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# Federal and State Policy in Family Caregiving: *Recent Victories but Uncertain Future*

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# Federal and State Policy in Family Caregiving: *Recent Victories but Uncertain Future*

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## INTRODUCTION

The vast majority of people with disabilities, regardless of their age, receive long-term care in their own homes, with families and friends providing the greatest share of services. The emotional, physical and financial problems can be overwhelming. For the most part, families have had little support from government. In the last several years, however, both federal and state governments have begun directing greater attention to the problems of family caregivers.

At the national level, several recent laws and rulings promise to increase funding for support services for family caregivers and for stimulating state innovations in long-term care. Key developments include the enactment of the National Family Caregiver Support Program in 2000; the U.S. Supreme Court Olmstead decision; the Long-Term Care Security Act; the proposed Long-Term Care and Retirement Security Act of 2001; a new federal funding initiative for home and community-based care; and the tobacco settlements.

In the states, the pace of legislative action in support of persons with disabilities and their family caregivers has quickened, too.  
Legislative

action has ranged from mandating new education and information programs for family caregivers to expanding adult day and respite

services. Although few states have created comprehensive statewide programs for family caregivers, a number are beginning to assess how they can better serve caregivers and coordinate caregiver services.

Still, troubling signs are on the horizon. On the heels of the \$1.3 trillion federal tax-cut bill and the disappearing budget surplus, concerns mount about costs. States are feeling fiscal pain, and are wary of rising Medicaid budgets. The growing shortage of home care workers on whom many family caregivers depend poses another concern.

This paper first summarizes recent national policy developments, then describes several state strategies to assist family caregivers, providing examples of recent state actions. Finally, the paper looks at the future, taking into consideration proposals now gaining support as well as developments that could have an adverse impact on family caregivers.

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## NATIONAL POLICY DEVELOPMENTS

In the past three years major federal legislative, judicial and administrative actions

have changed the landscape for family caregivers and affected state policy directly and indirectly. First, in 1999, when the 106th Congress began its work, President Clinton unveiled his three-part Long-Term Care Initiative. Two parts are now law: the National Family Caregiver Support Program (NFCSP) and the Long-Term Care Security Act (PL 106-265). The third element, a tax credit for family caregivers, remains under consideration (as the Long-Term Care and Retirement Security Act of 2001). Second, the landmark Supreme Court decision in *Olmstead v L.C.* unleashed a flurry of state activity nationwide to comply with its ruling.<sup>1</sup> Third, in the administrative branch, the Center for Medicare and Medicaid Strategies, or CMS (formerly known as the Health Care Financing Administration), has announced new grant programs to improve states' health and long-term care systems. Finally, the settlements reached by the state attorneys general and the tobacco industry in the late 1990s have created a new source of revenue for home and community-based care services and respite care.

### ***The National Family Caregiver Support Program (NFCSP)***

The passage of the National Family Caregiver Support Program (NFCSP), as an amendment to the reauthorization of the Older Americans Act in 2000, stands as the most significant legislative accomplishment to date on behalf of family caregivers. The NFCSP is the largest new program in the Older Americans Act since the nutrition programs began in 1972. Swift approval of its first year funding at the full authorization level (\$125 million) demonstrated that family caregiving is a legitimate political constituency issue in Washington. In releasing \$113 million in formula grants to the states, the

Administration on Aging provided the most minimal of guidelines, allowing the states to move forward quickly to expand existing caregiver programs operating under the Older Americans Act. The NFCSP has five basic components:

- ♦ Information to caregivers about available services.
- ♦ Assistance in gaining access to support services.
- ♦ Individual counseling, advice on organization of support groups and caregiver training.
- ♦ Respite care.
- ♦ Supplemental services to complement the care provided by caregivers.

States may use the funds to support services for grandparents and other relative caregivers of children 18 and under; older individuals providing care to persons with developmental disabilities; and family caregivers of elderly persons (60+). States are working with Area Agencies on Aging (AAAs) and other local and community service providers in developing programs.

