



Issue Brief

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State Support for Family Caregivers and Paid Home-Care Workers

Summary

As the U.S. population ages, the demands on family caregivers and the need for a well-trained, stable in-home workforce will increase. States are designing and financing diverse strategies to support both informal family caregivers and paid direct-service home-care workers, rebalancing their long-term care systems away from institutional care and toward strengthening integrated home and community-based services.

An estimated 44.4 million individuals provide health care for adult family members and friends who, because of disabling illnesses or conditions, have limited ability to perform activities such as bathing, managing their medications and preparing meals. Family caregiving exacts a heavy emotional, physical and financial toll on caregivers and costs their employers as much as \$29 billion per year in lost productivity.

While informal and family caregivers provide the lion's share of caregiving to older people, 28 percent of community-based elders receive assistance from paid workers. Direct-service home-care workers face poor working conditions, earn low wages, receive few benefits and generally lack knowledge about public benefits—all issues that contribute to the industry's high turnover rate. This turnover results in increased recruitment and training costs for providers, which eventually feeds into the rising cost of health care.



Assisting family caregivers

States can provide a variety of services to assist and support family caregivers, typically through six strategies.

Using state and federal funds to support respite services

- Funds from the relatively new federal National Family Caregiver Support Program are allowing states such as Maine and Michigan to broaden caregiver support services beyond state-funded

respite programs, which provide temporary care for elderly people to allow the primary caregiver some short-term relief.

- Through home and community-based services Medicaid waivers, states can offer respite and other services (i.e., home modifications and caregiver training) that indirectly support and sustain caregivers. Currently, 44 states include some form of respite in their waiver services.
- Several states including; Oklahoma, Oregon and Nebraska are using Lifespan Respite programs to integrate federal, state, and local funding and ensure the coordination of care for family and informal caregivers, regardless of the age of the care recipient.

Maximizing choice for consumers and caregivers

- Using the National Family Caregiver Support Program, states such as Georgia and Illinois are offering family and informal caregivers a range of consumer-directed options, including vouchers to purchase supplemental services, a variety of respite arrangements and direct payments to family members to provide respite or personal assistance services.
- North Dakota and other states are using state general funds to pay spouses and other relatives to provide respite and personal care.
- Cash and counseling programs pay cash allowances, coupled with information services, directly to consumers (through fiscal intermediaries) to hire workers (excluding spouses or representatives) and purchase other services or goods they feel best meet their needs. The cash and counseling demonstration program funded by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services has been operating successfully in Arkansas, Florida and New Jersey.

Improving the tax treatment of caregiver expenses

- Twenty-six states and the District of Columbia are providing tax deductions or tax credits to provide some financial relief to caregivers.

Expanding family and medical leave

- States have expanded the federal Family Medical Leave Act provisions in several ways: applying leave provisions to employees in workplaces with fewer than 50 employees (Oregon and Vermont); allowing leave for family medical needs that are not covered by the federal law (Maine, Massachusetts and Vermont); expanding the definition of family (Hawaii, Oregon, Rhode Island and Vermont); extending the periods for family and medical leave (California, Connecticut, Louisiana, Oregon, Rhode Island and Tennessee); and offering paid leave benefits (California).
- California, Hawaii, Minnesota, Oklahoma and Washington have at least one program that allows certain types of leave with some wage replacement through use of disability insurance or sick leave.

Promoting public/private partnerships and public awareness

- States including Delaware, Oregon and Texas encourage employers to develop corporate eldercare programs for their employees by holding statewide or regional conferences that bring together state agencies, advocacy organizations, providers and corporations to discuss employed caregiving issues.

- To make the most efficient use of limited resources and use economies of scale, Alabama, Alaska, Delaware, Indiana, Iowa, Maine and Washington have used a portion of their base NFCSP allocation for statewide promotional campaigns.
- By assembling cabinet officials, agency directors, state representatives, consumers and family members, states such as Maryland plan and coordinate a strategy to support the potential increase family caregiving responsibilities that will come with greater availability of HCBS options.

Using state revenue to support family caregivers

- At least six states— Delaware, Iowa, Michigan, New Jersey, Pennsylvania and West Virginia— use alternative funding sources, such as lottery or tobacco settlement funds, to support family caregivers.
- California and Pennsylvania are using funds from their general revenue accounts to support family caregivers.

