fiscal crisis, all state budgets are under pressure. Funding in the study states for long-term care has been relatively, but not completely, protected, in part due to the work of advocates for older people and younger persons with disabilities. Nonetheless, in some states, funding for home and community-based services has been cut, or at least, not increased at the rate that was the case in the past.

These budget constraints highlight the choices between institutional and noninstitutional services and go beyond the immediate fiscal crisis. These policy choices are relatively explicit in some states. For example, Texas' nursing home transition program in 2001 established the principle of money following the individual rather than being tied to a service setting, although in 2003 this position was changed and money associated with an individual transitioning to the community is no longer transferred from the nursing home budget to the community care budget. Wisconsin's Family Care program has gone far in integrating long-term care payments by setting a capitation rate that is for both nursing home and noninstitutional services. In other states, however, the choices between institutional and noninstitutional services are only beginning to be framed as policy tradeoffs.

As states, Area Agencies on Aging, and consumer and provider groups work to create more balanced long-term care systems that provide more home and community-based services, they face numerous challenges to assure adequate financing, administrative coordination, cost control, coverage of services that meet the needs of beneficiaries, and adequate quality. How well they succeed will have great consequences for how successfully people of all ages with disabilities will be able to remain in the community.

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