The NFCSP also includes funding for “competitive innovative grants” to assist in the development of multifaceted systems of caregiver support. These grants give states another opportunity to seek funds for work on behalf of family caregivers.

### ***Long-Term Care Security Act (PL 106-265)***

The Long-Term Care Security Act enables federal employees, retirees, and military personnel and retirees to purchase long-term care insurance as part of their benefits package. The expected availability date for this benefit is October 2002. Two or more insurance products are likely to be offered, potentially expanding the long-term care insurance market by 20 million persons, according to a recent estimate by *The Washington Post*. If a sufficiently high percentage of federal employees and military personnel enroll in long-term care insurance

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<sup>1</sup> In another Policy Brief in this series, “*Olmstead v. L. C.*: Implications for Family Caregivers,” Sara Rosenbaum discusses the *Olmstead* decision in detail.

plans, states may consider similar programs on behalf of their employees.

### ***Long-Term Care and Retirement Security Act of 2001 (H.R. 831 and S. 627)***

The Long-Term Care and Retirement Security Act of 2001, H.R. 831 and S. 627, is the reincarnation, and expansion, of tax-credit legislation passed during the 106<sup>th</sup> Congress, but vetoed by President Clinton. As introduced in the 107<sup>th</sup> Congress, this new legislation:

- ♦ Provides for a phased in, above the line tax deduction for long-term care insurance premiums.
- ♦ Gives a tax credit of up to \$3,000 to help cover long-term care expenses.
- ♦ Allows employer cafeteria plans to include long-term care insurance.

This bill has bicameral, bipartisan support and its champions are leaders who can assure its passage. Its author in the House is Rep. Nancy Johnson (R-CT) who chairs the Subcommittee on Health of the House Ways and Means Committee. Its authors in the Senate are Senators Charles Grassley (R-IA) and Bob Graham (D-FL), both members of the Senate Finance Committee.

### ***The Olmstead Decision***

In June 1999, the U. S. Supreme Court, in *Olmstead v L.C.* ruled that a state violates the Americans with Disabilities Act (ADA) when it fails to make reasonable modifications in existing services for persons whom its own health professionals have determined as capable of community residence. (See the Policy Brief entitled “*Olmstead v L.C.*: Implications for Family Caregivers” by Sara Rosenbaum for a thorough discussion of the *Olmstead* decision.)

In essence, *Olmstead* held that unnecessary institutionalization of persons with disabilities is discrimination under the ADA. Suddenly states faced new pressures to furnish more community services. By March 2001, according to the National Conference of State Legislatures, 37 states plus the District of Columbia had created task forces or commissions to develop comprehensive plans or white papers with recommendations. (See *Figure 1.*) These plans could serve as blueprints for future long-term care reforms.

*Figure 1.*  
STATES WITH LONG-TERM CARE/OLMSTEAD TASK FORCES

Alabama	Indiana	New York
Alaska	Iowa	North Carolina
Arizona	Kansas	North Dakota
Arkansas	Kentucky	Ohio
California	Maine	Oklahoma
Colorado	Maryland	Pennsylvania
Connecticut	Massachusetts	South Carolina
Delaware	Mississippi	Texas
Georgia	Missouri	Utah
Hawaii	Montana	Washington
Idaho	New Jersey	West Virginia
Illinois	New Mexico	Wisconsin
		Wyoming

Source: National Conference of State Legislatures, March 2001.

### ***“Systems Change” Grants***

For years, Medicaid long-term care spending has been heavily tilted toward nursing home care compared to spending on home and community-based services. For example, in 1999, nearly three-fourths (73 %) of total Medicaid long-term care spending (\$62 billion) went toward institutional services. However, a shift is underway, albeit slowly. Between 1994 and 1999, the share of Medicaid spent on home and community-based care doubled—a much higher growth rate than Medicaid spending on institutional care. Early reports on the 2000 budget show that spending for home and community-based waiver services grew to \$12 billion from \$10.5 billion in 1999 (a 14.6% increase).