Assisting and supporting in-home workers

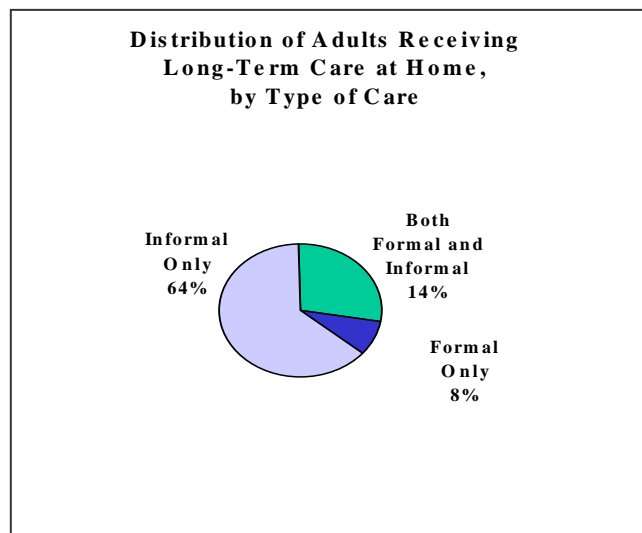
Concerns about poor working conditions and benefits for home-care workers, coupled with the projected 45 percent increase in demand for their services in the next 20 years, are prompting states to provide them with assistance and support.

Increasing access to health insurance for home-care workers

- Maine and Pennsylvania subsidize insurance premiums for low-income workers.
- Oregon and several counties in California are assisting in developing employer health insurance purchasing pools.
- Connecticut and Washington allow access to other public insurance plans to circumvent the barriers that exist in private insurance plans.

Providing targeted wage enhancements

- More than **20 states** have passed legislation to increase direct-care workers’ wages through wage pass-throughs—funds provided by state or Medicaid reimbursement for the express purpose of increasing compensation for direct-care workers.
- By creating direct-care worker resource centers, states such as Arizona, Michigan and Pennsylvania offer a full range of services, such as training and help in accessing child care, transportation and other community-based benefits.



State Support for Family Caregivers and Paid Home-Care Workers

The role of family caregivers

Family caregivers are the foundation of America's long-term care system. In 2000, the national economic value of the care provided by unpaid family members and friends was estimated at \$257 billion per year, exceeding the costs of nursing home care (\$92 billion) and home health care (\$32 billion).¹

An April 2004 [survey](#) estimates that 44.4 million individuals provide health care for adult family members and friends who, because of disabling illnesses or conditions, have limited ability to perform activities such as bathing, managing their medications and preparing meals.² A large body of research shows that family caregiving often exacts a heavy emotional, physical and financial toll, causing health risks, emotional strain, mental health problems, workplace issues and financial problems. As our society ages, the demands placed on family and other informal caregivers are likely to escalate, affecting nearly every American family.

Typically, caregivers are 46-year-old working women, who spend 20 hours per week providing care to their 77-year-old mothers. Thirty-four percent of them care for their mothers, while 11 percent care for a grandmother and another 10 percent care for a father. Many older care recipients are widowed and more than half (53 percent) live alone. Nearly half of all caregivers say they provide eight hours or less of care per week, and one in five say they provide more than 40 hours of care per week. The average length of caregiving is 4.3 years.³

Caregiving is a balancing act with competing priorities. Nearly 40 percent of family caregivers have children under age 18 at home,⁴ while six in ten caregivers work outside the home. It's no wonder that caregivers report that their most frequent unmet needs are finding time for themselves (35 percent), managing emotional and physical stress (29 percent) and balancing work and family responsibilities (29 percent).

Caring responsibilities cause 62 percent of family caregivers to make some workplace accommodations that frequently involve taking time off from work or reducing working hours. Common patterns include:

- arriving late, leaving early or taking time off (57 percent);
- taking a leave of absence (17 percent);
- dropping back to part-time (10 percent);
- turning down promotions (4 percent);
- taking early retirement (3 percent); and
- giving up work entirely (6 percent).

People caring for relatives with Alzheimer's disease or living with the person for whom they are caring, are particularly likely to be making workplace accommodations. All these workplace adjustments have a substantial impact on employers, costing between \$11.4 billion and \$29 billion per year in lost productivity.⁵

There's a financial impact of caregiving on the caregivers as well, with the financial burden of caregiving averaging \$12,500 per year.⁶ Data from the 2004 publication *Caregiving in the US* indicate that non-spousal caregivers spend about \$200 per month out-of-pocket on home modifications, medications, groceries and other expenses. Those who provide the most intensive caregiving spend significantly more—about \$324 per month. Over their lifetime, family caregivers who provide intense personal care for several years lose about \$659,000 in lost wages, pensions, earned interest, employer matched retirement saving and Social Security benefits.

The role of paid home-care workers

In addition to care provided by family, more than one-third of persons needing in-home assistance receive care from paid workers. Twenty-eight percent of community-based elders receive assistance from both family and paid in-home workers, and 8 percent of elders receive care solely from paid in-home workers.

On average, wages for paid in-home workers are just \$8.50 an hour—\$1.50 less than the wages paid to a certified nursing assistant in a nursing home. Paid in-home workers rarely have access to health insurance and are not entitled to federal earned income tax credits. They often work several different jobs to make ends meet. Ninety-three percent of in-home workers are women, and since one-third have children under age 18, child care is frequently a concern.

As a result of poor wages, minimal training, poor supervision and few opportunities for advancement, vast numbers of direct-care workers leave their jobs within the first few months of employment. This high rate of turnover compromises care, which depends on consistent, ongoing relationships. It also points to a looming crisis. Over the next decade, the demand for direct-care workers is going to grow enormously as our population ages and more people living with disabilities choose to live in the community.⁷

Assisting family caregivers

States can provide a variety of services to assist and support family caregivers, typically through six strategies:

- using state and federal funds to support respite services;
- maximizing choice for consumers and caregivers;
- improving the tax treatment of caregiver expenses;
- expanding family and medical leave options;
- promoting public/private partnerships and public awareness; and
- using state revenue to support family caregivers.

Using state and federal funds to support respite services

One way to relieve caregiver stress is through respite services that provide temporary care for an elderly or disabled person and relief to an informal primary caregiver. Respite care may be offered for regularly scheduled periods that allow caregivers to do routine chores, attend to their own healthcare needs and take a break, or for occasional, longer periods that enable caregivers to leave town for business or vacation, go into the hospital or attend to another emergency.⁸ Respite care is the caregiver support service most typically funded by state government, usually as a specific service within a package of home and

community-based services funded by aging and disabled Medicaid waivers or state general revenues. Some states also fund single-component respite programs, typically for family caregivers of persons with Alzheimer's disease and other cognitive illnesses. The definition, eligibility criteria, type of respite, funding mechanisms and amount of respite assistance available to families vary considerably within and across states.

National Family Caregiver Support Program funds

The National Family Caregiver Support Program (NFCSP), enacted under the Older Americans Act Amendments of 2000, is the first federally funded program implemented by the states specifically to support the critical service needs of family and informal caregivers of older people. Administered by the U.S. Administration on Aging, the program calls for state units on aging to work in partnership with area agencies on aging (AAAs) and local community services providers to develop multifaceted systems of respite care and other services, including:

- information about available services;
- assistance to caregivers in gaining access to services;
- individual counseling, support groups and caregiver training; and
- supplemental services (e.g., home modifications and assistive devices) on a limited basis to complement the care provided by family members.

The relatively new federal NFCSP dollars are allowing states to broaden caregiver support services beyond state-funded respite programs. For example:

- To support respite care, the **Michigan** Office of Services for the Aging is helping AAAs to explore innovative strategies for meeting the needs of family caregivers, such as establishing at least one community focal point for caregivers in their planning and service areas, and using statewide standards for caregiver education, support and training.
- Building on its existing home and community-based service system, **Maine** is implementing service delivery in addition to its state-funded respite services to reach a population beyond dementia caregivers and work with families earlier in the process of caregiving. This will allow the families to make more informed decisions while improving the quality of care for the loved one and the quality of life for the family caregiver.

Home and community-based services Medicaid waivers

Home and community-based services (HCBS) Medicaid waivers for the elderly and disabled play an important role in financing respite care for caregivers, even though they benefit the consumer (i.e., the care recipient), not the family caregiver or family unit. While current federal Medicaid policy does not allow services to be provided directly to benefit the family or informal caregiver,⁹ Medicaid waivers enable states to offer respite and other services (i.e., home modifications and caregiver training) that indirectly support and sustain caregivers. Preliminary findings from a recent 50-state study on caregiving suggest that 44, or 88 percent, of the 49 Medicaid state waivers cover respite assistance to benefit family and informal caregivers of frail elders or combined elderly and disabled populations.¹⁰ Case studies on caregiving in 10 states reveal that state program administrators (either state aging directors or Medicaid directors) believe that expansion of caregiver support programs can reduce the strain on Medicaid and other state-funded HCBS programs.