In January 2001, the U. S. Health Care Financing Administration (now the Center for Medicare and Medicaid Strategies, or CMS) announced new grant programs of more \$70 million to competing states in September 2001 to boost their health and long-term care efforts. These programs include:

- ♦ \$50 million in “Real Choice Systems Change Grants” designed to help states improve health and long-term care systems for older people and people with disabilities.
- ♦ \$15 million in grants to help all people with disabilities move from institutions to community-based settings.
- ♦ \$8 million to enhance community-based personal assistance services to ensure maximum control by people with disabilities of all ages.

### ***The Tobacco Settlements***

In November 1998, state attorneys general and the tobacco industry reached a Master Settlement Agreement that included \$246 billion to be paid over a 25-year period to 46 states, 5 territories, and the District of Columbia, bringing the total due from the industry nationally to \$286 billion. (Previously, the other four states—Florida,

Minnesota, Mississippi and Texas—had reached agreements totaling \$40 billion over a 25-year period.) The Master agreement calls for five up-front payments of \$2.4 billion between 1998 and 2003, with a 3 percent inflation factor for years 2000 to 2003. Many states are using a portion of these funds for home and community-based care services and respite care.

#### STATE STRATEGIES AND EXAMPLES

Approaches to helping family caregivers are as diverse as the 50 states themselves and as wide-ranging as state responses to long-term care programs and services in general. Major publicly funded programs like the Medicaid home and community-based waiver programs, for example, allow states to offer a range of services to persons with disabilities, such as personal assistance with daily activities like bathing and dressing. When paid home care aides or personal attendants provide this kind of assistance, family caregivers get a break from their daily chores.

Many states also offer services under waiver or state-funded programs that extend other kinds of respite—adult day services, for instance—to family caregivers. In addition, some states have developed specific caregiver support programs funded solely by state general revenues. Two states fund comprehensive statewide family caregiver programs from state general revenues:<sup>2</sup>

- ♦ The **California** Caregiver Resource Center (CRC) network (funded at \$12.25 million in 2000) provides information, education, respite assistance and other support services to families and friends who care for adults with cognitive impairment (e.g., Alzheimer’s disease). Eleven regional sites around the state deliver a range of support services for

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<sup>2</sup> For more details on these programs and other states, see *Survey of Fifteen States’ Caregiver Support Programs: Final Report*, October 1999, published by the California Family Caregiver Alliance.

families and caregivers. A Statewide Resource Consultant operates a statewide information clearinghouse on caregiving and brain disorders; conducts education, training and applied research; and maintains a statewide database on clients served. The CRCs annually serve 11,700 families and caregivers of people with adult-onset cognitive impairments.

- The **Pennsylvania** Family Caregiver Support Program (funded at close to \$11 million in 2000) provides a range of services and financial assistance to family caregivers. This program assists caregivers of functionally dependent older adults age 60 and older plus people of any age who have an organically based dementing illness. The program provides up to \$200 per month in respite and chore services, with a lifetime cap of \$2,000 for home modification as well as assessment of both caregiver and care recipient, counseling and caregiver training. The program serves more than 6,000 family caregivers.

State initiatives to assist family caregivers in recent years fall into five general categories:

- Education and information support initiatives for caregivers.
- Adult day services/respite programs.
- Tax incentives for family caregiving expenses.
- Expansion of Medicaid home and community-based services.
- Empowerment of consumers and payment of family caregivers with government funds.

### ***Education and Information Support Initiatives for Caregivers***

When caregivers first have to make tough long-term care decisions for family members, they often do not know where to turn. Even

“experienced” caregivers are in need of information as their loved one’s condition changes. Responding to this need, several states have created information and referral services for family caregivers.

- In 2001, the **Maryland** General Assembly established the Caregiver Support Coordinating Council in the Department of Human Resources to coordinate statewide planning, development and implementation of family caregiver support services. The council is to gather concerns of caregivers through surveys, public hearings and a telephone hotline. In addition, it will develop and distribute a handbook of respite and other family caregiver services in the state and identify unmet needs and priorities for additional

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funds. A report outlining a plan of action for family caregiver support services is due to the Governor and General Assembly by Oct. 1, 2002, with annual reports on activities thereafter.

- The **Washington** Legislature appropriated \$610,000 in 2000 to expand the existing respite care system to include education for caregivers, support groups and assistance in identifying and receiving appropriate long-term care services. Washington’s legislature in 1999 approved and funded the Family Caregiver Support Program, which provides a variety of services in addition to respite throughout the state, such as referrals to resource specialists, consultation from health professionals, training, and specialized medical equipment.

### ***Adult Day Services/Respite Programs***

Research has shown that respite is conceivably the most-valued and most-needed service by family caregivers. States fund these programs through both Medicaid and state general

revenues. Medicaid programs target individuals with very low income. Several states have appropriated money from their general funds to ensure that support services, particularly through respite programs and adult day services, reach more families—especially the “near poor” whose incomes are not quite low enough to qualify for federally supported programs.

Perhaps the most exciting trend in respite care is a program called Lifespan Respite—respite available to caregivers of children, adults and the elderly, regardless of the type of disability of the care recipient, as well as to families at risk of abuse, neglect or domestic violence. Four states—**Oklahoma, Oregon, Nebraska** and **Wisconsin**—have implemented Lifespan Respite programs, and many others have created Lifespan Respite coalitions that are trying to establish the program. The goal is to make respite more accessible by giving one agency authority to integrate available funds, ensure coordination of care, control costs and identify gaps in services and funds.

**Nebraska**’s model provides an example. State revenues fund the program. In 1999, the Legislature appropriated \$500,000 for both fiscal years 2000 and 2001 to develop the program. In May 2000, the state Department of Health and Human Services initiated a program to coordinate respite care services and in 2001 an additional \$1 million per year was appropriated for respite care. This program provides eligibility for respite care to caregivers of individuals with physical or developmental disabilities, special health needs, Alzheimer's disease, chronic illnesses, or with emotional or behavioral disorders, regardless of age. Over the next two-years, six community-based programs will each:

- ♦ Assess the specific need of the community served and determine if enough providers exist to handle the need.
- ♦ Conduct marketing targeted towards families, providers and businesses to

increase awareness of the program’s existence and the benefits of respite care.

- ♦ Recruit more providers, particularly those who accept Medicaid payment.
- ♦ Develop and administer comprehensive training programs for caregivers, whether they are professional service providers or families.
- ♦ Conduct self-evaluations to determine effectiveness.

### ***Tax Incentives for Family Caregiving Expenses***

To help family caregivers with their financial burden, some states have provided state income tax credits or exemptions. Altogether, 22 states have enacted state tax credit or deductibility legislation on long-term care. For example:

- ♦ On Jan. 1, 2001, a \$500 tax credit took effect for **California** taxpayers who require long-term care or provide long-term care to family members. The credit applies to individuals, their spouses or qualified dependents who need care for at least 180 days. To be eligible for the 2000 tax year, some care must have occurred in 2000. The person receiving the care must meet age-related, long-term care requirements, be in a specified relationship with the caregiver and have a physician’s certification to verify long-term care needs.
- ♦ In several states—**Maryland** (1999), **Michigan** (2001), **New York** (2001), and **Pennsylvania** (2000 and 2001)—tax incentive legislation has been introduced but not enacted, possibly in anticipation of the enactment of federal legislation, proposed first by the Clinton Administration, now the Bush Administration, to give tax relief to family caregivers.

### ***Medicaid Home and Community-Based Care Services***

Responding to the desire of people with disabilities and chronic illnesses to remain in their homes rather than enter a nursing home

for the necessary care, states have also used Medicaid home and community-based services to support family caregivers. For years, Medicaid long-term care spending has been heavily tilted toward nursing home care compared to spending on home and community-based services. For example, in 1999, nearly three-fourths (73%) of total Medicaid long-term care spending (\$62 billion) went toward institutional services, with only 27 percent going to home and community-based care. However, these totals mask the shift that has been occurring, albeit slowly, in the proportions that states are allocating between institutional and home and community-based care. Between 1994 and 1999, the percentage of Medicaid spending on home and community-based care doubled—a much higher growth rate than Medicaid spending on institutional care, and early reports on the 2000 budget show that spending for home and community-based waiver services increased 14.6 percent, to \$12 billion from \$10.5 billion in 1999.