Combined funding sources

[Lifespan Respite](#)—a coordinated system of accessible, community-based respite care services for caregivers and individuals—is taking hold as a way to integrate federal, state and local funding and ensure coordination of care for family and informal caregivers. **Oklahoma, Oregon and Nebraska** have implemented Lifespan Respite programs and numerous other states have created coalitions to advocate this approach.

- **Nebraska** launched Lifespan Respite in 1999 with the passage of legislation to serve individuals of any age who provide care for persons with any disease or disability who are unable to care for themselves. The Nebraska Department of Health and Human Services serves as the lead agency for the Nebraska Respite Network of six community-based programs that coordinate lifespan’s respite resources. Each local program provides information and referral for families needing access to respite; recruits respite workers; conducts marketing to increase the public’s awareness of the program; develops and conducts training for providers and families; and conducts program evaluation and quality assurance efforts. A Lifespan Respite subsidy is available to provide short-term relief for family caregivers who do not receive respite services from other government programs. The program provides a respite subsidy of up to \$125 per eligible family client per month, which can be banked for up to three months.

Maximizing choice for consumers and caregivers

States increasingly apply models of consumer direction that shift decision-making and control from service providers to consumers and improve consumer satisfaction with everyday long-term care. Popular consumer-directed options include offering vouchers to family and informal caregivers to purchase supplemental services, offering a variety of respite services and making direct payments to the family caregivers. Some state-funded home and community-based services (HCBS) programs and programs funded by the National Family Caregiver Support Program (NFCSP) offer consumer-directed options

NFCSP-funded programs

Under NFCSP, states can offer family and informal caregivers a range of consumer-directed benefits, including vouchers to purchase supplemental services (i.e., assistive devices and consumable supplies), a variety of respite arrangements (i.e., permitting family caregivers to select, manage and dismiss their own respite workers), and direct payments to family members for providing respite or personal assistance services.

- Using funds from the NFCSP, the **Illinois** Department on Aging permits local AAAs to offer vouchers (averaging \$1,000 per year) to family caregivers for goods or services ranging from respite and home modifications to haircuts and lawn care. The goal is to give family caregivers the choice and control to select those service options that work best for them.
- The **Georgia** Division of Aging Services is using an NFCSP demonstration grant from the U.S. Administration on Aging to develop self-directed care voucher projects for the non-Medicaid elderly in rural areas, which can be replicated in other states.

General revenue funding programs

Faced with the challenge of offering in-home services with an increasing shortage of direct-care workers, some rural states are using state general funds to pay spouses and other relatives to provide respite and personal care. This approach enables family members to stay at home to take care of a relative, which might not be financially viable without the monthly payment.

- A state-funded family home-care program administered by the **North Dakota** Department of Human Services, Adult and Aging Services Division, provides eligible spouses and other family members up to \$700 per month to provide personal care to a relative—residing in the caregiver’s home—who may otherwise be eligible for nursing home admission. The maximum amount is far less than the \$3,200-average monthly cost of nursing home care. Family caregivers are also eligible for up to \$550 of respite assistance per month. North Dakota monitors the program through consumer satisfaction surveys and case manager reviews.

Cash and counseling

Another model of consumer direction, called cash and counseling, pays cash allowances, coupled with information services, directly to consumers (through fiscal intermediaries) to hire workers (excluding spouses or representatives) and purchase other services or goods they feel best meet their needs. The cash and counseling program, funded by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, began as a research demonstration for eligible Medicaid recipients and has been operating in **Arkansas, Florida and New Jersey**. Due to the demonstration’s early success, the program is being expanded to another 10 states in 2004 for testing over three years.

- [Arkansas](#) was the first state to implement the cash and counseling demonstration through its Independent Choices program, administered by the state department of human services’ division of aging and adult services. Arkansas’ experience shows that Medicaid beneficiaries who had the opportunity to direct their personal assistance services received better care than those who received traditional agency services. They also reported higher satisfaction, better quality of life, fewer unmet care needs, better access to services and less nursing home use—without compromising health or safety or adding significant costs to Medicaid.¹¹ Among treatment-group members in the state, about two-thirds hired family members, and most others hired other informal support, largely friends, neighbors or acquaintances.¹²

Improving the tax treatment of caregiver expenses

States provide tax deductions or tax credits to provide some financial relief to caregivers. Some states offer a deduction for expenses, usually up to \$2,400, but most offer tax credits of \$500 to \$1,000 instead.¹³ Unlike deductions, tax credits generally benefit lower-income taxpayers and are often viewed as a more equitable way of providing tax incentives to family caregivers. These tax credit programs build on the federal tax credit, which reduces the amount of income taxes a family owes for dependent care. At least **26 states** and the **District of Columbia** have refundable or nonrefundable dependent-care tax credits.

Expanding family and medical leave

By expanding the Family and Medical Leave Act (FMLA), states can help caregivers better balance their important but competing family roles. Caregivers often have to take off work to tend to their caregiving responsibilities. In fact, nearly one in five take a leave of absence just to tend to caregiving matters. With an average length of caregiving of 4.3 years, and with some illnesses, such as Alzheimer's disease, lasting from 4 to 20 years, FMLA falls short of addressing the reality that many informal and family caregivers face.

Enacted in 1993, FMLA was the first federal law to offer some important protections to working people to fulfill both their work and family responsibilities, including family caregiving. It guarantees employees of businesses with at least 50 employees 12 weeks of unpaid leave each year to care for a newborn or newly adopted child or seriously ill family member, or to recover from their own serious health conditions, without risking their jobs. States have expanded the federal FMLA provisions in several ways:

- applying leave provisions to employees in workplaces with fewer than 50 employees (**Oregon** and **Vermont**);
- allowing leave for family medical needs that are not covered by the federal law (**Maine, Massachusetts** and **Vermont**);
- expanding the definition of family (**Hawaii, Oregon, Rhode Island** and **Vermont**);
- extending the periods for family and medical leave (**California, Connecticut, Louisiana, Oregon, Rhode Island** and **Tennessee**); and
- offering paid leave benefits (**California**).

Paid leave for family caregiving

Many states have at least one program that allows certain types of leave with some wage replacement through disability insurance or the use of sick leave.

- **California** became the first state to enact a paid family leave law (SB 1661), which expands the state's disability insurance program to provide up to six weeks of paid family leave for workers who take time off to care for a seriously ill child, spouse, parent or domestic partner. As of July 2004, workers can receive 55 to 60 percent wage replacement, up to \$728 per week. The [program](#) is 100 percent employee funded at an estimated average cost of \$27 per worker per year. Businesses with fewer than 50 employees are not required to hold a job or a worker who goes on paid family leave.
- At least **40 states** have laws or regulations allowing public employees to use sick leave to care for certain ill family members.
- **California, Minnesota** and **Washington** require private employers to allow employees to use sick leave to care for certain ill family members.
- **Hawaii** enacted provisions that require an employer who provides sick leave to allow their employees to use up to 10 days of sick leave for family leave purposes.

- In **Oklahoma**, a law passed in 2001 permits state employees to use their sick leave to care for family members. It also establishes a leave-sharing program in which state employees can donate their annual or sick leave to a fellow state employee in need of family and medical leave.
- In **Washington**, the 2002 Family Care Act allows public- and private-sector employees to use their existing leave benefits to care for a child, spouse, parent, in-law or grandparent.

Promoting public/private partnerships and public awareness

Because caregiving can affect workers' productivity, some states encourage employers to develop corporate eldercare programs for their employees by holding statewide or regional conferences that bring together state agencies, advocacy organizations, providers and corporations to discuss employed caregiving issues.

- **Delaware** pulled together groups such as AARP, the state office on aging, Dupont and local healthcare organizations for a conference to inform employers about the impacts of caregiving on productivity and potential human resource solutions.
- In **Georgia** the Atlanta Regional Commission provides resources and professional assistance to employers to support their caregiving employees, and provides additional corporate services to help local employers better manage an aging workforce. Services provided include consultation and referral, caregiver support groups and employee seminars.¹⁴
- The **Oregon** Department of Human Services is partnering with Oregon Public Broadcasting to conduct statewide outreach for caregiver documentaries, and sponsoring annual Senior Expo events focused on help for family caregivers.
- North Carolina has a steering team of statewide leaders in health and human services, business and the faith community with the purpose of raising awareness about the needs of family caregivers across all settings, cross network collaboration, and to identify and leverage resources.