For the most part, Medicaid waiver programs are small and many such programs serve people with developmental disabilities. Over the last five years, however, states have begun to expand their waiver programs for older persons and adults with physical disabilities:

- ♦ The 2001 **Maryland** General Assembly required the state to administer a Community Attendant Services and Support Program to 300 additional adults with physical disabilities by expanding an existing Medicaid waiver program. Budgeted at \$10 million in FY2002, the program permits individuals to select, manage and control their services and to choose their personal assistants, including the hiring of family members except spouses.
- ♦ Acting on a request by the governor for funds to reduce waiting lists for home and community-based services for older persons, the **Georgia** General Assembly in 2001 approved an additional \$6 million for Medicaid-funded home and

community-based services and \$4 million for non-Medicaid services. The appropriations will reduce the waiting list for Medicaid services by 2,000 and for non-Medicaid services by another 2,000.

- ♦ In **Florida**, the Legislature increased funds for the Department of Elder Affairs by nearly 20 percent to an estimated \$49 million for FY 2002—the largest single yearly increase the Department has ever received. The increase will provide alternatives to nursing home care to 2,800 additional consumers; of that number, 1,500 will be able to receive services through the home and community-based services waiver program. (State officials believe that another 10,000 older persons or their caregivers will receive services as a result of increases in federal funding, including increases in the reauthorization of the Older Americans Act. These services include respite care for caregivers and support services such as counseling, adult day care, transportation and meals.)

### ***Empowerment of Consumers and Payment of Caregivers with Public Funds***

There is a growing movement within states to give beneficiaries who are eligible for long-term care services more choice and control in arranging for personal assistance. Currently, an estimated 60 percent of state Medicaid programs offer some “consumer direction” and many other state-funded programs also provide the option. At a minimum, the programs permit consumers to have a direct employer-employee relationship with their personal care attendants, instead of requiring that attendant care be provided through professional agencies. Many of the programs also allow the recipient to hire a family member.

Now, a handful of experimental programs are pushing the concept of consumer-direction even further. The largest of these is the “Cash and Counseling” Demonstration, co-sponsored by the Robert Wood Johnson Foundation

(RWJF) and the U.S. Department of Health and Human Services. Three states—**Arkansas, New Jersey and Florida**—are participating in the Cash and Counseling Demonstration under Medicaid Section 1115 research and demonstration waivers. These waivers allow program participants to receive some or all of their Medicaid benefits in the form of a cash payment.

Participants in the Cash and Counseling experiments:

- ♦ Receive a monthly allowance or budget, electing to manage the funds on their own or to have the funds managed for them by an accounting service.
- ♦ Develop their own “care plans” and may spend their allowances in whatever way they choose, for virtually any facet of personal assistance, services or items, so long as the goods and services they purchase are linked to meeting their disability-related needs.
- ♦ May consult a counselor for assistance.
- ♦ May hire family (excluding spouses and legal guardians), friends, professionals or neighbors.

Although the RWJF Cash and Counseling demonstration is not adding new states, **Oregon** recently received a research and demonstration waiver to implement a smaller experiment along similar lines and two other states have pending waiver applications for small demonstrations.

#### UNCERTAIN FUTURE FOR POLICY

Despite recent policy achievements at the national and state levels and both promise and momentum to improve support for long-term care and family caregiving, serious policy challenges lie ahead. On the bright side are growing commitment to federal tax relief for long-term care, interest in a Universal Caregivers Act, some untapped potential in federal housing policy and the possibilities offered by increased use of long-term care insurance. Casting shadows on the future are

rising Medicaid costs, decreased government revenues and long-term care workforce shortages.