Public awareness campaigns

To make the most efficient use of limited resources and create economies of scale, several states have directed a portion of their base NFCSP allocation to each area agency on aging (AAA) for statewide promotional campaigns.

- AAAs in a number of states, such as **Alabama, Arkansas, Indiana, Iowa and Maine**, collaborate on outreach and marketing efforts (e.g., statewide logo and tag line, toll-free number, Web site and brochures) by pooling state dollars to promote a consistent, statewide identity for the new caregiver program funded by the NFCSP. This is viewed as an important strategic activity to make the public aware of new caregiver services in the state and reach people who care for their older relatives but do not identify with the term "caregiver."
- The **Kansas** Association of Area Agencies on Aging is implementing a statewide paid media campaign, known as the Circle of Caregiving, that provides caregiver tips and resources.

Through television, radio and billboards, the campaign increases public awareness of caregiving and available resources, as well as self-identification by caregivers.

State commissions and task forces

As states grapple with rebalancing their long-term care system and strengthening integrated HCBS, they need to consider the impacts of these policy shifts on family caregivers. By assembling cabinet officials, agency directors, state representatives, consumers and family members, states can plan and coordinate a strategy to support the potential increase in family caregiving responsibilities that will come with greater availability of HCBS options.

- The **Maryland** Caregivers Support Coordinating Council, created by legislation enacted in May 2001, seeks to understand the needs of Maryland caregivers from the perspective of the caregiver; assemble from local, state and national sources the best approaches to assist caregivers; make recommendations for, and coordinate statewide planning and implementation of, family caregiver support services; and reduce and avoid difficulties encountered by Maryland caregivers. The council's 17 members are appointed to three-year terms by the governor, and the council is housed in the department of human resources.

Using state revenue to support family caregivers

General revenue

California and **Pennsylvania** have been at the forefront of developing multi-component comprehensive family caregiver programs using state general funds.

- The **California** [Caregiver Resource Center](#) (CRC) system (established by law in 1984) replicates statewide the model program first developed by the San Francisco-based Family Caregiver Alliance to provide a comprehensive package of services to family caregivers of adults with cognitive impairment (e.g., Alzheimer's disease, Parkinson's disease and traumatic brain injury). Administered by the California Department of Mental Health, the system includes 11 CRCs operated locally by regional, nonprofit agencies. Services include information and assistance; in-home caregiver assessment; family consultation and care planning; counseling; Internet decision support; psycho-educational classes; in-person and online support groups; legal and financial consultations with attorneys; a range of respite options (through a voucher program of up to \$3,600 per year); and education and training. A separate state contract funds a statewide resources consultant to operate an information clearinghouse; conduct education, training and applied research; carry out program and policy development; maintain a uniform, statewide database on CRC clients; and provide technical assistance to CRC sites. Since passage of the federal NFCSP, many California AAAs have contracted with the CRCs to expand the population of caregivers they serve.
- The **Pennsylvania** Family Caregiver Support Program, established by law in 1990, assists family caregivers of functionally dependent adults age 60 and older or relatives with dementia of any age. Administered by the Pennsylvania Department of Aging through 52 local AAAs, the program provides assessment, care management, benefits counseling, caregiver counseling, training and education, access to support groups, and reimbursement for respite and other goods and services. Each family tailors services to fit its own needs. The state has used the federal

NFCSP to supplement and expand eligibility and benefits under its existing state-funded program. For example, the state has expanded eligibility to include family and informal caregivers, regardless of whether or not they are related or reside with the care recipient. The reimbursement rate for eligible caregivers under the state-funded FCSP is \$200 per month for needed services and supplies; under the federal NFCSP, eligible caregivers can receive \$300 per month for respite and other goods or services. Families may also be eligible for one-time grants of up to \$2,000 to modify the home or purchase assistive devices for the family member.

Alternative funding sources to assist family caregivers

In addition to the NFCSP and state general funds, states use a variety of revenue sources to provide caregiver support services, including:

- casino funds for respite care (**New Jersey**);
- lottery money (**Pennsylvania** and **West Virginia**);
- tobacco settlement revenues to expand respite options (**Iowa** and **Michigan**); and
- escheat funds (from selling property that has reverted to the state when no legal heirs or claimants exist), commonly from Blue Cross/Blue Shield checks that have not been cashed within five years (**Michigan**).

Assisting and supporting in-home workers

Direct service home-care workers are the foundation of the nation's formal home and community-based long-term care system. While informal and family caregivers provide the lion's share of caregiving to older people, one-third of family caregivers use paid home-care workers who assist with tasks such as home health care, personal care and respite care.



Direct service home-care workers face poor working conditions, earn low wages, receive few benefits and generally lack knowledge about public benefits—all issues that contribute to the industry's high turnover rate. This turnover results in increased recruitment and training costs for providers, which eventually feeds into the rising cost of health care.

These concerns, coupled with a projected 45 percent increase in the need for direct service workers in the next 20 years, are prompting states to assist and support home-care workers through:

- increased access to health insurance;
- targeted wage enhancements; and
- direct-care worker resource centers.

Increasing access to health insurance for home-care workers

Between 40 and 45 percent of all paraprofessional home-care workers lack health care coverage, significantly undermining the financial stability of home-care workers and their families. States can provide in-home workers with access to health care coverage through strategies such as the following.

Subsidized premiums for workers or employers

- **Maine's** new Dirigo Health Plan will provide subsidies for low-income workers, including direct-care workers, to buy into employer-based private health insurance if they work for small businesses with less than 50 employees. Employees will be eligible if they work a minimum of 20 hours a week. Medicaid matching funds will provide partial funding for these subsidies.
- **Pennsylvania's** adult premium subsidy program is for adults aged 19 to 64 with incomes up to 200 percent of the federal poverty level. The subsidy is paid on a sliding scale depending on the individual's income and the percentage of the health insurance premium that the employer pays. This program is funded with \$76 million from the state's tobacco settlement.

Assistance in developing employer health insurance purchasing pools

- **Oregon** and several counties in **California** have organized public authorities that serve as an employer-of-record for self-employed home-care workers. The authorities serve as purchasing agents, making it possible to enroll individuals in a health insurance plan.

Access to other public insurance plans to circumvent barriers in private insurance plans

- In **Connecticut**, personal care attendants belonging to professional associations can purchase insurance through a municipal health insurance plan.
- **Washington's** Basic Health Plan provides subsidies to help uninsured individuals buy into a state operated insurance plan.

Providing targeted wage enhancements

The 2002 median annual income for in-home-care workers was \$12,265—more than \$1,000 less than the salary of nursing home aides, and \$4,500 below the poverty level for a family of four. More than 20 states have passed legislation targeted at increasing direct-care workers' wages, often called wage pass-throughs. Wage pass-throughs are funds provided through state or Medicaid reimbursement for the express purpose of increasing compensation for direct-care workers. The additional funds go to providers with instructions that the money is to be passed on to direct-care workers, rather than going into provider agencies' operating budgets.

States commonly use two methods to calculate the amount to be allocated for wage pass-through programs. They can either identify a set dollar amount to increase worker wages per hour or per patient-day within the Medicaid reimbursement rate, or require that providers spend a percentage of a specific rate increase on higher compensation.

- **Illinois** has implemented a plan, using funds from the state tobacco settlement, to increase wages 34 percent over four years for personal assistants who provide in-home care to the disabled through the state office of rehabilitative services.
- The **Wyoming** Department of Health recommended increasing entry-level wages of direct-care workers by \$3.31 per hour from an average of \$6.92 to \$10.23 per hour. The recommended new wage rate was set at 90 percent of the regional average hourly wage paid to all low-wage workers in similar jobs in 12 Western states. A statewide survey of former direct-care workers who had

left the field supported the department’s recommendation. The survey found that \$10 per hour (more for workers with experience) is the wage at which most former workers reported they would have stayed on the job. In addition, direct-care worker wages in the state were compared with wages of workers with equivalent levels of education and training. The state found that merely matching the local entry-level wage in retail and service industries would not be sufficient, given the stress and difficulty of direct-care positions.