### ***Commitment toward Federal Tax Relief for Family Caregivers***

Before 2000, proposals to provide tax credits for family caregivers traveled down one track and proposals to make premiums for long-term care insurance deductible traveled down another. Recently, however, AARP and the Health Insurance Association of America have come together in support of legislation that knits the two together. Further, the bipartisan Americans for Long-Term Care Security has formed as a grassroots lobbying presence in Washington D.C. to help legislation that offers tax relief for long-term care costs, namely, the Long-Term Care Security and Retirement Act of 2001. In the first half of the 107<sup>th</sup> Congress, this legislation already had twice as many co-sponsors in the House as in all of 2000. Efforts are underway to increase House and Senate co-sponsors. In early summer 2001, co-sponsors numbered close to 150 in the House and 20 in the Senate.

However, cost is a potential drawback to this bill. The Joint Committee on Taxation estimates its provisions will cost \$50 billion over 10 years. Concern over the declining budget surplus makes passage of any new tax-cut legislation even more difficult. On the other hand Medicaid savings would offset the cost of full deductibility within five years, according to a 2000 Health Insurance Association of America study. As the study notes, “a portion of the Medicaid savings ultimately realized through more widespread LTC insurance coverage would also accrue to the states.” Another cost-benefit consideration relates to family caregivers, especially those who are employed. A tax credit that allows the caregiver to take advantage of more services, such as respite care, will lead to greater productivity by that worker, which in turn helps the economy.

### ***Universal Caregivers Act***

One of the authors of this paper (Blancato) has promoted a policy approach to meld all the various caregiver initiatives under one umbrella. Called the “Universal Caregivers Act,” it is modeled on two landmark laws that also have integrated fragmented policy proposals affecting a specific constituency: the Older Americans Act and the Americans with Disabilities Act. The concept of a Universal Caregivers Act has received an initial level of Congressional interest and review. The proposed Universal Caregivers Act would:

- ♦ Make Medicaid waivers permanent, as they can be especially valuable in providing needed resources to low-income caregivers.
- ♦ Provide expanded adult day care and respite care coverage under Medicare.
- ♦ Work to increase funding in the critical second year for the National Family Caregiver Support Program.
- ♦ Provide an indexed tax credit for family caregivers beginning at \$3,000 and a full tax deduction for long-term care insurance premiums, plus work to build in additional provisions to make these policies as responsive as possible to caregivers.
- ♦ Expand the Family and Medical Leave Act to those caring for aging relatives and grandparents raising grandchildren; drop the existing requirement that a person must work more than 1,250 hours a year to qualify, as many caregivers are in less-than full time jobs, but deserve the same protections under this law; and provide new exemptions for firms and businesses based on size.
- ♦ Amend the Older Americans Act to allow senior centers to become intergenerational respite caregiving centers to permit seniors to continue coming in a senior center, even if they assume a primary caregiver role for a grandchild or other child relative; and

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***“How states handle their Medicaid program budgets plays a major role in efforts to support family caregivers.”***

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- ♦ bolster the elder abuse prevention provisions with special provisions to counsel caregivers on preventing abuse.
- ♦ Establish a specific national clearinghouse of information, referral and listing of federal, state and local as well as public and private programs specifically to help caregivers.
- ♦ Begin providing direct cash aid to family caregivers, starting with the most economically needy caregivers through a demonstration program modeled after the Cash and Counseling programs.
- ♦ Offer additional tax incentives, including those related to transportation costs and long distance telephone charges for long distance caregivers; for employers who voluntarily provide accommodations for caregivers or who provide onsite elder care programs; and for families who must make modifications to their homes to accommodate caregiving responsibilities.

### ***Potential of Federal Housing Policy***

An area ripe for consideration in meeting the growing caregiver challenge is federal housing policy. For example, low- and moderate-income public housing units could be converted into assisted living. Federal policy could also be established that no person should face eviction if forced to become the primary caregiver for a grandchild.

### ***Medicaid Budgets***

Recent falling revenues and rising Medicaid costs cast uncertainty on the sustainability of public policy activity at both federal and state levels. An *ad hoc* survey by the National Association of State Budget Officers shows that about two-thirds of states estimate that Medicaid expenditures in the current fiscal

year will exceed budgeted amounts. Medicaid cost increases are expected to continue into the near future: “According to the most recent *Fiscal Survey of States*, Medicaid cost increases for fiscal 2000 were 7.7 percent. The Congressional Budget Office (CBO) estimates that Medicaid expenditures will increase by 7.8 percent in fiscal year 2001 and will average more than 8 percent a year thereafter.

According to the CBO, this renewed growth may result from increased spending on pharmaceutical products and noninstitutional long-term care. It is anticipated that the increased use of noninstitutional long-term care and the rise in pharmaceutical prices will continue to drive up costs in future years.”<sup>3</sup>

To comply with the *Olmstead* decision, many states are expected to expand home and community-based care services for persons with disabilities or at least show progress toward reducing waiting lists for such services. Thus, pressures continue to mount on state governments as they face perhaps conflicting goals: to expand services that assist persons with disabilities and their caregivers and to restrain Medicaid long-term care spending. If states control Medicaid spending by limiting home and community-based services, families will face greater burdens in filling potential service gaps.

### ***Shortages in Long-Term Care Workforce***

The shortage of critical long-term care workers is a daunting policy challenge and an immediate problem for family caregivers. In fact, some state programs report waiting lists for services not because of a lack of funds but because of a shortage of available workers.

<sup>3</sup> 1998-1999 *State Health Care Expenditure Report*, published in March 2001

The key to quality care lies in good staff, particularly well-trained and compassionate individuals who provide “hands-on” personal care to millions of persons with disabilities of all ages. These paraprofessionals—the nursing assistants, home health and home care aides and personal care attendants who provide from 80 to 90 percent of paid care to nursing home residents and 70 to 90

percent of paid care to home care consumers—are the backbone of the industry. Today, however, long-term care providers and families are increasingly finding it difficult to recruit and retain these workers. The reasons range from low wages and low or no benefits to the difficult conditions and workloads under which these aides work. With a full-employment economy, paraprofessionals can often find higher-paying jobs with better working conditions.

State strategies for addressing the shortages have varied. One approach has been to raise wages through Medicaid reimbursement. According to a North Carolina state agency study, as of August 2000 at least 16 states had adopted “wage pass through” laws, which raise Medicaid reimbursement for long-term care providers (nursing homes, home health agencies), earmarking all or some of the increase to wage and benefits. Some states also have established or are considering higher reimbursement rates for home care services provided at night, weekends and holidays, or they have required home care agencies to pay aides for their travel time between assignments. Others are creating career ladders for home care workers that would enable aides with training to move into positions with greater responsibilities, with higher pay at higher levels.

## CONCLUSION

Neither the federal government nor the states can afford to operate in a vacuum in developing policies on long-term care and family caregiving. Policymakers in Washington and the state capitols around the country have been using a hybrid of incremental options to shift more resources toward supporting family caregivers and community-based care in response to consumer demand, the *Olmstead* decision, the availability of new federal funds and tobacco settlement revenue. The family caregiving initiatives have occurred, however, within the context of federal and state budget surpluses throughout the mid- to late-1990s. The fiscal realities around long-term care and the increasing political empowerment of caregivers are two forces that will significantly impact both federal and state policy.

This year the federal surplus has declined precipitously as the economy has weakened and President Bush's tax-cut program has been implemented. In recent years, state revenue growth has not kept pace with the growth in Medicaid spending, which far exceeds the three to four percent rate of general revenue growth. Policymakers are examining strategies to contain program costs.

While these developments cloud the future of government initiatives on behalf of family caregiving, many federal and state policymakers appear committed to a policy agenda that promises continued support to families. They recognize the enormous contributions of family caregivers to society and to their loved ones. Caregiver support has become a major policy issue in the state capitols around the country.

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