Creating direct-care worker resource centers

Although wages and health care benefits are essential for a stable home-care workforce, improving the quality of home-care jobs also requires a full range of other strategies, from more extensive training to helping workers access child care, transportation and other community-based benefits. For example:

- In **Michigan**, the AARP state office has provided pro bono accounting assistance to direct-care workers to help them apply for their federal Earned Income Tax Credits. These tax credits are available for low-income workers, providing a maximum tax refund of \$4,200. The Internal Revenue Service has estimate that millions of credits are unclaimed.
- **Pennsylvania** is organizing a direct-care worker resource center targeted to paid home-care workers that will centralize support and training services at the county level through the local area agencies on aging. A similar program has been created in **Tucson, Arizona**, by the Direct CareGiver Association with support by Workforce Investment Act funds and other state and federal funds.

Wage Pass-Through

A thorough review of this approach and design issues was published by the Paraprofessional Healthcare Institute and the Institute for the Future of Aging Services in a brief titled “[State Wage Pass-Through Legislation: An Analysis](#).” Also, a Web-based calculator can help states assess the real costs of increasing Medicaid-funded wages for home- and community-based direct-care workers. Both are available at www.paraprofessional.org.

Conclusion

As the U.S. population ages, the demands on family caregivers and the need for a well-trained, stable in-home workforce will increase. States are designing and financing diverse strategies to support both informal family caregivers and paid direct-service home-care workers, rebalancing their long-term care systems away from institutional care and toward strengthening integrated HCBS.

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Additional Resources:

Arkansas Independent Choices Program: www.independentchoices.com/ICHome.htm

California Caregiver Resource Center System: www.dmh.ca.gov/SpecialPrograms/Caregiver/caregive-overview.asp

California's Paid Family Leave Law: www.paidfamilyleave.org/law.html,
www.nationalpartnership.org/content.cfm?L1=8&L2=1&DBT=Guides&GSID=517&HeaderTitle=Paid percent20Leave percent2FFamily percent20Leave percent20Benefits

Eldercare Locator: 800-677-1116, www.eldercare.gov

Kansas Circle of Caregiving Media Campaign: www.ksn.com/inside/caregiving/

Lifespan Respite: www.archrespice.org/NRC-Lifespan.htm

Maryland Caregivers Support Coordinating Council: www.dhr.state.md.us/oas/mcsccl.htm

National Alliance for Caregiving: www.caregiving.org

National Center on Caregiving, Family Caregiver Alliance: www.caregiver.org

Nebraska Lifespan Respite Program: www.hhs.state.ne.us and nebrakarespitecoalition.org

North Dakota Family Home Care Program: www.state.nd.us/humanservices/services/adultsaging/

Pennsylvania Family Caregiver Support Program: www.aging.state.pa.us/

U.S. Administration on Aging (AoA): www.aoa.gov

¹ Arno, P.S., Presentation at the Annual Meeting of the American Association of Geriatric Psychiatry, February 2002.

² National Alliance for Caregiving and AARP.

³ National Governors Association. *Chairman's Initiative Fast Facts: Formal and Informal Workforce*. (Washington, D.C., 2003).

⁴ National Alliance for Caregiving and AARP.

⁵ National Alliance for Caregiving and MetLife Mature Market Group.

⁶ G. Smith, P. Doty and J. O'Keefe, "Supporting informal caregiving," in *Understanding Medicaid Home and Community Services: A Primer* (Washington, D.C.: George Washington University, Center for Health Policy Research, 2000).

⁷ Family Caregiver Alliance. *The State of the States in Family Caregiver Support (preliminary findings)*. (2004).

⁸ Family Caregiver Alliance. *Respite Care: State Policy Trends and Model Programs*.

¹⁴ Family Caregiver Alliance, *The State of the States in Family Caregiver Support*.

¹⁵ <http://www.rwjf.org/news/releaseDetail.jsp?id=1073479314892&contentGroup=rwjfrelease.???>

¹⁶ S. Dale, R. Brown, B. Phillips, J. Schore and B.L. Carlson. “The effects of cash and counseling on personal care services and Medicaid Costs in Arkansas,” *Health Affairs*, <http://content.healthaffairs.org/cgi/content/full/hlthaff.w3.566v1/DC1>, 566-575

¹⁷ National Conference of State Legislatures *Tax Incentives for Caregivers*. (Washington, D.C., 2000).

¹⁴ Donna Wagner, *Workplace Programs for Family Caregivers: Good Business and Good Practice* (Family Caregiver Alliance, 2003).